TRANSITIONS
IN
LATER LIFE

SCOPING RESEARCH

**CALOUSTE GULBENKIAN
FOUNDATION**

UK BRANCH

GUY ROBERTSON

PREFACE

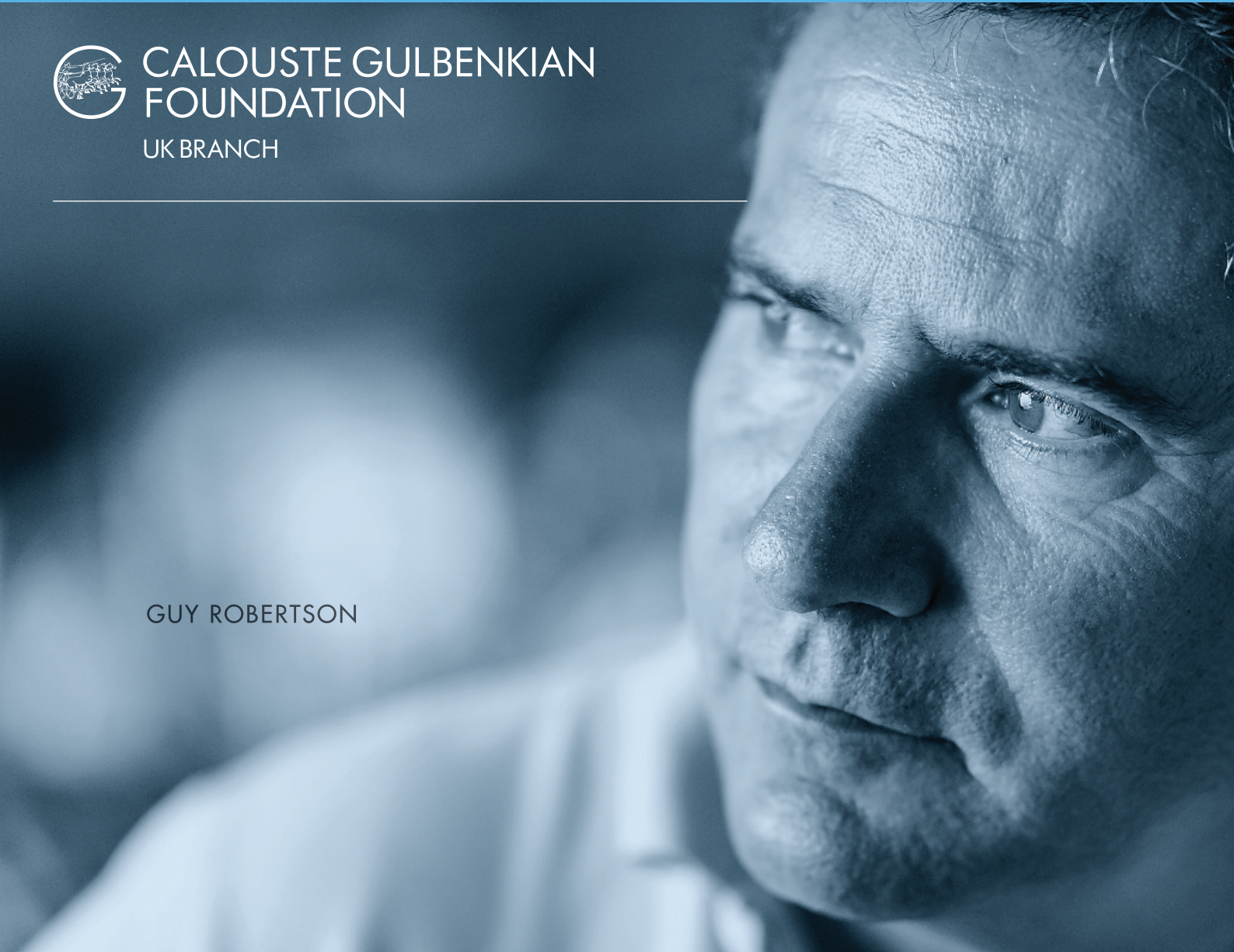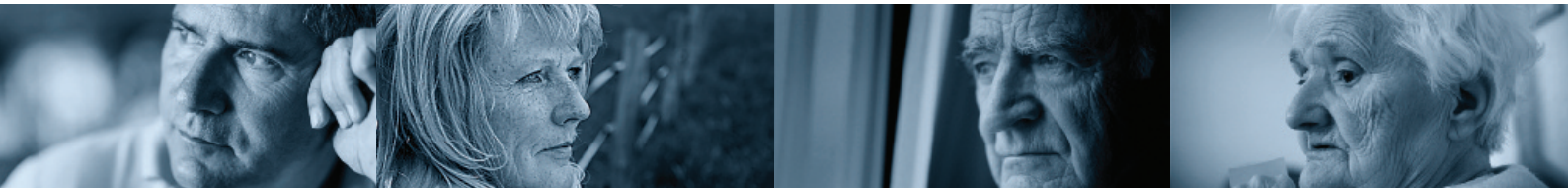**This report by Guy Robertson is the foundation stone of our current work on Transitions in Later Life. We decided to republish it as a companion piece to Kate Jopling and Dr Isaac Sserwanja's report because it reinforces the message that later life transitions can be a trigger for loneliness.**

In 2014, following the success of the Campaign to End Loneliness, an organisation we are proud to say has its roots in the Foundation, we began to think in terms of prevention rather than cure.

We knew through our work and the Campaign's that chronically lonely older people tend to have suffered certain setbacks or life changes. Many of them, we had discovered, stemmed from the transitions later life can bring. Changes such as retirement, health problems, moving out of the family home and losing a spouse all bring challenges – and for some these are overwhelming.

The purpose of the UK Branch of the Calouste Gulbenkian Foundation is to bring about long-term improvements in wellbeing, particularly for the most vulnerable. So to build on our legacy of work with the Campaign to End Loneliness we began to think about ways to help people 'future-proof', to reduce the likelihood of chronic loneliness affecting their later years.

In Guy's research, not only are the key transitions in later life and their defining effects on individuals mapped, but also the initiatives used to mitigate these are assessed. One of Guy's recommendations within this report was the importance of addressing the emotional and psychological aspects of the major transitions that people usually face in later life. This went on to characterise our Transitions in Later Life work. We want to share this report because we believe it is relevant for every organisation interested in helping people in mid to later life positively embrace their next stage of life.

Andrew Barnett
Director, Calouste Gulbenkian Foundation (UK Branch)

CONTENTS

ABOUT THE AUTHOR

Guy Robertson is Director of Positive Ageing Associates, an organisation specialising in promoting positive approaches to the later life agenda at both the personal and organisational level. Guy headed up the Local Government Association's Ageing Well Programme which supported councils across England to prepare for an ageing society. Prior to that, Guy led work on prevention and early intervention within the Older People and Dementia division of the Department of Health (DH), and in particular, led the support to the Partnerships for Older People Projects (POPP) programme.

Guy has worked as head of strategic planning for older and disabled people's services in Adult Social Care and as strategic commissioning manager in a large urban unitary authority. He led work on the implementation of various modernisation themes, including joint working between health and social care. This involved improving support for people with complex needs and the development of a corporate approach to raise the quality of life of older people. As well as his significant change management experience Guy also has an academic background, having been a lecturer on local government and social care policy.

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Andrew Barnett, Director,
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1
INTRODUCTION

The Gulbenkian Foundation has commissioned this literature review on life transitions and the mapping of relevant initiatives and projects addressing life transitions to help the Foundation gain an insight into the issue and therefore inform where action might be taken in the next phase of the Foundation's programme on ageing.

This report:

1. Summarises key literature on transitions across the life course, with emphasis on transitions in older age

2. Distils from the research what the key transitions are in later life, their characteristics and defining effects on individuals

3. Maps initiatives concerned with transitions across the life course but particularly in older age

4. Distils from this mapping any evidence about outcomes, impact and general effectiveness

5. Makes recommendations on key gaps and opportunities for action

The review addresses the following questions:

- How do we understand which transitions are more important or urgent and which less, and what criteria should we use for making these decisions?

- What are the current responses which seek to help people transition?

- How effective are these responses?

- Is there an appropriate balance between what is needed and what is available?

This report will help the Foundation form a view about which transitions in later life attract a plethora of action and which do not, to help us identify any emerging gaps.

The Foundation was interested in one further factor. It is well known that resilience plays an important part in how well people cope with major life changes. Individual resilience can make a real difference to how one manages transitions, but so too can the resilience that is offered through a strong social network of friends, families and communities. Resilient systems and services are important too, particularly as we adjust to population ageing. The Foundation is aware of some of the existing work which seeks to intervene early to help build peoples' resilience to deal with change, to help protect and 'future-proof' individuals against the negative impacts of transitions as they age. We were keen that this report would help us learn more about 'future-proofing' activities and the effect of resilience (personal and shared) on transitions.

2
TRANSITIONS

2.1
AN OVERVIEW OF TRANSITIONS ACROSS THE LIFE COURSE

All the world's a stage,
And all the men and women merely players;
They have their exits and their entrances;
And one man in his time plays many parts,
His acts being seven ages.
At first, the infant,
Mewling and puking in the nurse's arms.......
Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything.

—Shakespeare

LIFE STAGES

As Shakespeare so eloquently portrays, the path from birth to death takes the individual through different stages in life, each of which is generally associated with an expected timescale and sequence. Each stage has its own characteristics, pre-occupations and roles. While theorists may differ as to how many stages there are, and exactly when they begin and end, there is general agreement that this is the pattern to be expected in life. The course of a life is peppered with different life events and transitions.

In order to gain some clarity about life transitions it is necessary to look briefly at the development of the concept, and in particular how the concept fits within the idea of a 'life course approach'.

Life transitions emerged from life stage theory in the 1940's, pioneered by theorists such as Daniel Levinson [1] who identified a key distinction between two types of phases in life – stable periods and transitional periods. Levinson introduced the idea of six phases or stages of adulthood:

1. **Early adult transition** (17–22 years old) in which the individual leaves adolescence and makes the preliminary choices for adult life

2. **Entering the adult world** (22–28 years old) in which initial choices are made in terms of romantic relationships, occupation, friendship, values and lifestyle

3. **Age 30 transition** (28–33 years old) in which changes occur in life structure, often entailing severe and stressful crisis

4. **Settling down** (33–40 years old) in which an individual establishes a niche in society in both family and career accomplishments

5. **Mid-life transition** (40–45 years old) in which life structure is questioned and there is usually a crisis in the direction and value of life

6. **Entering middle adulthood** (45–50 years old) in which choices must be made, a new life structure formed and new tasks committed to

Levinson's theory has been criticised for not including a later adulthood stage and for focussing solely on the life stages of middle class men.

These early attempts to understand the different stages in life became more sophisticated and ultimately developed into what became known as 'the life course approach'.

THE LIFE COURSE

The life course approach is essentially a device to study the interaction between individual lives and social change [2]. It is a way of conceptualising lives within the contexts of families, society and historical time. The life course can thus be defined as a sequence of positions (or roles or identities) of a particular person in the course of time. A life course analysis studies the frequencies and the timing of changes in positions, generally of groups such as birth cohorts [2]. These changes are called 'events' or 'transitions', and every life course is characterised by a sequence and combination of transitions – such as leaving home, getting married, retiring etc.

One of the key observations in life course theory is that people mostly follow a normative pattern of behaviour – i.e. behaviour takes place at the 'proper time' and in the 'right sequence', for example, education followed by employment followed by marriage. Such standard patterns are known as 'social pathways' or 'cultural scripts' [3]. These are often gender and class specific. The life course can be thought of as a path – though it is never a straight path. Rather, it has many twists and turns.

One of the central ideas underpinning life course theory is the idea that we can only understand people's choices and behaviours by taking into account experiences in earlier stages of their lives. *"The life course is a cumulative process and should therefore be studied as a whole"* [3].

According to its advocates, the life course *"provides a framework for studying phenomena at the nexus of social pathways, developmental trajectories, and social change"* [3]. The life course approach is *"highly holistic in its aspiration to grasp the behaviour of individuals within*

their personal networks and within a specific place, historical time and society" [2]. Amongst other things a life course approach can chart a person's wellbeing over time (**Fig. 2.1.1**.)

Cohorts

The life course approach generally starts off with the idea of a 'cohort', which is a group of people who were born at the same time and who therefore experience particular social changes within a given culture. An obvious example in the context of this paper is the 'baby boomer' cohort. The important point about cohorts is that they experience a defined range of possible experiences and choices due to their existing in the same time and, depending on the selection, place etc. In other words, individuals within birth cohorts are influenced strongly by the historical context and specific location within which they live their lives.

Trajectories

When one adds socioeconomic factors such as culture, class, gender etc to the historical context and location, one begins to see that people's lives can be understood in terms of longer term patterns of stability and change. These are commonly referred to as 'trajectories'. Transitions (which are shorter term changes) are embedded within, and constrained by, these longer term patterns.

Transitions

Transitions can be defined as *"changes in roles and statuses that represent a distinct departure from prior roles and statuses. They are discrete and bounded; when they happen, an old phase of life ends and a new phase begins"*. Examples include starting school, first job, marriage, retirement, bereavement etc. But people do not all experience transitions in the same way. Schlossberg [4] noted that perception plays a key role in transitions. An event only meets the definition of a transition if it is so

FIG. 2.1.1. Example of a self-report lifeline charting wellbeing through typical life events
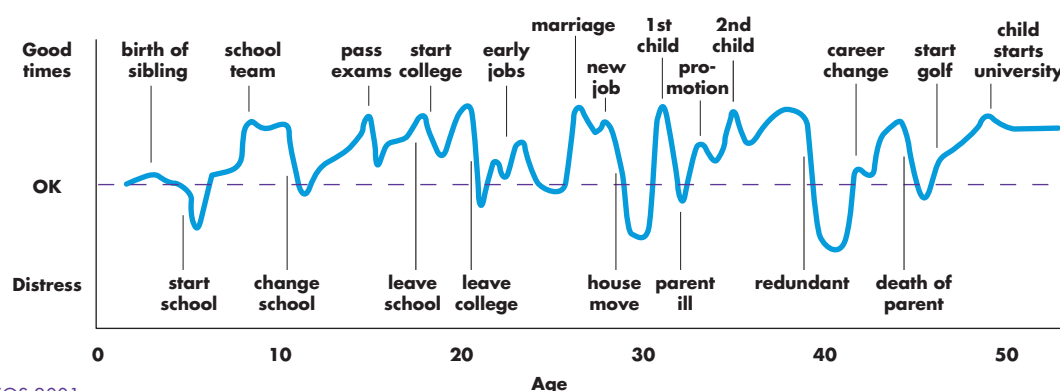
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defined by the individual experiencing it. In order to understand the meaning that a transition has for a particular individual, the type, context, and impact of the transition for them must be considered.

Having recognised the individual nature of transitions there are nevertheless a number of key features:

- Transitions may be: predictable or unpredictable; positive or negative; entered into voluntarily or involuntary; gradual or sudden

- they can follow a predictable course, although this depends on the meaning to each person (e.g.loss of work may affect people differently depending on the meaning of work to them).

- Generally transitions involve stress; this can be partially controlled or managed.

- Transitions affect individuals differently and each person has a characteristic style of managing anxiety and resolving cognitive tasks (see section on Resilience).

FIG. 2.1.2

LIFE EVENT	STRESS RATING
Death of a spouse	100
Divorce	73
Marital separation from mate	65
Detention in jail or other institutions	63
Death of a close family member	63
Major personal injury or illness	53
Marriage	50
Being fired at work	47
Marital reconciliation with mate	45
Retirement from work	45
Major change in the health or behavior of a family member	44
Pregnancy	40
Sexual difficulties	39
Gaining a new family member (e.g. through birth, adoption, elder moving in)	39
Major business readjustment (e.g. merger, reorganisation, bankruptcy)	39
Major change in financial state (a lot worse off or a lot better off than usual)	38
Death of a close friend	37
Changing to a different line of work	36
Major change in the number of arguments with spouse (more or less)	35
Taking out a mortgage or loan for a major purchase	31
Foreclosure on a mortgage or loan	30

- People can be helped to adapt and gain from a transition.

Transitions are defined and characterised in more detail later on.

Life events

Transitions don't take place in a vacuum; they are triggered by life events. These are defined as "*significant occurrences involving relatively abrupt changes that may produce serious and long lasting effects*" [5]. The term refers to the happening itself and not to the transition that will occur because of the happening. Life events also commonly involve a level of stress. One common method for evaluating the stress associated with life events is the Schedule of Recent Events, also called the Social Readjustment Rating Scale [6]. An extract from the Schedule of Recent Events, along with the rating of the stress associated with each event, appears alongside. Holmes and Rahe [6] constructed their schedule by asking respondents to rate the relative degree of adjustment required for different life events – **Fig. 2.1.2**.

This kind of listing, although helpful in casting some light on the sorts of things that trigger life transitions, has limitations. Life events inventories like this are:

- not finely tuned

- biased towards undesirable events

- don't take account of the fact that specific life events have different meanings to different individuals and groups of people

- biased towards the sort of events that more commonly affect certain groups of people (i.e. middle class men)

One suggestion to address some of these limitations is to classify life events along several dimensions [5] i.e.:

- major versus minor

- anticipated versus unanticipated

- controllable versus uncontrollable

- typical versus atypical

- desirable versus undesirable

- acute versus chronic

See more on this in the section below about transition characteristics.

There is a question as to whether all 'life events' trigger a 'life transition'? There are clearly many types of change and varying degrees of impact. Not all changes cause transitions. Most transitions are associated with *significant* life events. Rutter [7] suggests that there are three types of life events that can trigger transitions:

- Life events that either close or open opportunities

- Life events that make a lasting change to the person's environment

- Life events that change a person's self concept, beliefs or expectations

Transitions are typically associated with trauma and loss, but research and practice also indicate that positive life events e.g. marriage, birth of a child or new job have as much potential for psychological disruption as negative events. Transitions can involve serious challenges, but they can also be windows of opportunity for growth.

Social determinants

An important aspect of life course theory is the idea that people's lives are linked — "no one is an island". We are all interdependent. This is particularly true within families and is an important dimension to take into account when looking at events and transitions within the life course.

The life course, and the life events and transitions within it, are to a large extent socially constructed. As George [8] argues, many transitions are governed by societal norms and are therefore predictable. With these situations, socialisation generally provides individuals with the skills needed to master transitions and perform their new roles effectively. However, Hulme [9] argues that it must be recognised that simply because a transition is predictable, does not mean that an individual will react to that transition in the expected way. Different people will experience differing levels of control in different life transitions, and this tends to result in differing levels of stress. Furthermore, different life transitions can have differing levels of impact upon those surrounding the individual in question.

Hulme [9] goes on to point out that many people experience what are known as 'revolving transitions' as they find themselves caught in negative cycles such as those based around health or criminality. In these cases, people tend to bounce from one transition to another without the ability to re-take control of their lives. This can create a build-up of depression and loneliness due to the on-going sequence of events and also weighs heavily upon the resources of agencies attempting to provide for such situations.

Critiques

There are critiques of life course theory. For example, some query whether individual behaviours and lives can satisfactorily be aggregated into 'life transitions'. People, the argument goes, are so individual that they cannot be satisfactorily categorised into groups? People have their own 'agency' — that is, they make their own choices and determine, within given constraints and opportunities,

their own life course. Whilst it is clearly true that there is wide-ranging variety in human circumstances, behaviour, characteristics and choices, it can nevertheless be argued (as Shakespeare recognised) that there is sufficient conformity and continuity within and between individuals' lives for some general ideas about life stages and transitions to be generated.

Psychosocial dimensions

There is a psychological aspect to people's lives which needs to be taken into account, and some wonder whether life course theory addresses this sufficiently. As we have already noted, most theories of the life course view early life influences as of crucial importance on future developments. It is the formative years which can determine the direction that a child follows through life. Psychologists tend to look at this in terms of cognitive and emotional development. Erikson produced some of the seminal thinking on life stages from the psychological viewpoint [10]. He developed a theory called the "Eight Stages of Psychosocial Development" [10], which theorised that life stages are precipitated by crises that all individuals face as they move from birth to death. According to Erikson, each stage presents the individual with a psychosocial conflict that must be resolved. In other words, each stage has a positive and negative pole. For instance, during the first stage the infant struggles with whether to trust the environment or not. If he or she is born into a relatively stable, dependable environment the infant learns to trust and out of that trust hope emerges. If, however, the infant is born into an environment that is erratic, and undependable he or she may grow up considering the world to be an untrustworthy place. This will colour future life experiences and rather than entering the world with a hopeful outlook, the individual may feel hopeless.

By looking at the development of personality characteristics through the lens of Erikson's life-stages we can see a path through life, that if navigated successfully could lead to maturity and wisdom. The model also helps us see what psychological work we need to do when there has been difficulty in navigating a particular stage in life. As we move towards life completion, the desire to heal, to become whole, becomes predominant as the more physical aspects of living take on less significance. (**Fig. 2.1.3**)

FIG. 2.1.3. Eight stages of psychosocial development

STAGE	CRISIS	RESULT
Stage 1 Hope – Infant stage. Social environment caring, stable or erratic and threatening.	**Basic Trust vs. Mistrust** – Does the child believe its caregivers to be reliable? Does the environment foster hope or mistrust?	Child becomes trusting, hopeful in life or frightened, insecure and mistrustful.
Stage 2 Will – Toddler stage child supported and encouraged or, either unknowingly neglected or through malevolent intent shamed and punished	**Autonomy vs. Shame and Doubt** – Does the child believe him/herself to be intrinsically worthy, good or intrinsically bad	Child learns autonomy or internalises sense of shame, self-doubt and criticism.
Stage 3 Purpose – Kindergarten. Child taught to do things for self and praised or child is not taught or is criticised for failures.	**Initiative vs. Guilt** – Does child believe in own ability to plan and act or does he/she feel it is wrong to function independently?	Child learns a sense of accomplishment. Otherwise, develops guilt about functioning independently.
Stage 4 Competence – age 6 to puberty. As child enters larger social environment, compares self worth to others (such as in a classroom).	**Industry vs. Inferiority** – begins to recognise major disparities in personal abilities relative to other children and judges self through attitudes of significant others, i.e., teachers	Child develops self-worth and learns competency in concrete world or develops sense of inferiority in relation to others.
Stage 5 Fidelity – Teenager. Questioning of self: encouraged to explore and create self-identity or pushed to conform	**Identity vs. Role Confusion** – separates views from parents and authority figures, identifies with peers, explores new outlooks constructively or rebels destructiveley	Teenager either develops an identity of his/her own, or becomes confused and easily led by others, unable to discern roles, loyalties, best interests, direction in life
Stage 6 Love – Young adult. Lasting longer as young adults choose to stay in school and not settle but has typically been a stage of forming significant relationships and settling down.	**Intimacy vs. Isolation** – through dating and exploring relationship, develops capacity for emotional connection and love or experiences inadequacy or failure in relating to others	Young adult able to connect with significant other and be intimate, establish committed relationshp or learns to isolate from others, becomes alienated.
Stage 7 Caring – Mid-life crisis: self-evaluation occurs, leading to positive new direction and sense of role relationship in the life cycle	**Generativity vs. Stagnation** – through measuring success and failures of life, adult is inspired to helping others, next generation or experiences crisis and is unable to relate to or guide next generation	Adult becomes inspiration and guide for younger generation or stagnates and is unable to relate to next generations
Stage 8 Wisdom – Old age. Elder suffers decline due to aging, illness, possibility of dying, role displacement.	**Ego Integrity vs. Despair** – reflecting on past, elder reviews accomplishments, failures and has crisis between acceptance and bitterness	Elder is able to resolve previous and present challenges and develops wisdom or is unable to resolve earlier crises or face current illness or possibility of death and despairs in face of aging challenges

Source: Erikson [10]

Erikson is not alone in developing a theory of psychosocial stage development. Havighurst [11] also developed a theory within which he identified six major stages in human life covering birth to old age:

- Infancy and early childhood (Birth till 6 years old)

- Middle childhood (6–13 years old)

- Adolescence (13–18 years old)

- Early Adulthood (19–30 years old)

- Middle Age (30-60years old)

- Later maturity (60 years old and over)

From there, Havighurst recognised that each human has three sources for developmental tasks. They are:

- Tasks that arise from *physical maturation*: Learning to walk, talk, control of bowel and urine, behaving in an acceptable manner to opposite sex etc.

- Tasks that arise from *personal values*: Choosing an occupation, figuring out ones philosophical outlook.

- Tasks that have their source in the *pressures of society*: Learning to read, learning to be a responsible citizen.

The developmental tasks that Havighurst identified all serve pragmatic functions.

Staged theories of adult development, such as Erikson's eight stages of man and Havighurst's six life stages and related developmental tasks have both been criticised [12] as being:

- based on narrowly-researched, culturally-specific studies

- failing to incorporate diversity

- too fixed and deterministic

- reinforcing socially constructed expectations.

It is also interesting to note that neither of them have a well developed approach to later life – and certainly not one which appropriately reflects the huge increases in longevity that have been achieved within the last few decades.

2.2
TRANSITION PROCESSES

Most transitions take around 6–12 months to complete, and sometimes longer. There are factors which will influence how that process is experienced, and the process of transition itself is thought to have internal stages and other characteristics.

INFLUENCING FACTORS

There are three key points about transitions:

- Transitions generally involve grieving for the loss of the old and readjusting to the new

- Transitions often work best when they are predictable and approached intentionally

- Transitions often work best when there is an understanding of the personal challenges that they represent and when there are societal or personal supports in place to help the individual cope with and overcome these challenges

ENABLING CONDITIONS

A number of conditions appear to enable successful transitions:

- **Economic security** — surplus resources, no debt, stable income, own home, low commitments, multiple-income household

- **Emotional security** — supportive partner, stable childhood, support networks, openness on emotional and mental health issues

- **Health** — good physical fitness, prudent lifestyle, quality time for leisure.

- **Prior transition skills** — positive transition experiences, clear goals

- **Supportive work environment** — high respect / low control culture, good team morale, clear role and contract terms, life work boundaries respected

- **Transition support** — briefing, monitoring issues, practical support, life career planning, tolerance, dignity, valuing the past, time off before illness, confidential counselling, freedom/recognition for new ideas.

- **Positive outcomes:** minimise severity of distress in the crisis phase, minimise risks of quitting or extended crisis, optimising recovery time, high innovation, personal transformation, healing old wounds, 'rejuvenated' staff, high group morale and synergy, enable organisational transformation.

Others have developed more complex frameworks to conceptualise those factors which would influence a person's ability to cope with a transition. Schlossberg [13] identified four major sets of influences: situation, self, support, and strategies – which are also known as the 4 S's.

- **Situation**

  - **Trigger**: What precipitated the transition?

  - **Timing**: Is the transition considered "on time" or "off time" in terms of one's social clock?

  - **Control**: What aspect of the transition does the individual perceive as being within his/her control?

  - **Role change**: Is a role change involved and, if so, is it viewed as a gain or a loss?

  - **Duration**: Is it seen as permanent, temporary, or uncertain?

  - **Previous experience with a similar transition**: How effectively did the person cope then, and what are the implications for the current transition?

  - **Concurrent stress**: Are other sources of stress present?

  - **Assessment**: Who or what is seen as responsible for the transition, and how is the individual's behavior affected by this person?

- **Self**: factors considered important in relation to the self are classified into two categories

  - **Personal and demographic** characteristics affect how an individual views life, such as socioeconomic status, gender, age, stage of life, state of health, and ethnicity.

  - **Psychological resources** include ego development, outlook, and commitment and values.

- **Social support**

  - Intimate relationships

  - Family units

  - Networks of friends

  - Institutions and communities

FIG. 2.2.1. The individual transition
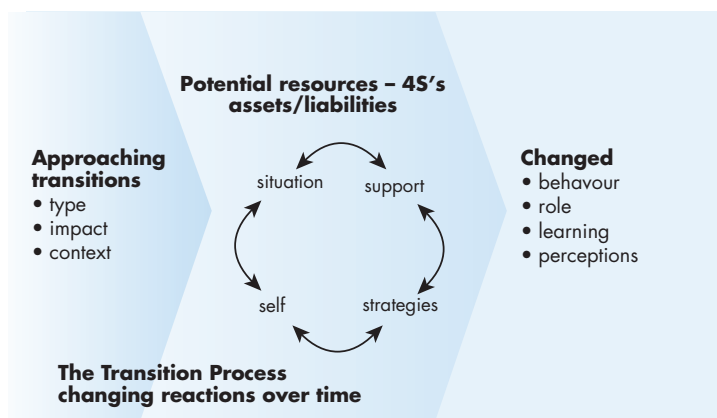
Adapted from: Schlossberg (1995)

FIG. 2.2.2. Self-esteem changes during transitions

Source: Hopson and Adams (1976)

- **Strategies**, or coping responses, are divided into three categories

  - Those that modify the situation

  - Those that control the meaning of the problem

  - Those that aid in managing the stress in the aftermath

This can all be represented in the diagram above (**Fig. 2.2.1**).

Process dynamics

Transitions take place over time and within that time researchers / theorists have identified some common stages.

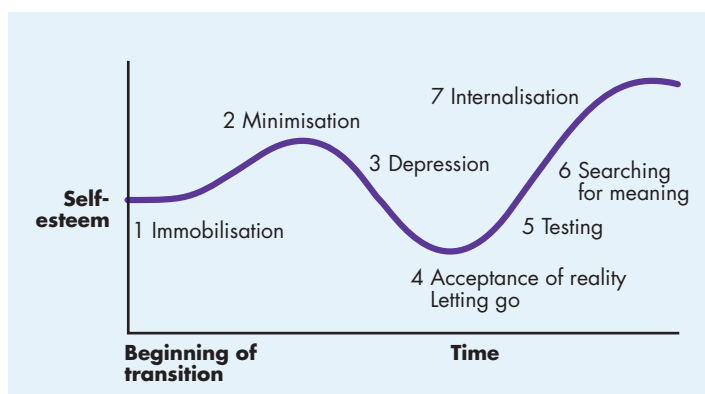Hopson and Adams [14] developed a model that focuses mostly on people experiencing crises. They proposed a broad conceptual model of a transitional cycle with seven phases. This represents a cycle of experiencing disruption, acknowledging its reality, then testing and

understanding oneself and incorporating changes into ones behaviour. Self esteem is thought to vary across these phases and appears to follow a general pattern, although people seldom move in a progressive and orderly fashion. Rather, each is unique, depending on the meaning of the transition to a person e.g. individuals may move both forward and backward. (**Fig. 2.2.2**)

- **Immobilisation.** There is a sense of being overwhelmed, unable to act. Unfamiliar transitions, and those of which we have negative expectations, tend to intensify this stage.

- **Minimisation.** As a way of coping with the change it is common to deny that it is happening. This is a frequent reaction to a crisis which is too difficult to face.

- **Depression.** People often get depressed when they face up to the implications of change.

- **Accepting reality.** At this point the person begins to let go of their old state of being, accepting the reality of what is happening to them.

- **Testing.** Having begun to accept the situation, then it becomes possible to test out new behaviours to cope with the new situation.

- **Seeking meanings.** This is a reflective stage where people try to work out how and why things are different.

- **Internalisation.** Finally, understandings of the situation and new meanings become internalised and accepted. They then become part of the person's behaviour.

It is proposed within the model that the key to successful adjustment to change is to work through this cycle of reactions. But not everyone will experience all these stages and some people may become stuck along the way, for example experiencing on-going depression.

Other models are available. Ralph Lewis and Chris Parker [15] described a 'Transition Curve' model which is represented in a seven stage graph, based on original work by Adams, Hayes and Hopson [16]. The Lewis-Parker 'Transition Curve' seven stages are summarised as follows: (**Fig. 2.2.3**)

1. **Immobilisation** – Shock. Overwhelmed mismatch: expectations v reality.

2. **Denial of Change** – Temporary retreat. False competence.

3. **Incompetence** - Awareness and frustration.

4. **Acceptance of Reality** – 'Letting go'.

5. **Testing** - New ways to deal with new reality.

6. **Search for Meaning** – Internalisation and seeking to understand.

7. **Integration** - Incorporation of meanings within behaviour.

Another model is The Transition Cycle (**Fig. 2.2.4**), adapted from Nicholson and West [17], which provides a more flexible approach to the stages of role transitions. Underpinning the model are assumptions that although the stages are distinct, there is a strong interdependence and what happens at one stage has a powerful influence on the next. It is also argued that cycles can recur and have a cumulative effect, so if people experience failure or dissatisfaction at early stages, this can lead to cycles of disaffection. And also the opposite; that successful transitions will work to increase confidence and success.

FIG. 2.2.3. Career crises and transitions
A seven-phase model of stages accompanying transition
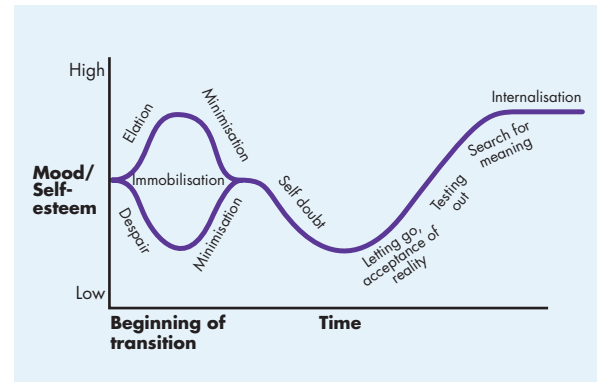
Source: Understanding and Managing Personal Change, by J. Adams, J. Hayes and B. Hopson, © 1977

FIG. 2.2.4. Transition cycle

ASSUMPTIONS

Recursion: Cycles recur and have a cumulative effect

Interdependence: What happens at one stage has a powerful effect on the next

Discontinuity: Each stage has distinct tasks, experiences, problems and solutions
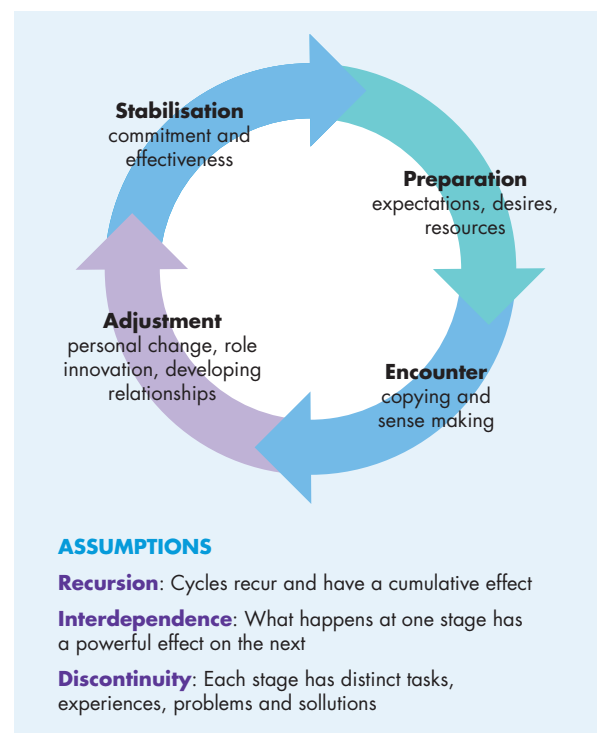
Source: Nicholson and West [18]

SUPPORTING PEOPLE THROUGH TRANSITION

All the preceding models appear to have some value in providing a framework for understanding some of the internal processes that people will go through when experiencing a life transition. When supporting an individual facing a life transition the following guidance can be distilled from these models:

- Individuals differ in vulnerability to transitions.

- Transitions often reach a crisis about 6 months after change, +/- 1 month.

- They can have several outcomes depending on circumstances.

- Effects can transcend the individual's life/work boundary into other roles.

- They can cause transitions for others: family, friends, colleagues, and helpers.

- Change involves situational and intrapersonal learning and un-learning.

- Transitions involve at least two levels of adaptation — behavioural and cognitive restructuring. These occur at different phases of the cycle (see more below).

Helping people to comprehend what is happening may help them identify ways of moving through the process and develop their own coping strategies.

Skills

There are a number of skills which have been identified to help clients cope with transition, including:

- Active listening/empathic skills/developing a relationship of trust

- Understanding the issues — reflecting and questioning/helping clients understand 'where you are now'

- Focusing — what the client needs to deal with

- Information & feedback

- Challenging perspectives

- Goal setting — action planning, 'testing out'

Coping strategies

In helping clients to develop coping strategies, three main approaches have been identified:

- Reinforce existing skills
  Appraise and redefine the meaning of the situation (appraisal-focused)

- Learning new skills
  Focus on practical aspects, aim to change the situation (problem-focused)

- Restoring ability to cope
  Manage feelings, emotions provoked, control stress (emotion-focused)

Sources of support

In practice, there are a number of sources of support (beyond that which is offered by the state) that people can and do access. Golan (1981, cited in Sugarman, 2001: 194) identifies five potential sources of assistance:

- the self

- the natural help system

- the mutual help system

- the 'non-professional' help system

- the professional help system

Rarely does a person rely on one source alone, but selects an intricate combination of the sources available to them personally and preferable to them personally. So, for example, a study of "high functioning elders" recovering from hip surgery found that *the actions elderly people take to create opportunities for mentally restorative experiences are related to past patterns of restorative activities, opportunities made available by the facility, special circumstances of their care, environmental limitations in the immediate care environment, and the degree to which external factors (such as family visits) are readily available* [19]. The support of family and friends is very important — particularly if they can bring experience and helpful advice to inform their support — however it is perhaps the individual's inner resources and ability to accept and adapt to change which is crucial. This is addressed further in the section on resilience.

2.3
TYPOLOGY OF TRANSITIONS

Having located life transitions within the context of a life course approach it is now necessary to look at their characteristics and explore possible typologies.

Hulme [9] sets out a taxonomy of transitions. She states that in practice, life transitions are complex, and that they can affect different people in different ways, at different times, and for different reasons. Multiple interrelated transitions may also occur concurrently or in succession. Thus, it is difficult to offer a list or taxonomy of life transitions that is definitive and universally applicable. However, it is useful to have frameworks that can help to systematically analyse and categorise transitions in a given context.

One framework posited by Hulme [9] is organised along two dimensions: voluntary vs. involuntary and gradual vs. sudden. (**Fig. 2.3.1**)

FIG. 2.3.1. Nature and timing of transition
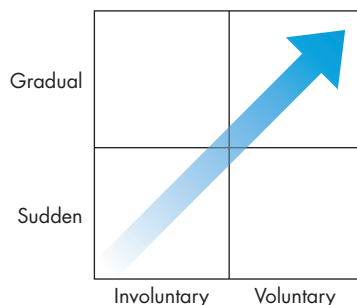
While the same transition could occupy different categories for different people or contexts, Hulme argues that this framework is useful in thinking about how to change how individuals experience a given transition. Control is important in reducing stress and so, where possible, transitions should be voluntary. Similarly, having a gradual transition will usually increase the likelihood that the individual will cope well with the change. Thus, in order to ease the psychological cost of a transition, effort should be made to make it voluntary and gradual.

Useful as this framework is, it fails to encompass the complexity of many common transitions. For example as we have seen, others classify life events along several dimensions [5]:

- major versus minor
- anticipated versus unanticipated
- controllable versus uncontrollable
- typical versus atypical
- desirable versus undesirable
- acute versus chronic

Paradoxically, one also has to incorporate 'non-events' – such as failure to achieve a particular milestone (e.g. not getting married, or not getting promotion).

A more dynamic framework for capturing the complexity of life transitions is outlined below. It is adapted and developed from a theory of transition suggested by Meleis [20].

NATURE OF THE TRANSITION

- **The types** – the various types of transition put forward by Meleis include:
  - **developmental** – e.g. retirement or becoming a grandparent
  - **health and illness** – e.g. acquiring a serious health condition
  - **situational** – moving home or entering residential care
  - **organisational** – e.g. promotion

- **Patterns of transitions** – Many people experience multiple transitions at the same time, rather than experiencing a single transition, and sometimes this complexity makes it very difficult to distinguish a period of transition from the contexts of their daily life. It is important to consider whether multiple transitions are sequential or simultaneous, and the extent of overlap between the transitions. It is also important to be aware of the nature of the relationship between the different life events which are triggering transitions for the person.

- **Properties of the transition experience** – which include:
  - **awareness** – perception, knowledge and recognition of a transition experience
  - **engagement** – the level of personal involvement in the transition. The level of awareness clearly influences the level of engagement.

– **changes and differences** – all transitions involve change; they bring a sense of movement or direction to internal processes. It is necessary to uncover and describe the effects and meanings of the changes involved and the dimensions of the changes [5]:

– major versus minor

– anticipated versus unanticipated

– controllable versus uncontrollable

– typical versus atypical

– desirable versus undesirable

– acute versus chronic

In order to understand the range of potential internal/psychological changes which occur in a transition another framework drawn from the field of humanistic psychology Dilts [21] is included (see more on Dilts below):

– **Sense of purpose** – impact on people's motivation and meaning in life

– **Identity** – impact on how people feel about their role and place in society

– **Beliefs** – impact on what people believe to be true or important

– **Capabilities** – how people's talents and abilities are affected

– **Behaviour** – what changes might be required in the actions the person takes in their day to day life

– **Environment** – what changes may be required in their living arrangements or where they carry out their day to day activities

● **Time span** – all transitions move over time. Transitions can be said to have an identifiable starting point (a life event), extending from the first signs of anticipation of change (if it is predicable); moving through a period of instability, confusion and distress; to an eventual 'ending' with a new beginning or period of stability (see more on transition processes below). One needs to note that it might be difficult to put boundaries on the time span of certain transition experiences.

TRANSITION CONDITIONS

● **Facilitators and Inhibitors** – these are the circumstances which influence the way a person moves through a transition, and that facilitate or hinder progress toward achieving a healthy transition [22]. Transition conditions include personal, community or societal factors that may affect whether the transition has a healthy outcome (note relationship to the idea of 'resilience' addressed elsewhere):

– **personal conditions** – the meanings that people ascribe to events are an important determinant of whether a transition is experienced as healthy or otherwise [23]. Preparation or lack of it can also inhibit someone's transition experience.

– **community conditions** – resources within the community can impact significantly on the experience of the transition (e.g. compare the public resources, and resulting outcomes, devoted to supporting new mothers as opposed to the little support there is for bereaved older people).

– **societal conditions** – cultural beliefs and attitudes are important influences here, as are socioeconomic status, which itself defines the key cultural framework for an individual. Attitudes in society about the nature and timing of life events and their associated transitions can pre-determine an individual's experience of a transition.

PATTERNS OF RESPONSE

● **Process and outcome indicators** – things that characterise whether the transition has been undertaken successfully:

– **Process indicators**
The process indicators suggested [23] include:

– Feeling connected

– Interacting

– Developing confidence

– Coping

– **Outcome indicators**

– Mastery

– Fluid integrative identities

A healthy completion of a transition can be determined by the extent to which people demonstrate mastery of the skills and behaviours needed to manage their new situations or environments. Identity reformulation can also represent a healthy completion of a transition. The need to feel and stay connected is generally an indicator of a healthy transition. Through interaction, the meaning of the transition and the behaviours developed in response to the transition can be uncovered, clarified, and acknowledged, which usually leads to a healthy transition [20].

This framework is represented graphically opposite – adapted and amended from Meleis [23] (**Fig. 2.3.2**). **This framework will be used to guide the analysis of each of the life transitions addressed in this report.**

FIG. 2.3.2

NATURE OF TRANSITION

Types
Developmental
Situational
Health/illness
Organisational

Patterns
Single
Multiple
Sequential
Simultaneous
Related
Unrelated

Properties
Awareness
Engagement
Time span
Critical points/life events

Change and difference
Sense of purpose
Identity
Beliefs
Capabilities
Behaviours
Environment

TRANSITION CONDITIONS: FACILITATORS AND INHIBITORS

Personal
Meanings
Cultural beliefs and attitudes
Socioeconomic status
Preparation and knowledge

Community   Society

PATTERNS OF RESPONSE

Process Indicators
Feeling connected
Interactions
Developing confidence
Coping

Outcome Indicators
Mastery
Fluid integrative identities

DILTS FRAMEWORK

As noted above, the Dilts 'neurological levels' framework has been incorporated into the model for understanding transitions. It is used because of its power to help categorise the nature and impact of a transition on a person's 'inner world'. This framework allows us to gain some insight into how significant a transition might be to a person on the emotional level:

- **Sense of purpose** – impact on people's motivation and meaning in life

- **Identity** – impact on how people feel about their role and place in society

- **Beliefs** – impact on what people believe to be true or important

- **Capabilities** – how people's talents and abilities are affected

- **Behaviour** – what changes might be required in the actions the person takes in their day to day life

- **Environment** – what changes may be required in their living arrangements or where they carry out their day to day activities

The Dilts pyramid is a model of personal consciousness. It consists of a series of levels, each of which is constituted from, while also constraining, the one below. For example, one's capabilities define which behaviours one is able to engage in, but are also made up from one's behaviours to date. And one can only gain new capabilities by engaging in new behaviours.

When applied to the various transitions in later life it is possible to gain a high level picture of how they might impact on people emotionally: (**Fig. 2.3.3**)

FIG. 2.3.3

Key

⬛	High Impact	Scores **3**
⬛	Moderate Impact	Scores **2**
⬛	Low Impact	Scores **1**

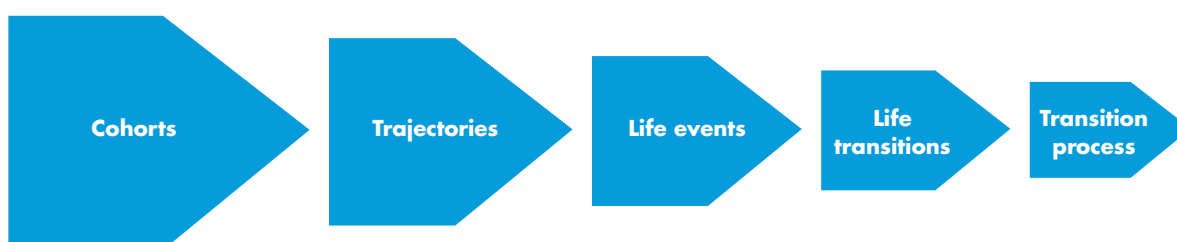|	Retirement	Moving Home	Grandparent	Relationship breakdown	Becoming a carer	Bereavement	Health Condition	Entering Care	End of Life
Purpose	High	Low	Moderate	Moderate	High	Moderate	Moderate	High	High
Identity	High	Moderate	Moderate	High	High	High	Moderate	High	High
Beliefs	Low	Low	Low	Low	Low	Low	Moderate	Low	Moderate
Capabilities	Moderate	Low	Low	Low	High	Low	High	Moderate	Moderate
Behavior	High	Low	High	High	High	Moderate	High	High	Moderate
Environment	High	High	Low	High	High	Low	Moderate	High	Low
Total score	15	9	11	13	16	11	14	14	13

A high score indicates a greater level of 'disturbance' across a range of psychological domains. It does not indicate whether the emotional impact is positive or negative – just an indication of the scale of changes that have to be addressed psychologically and emotionally. This analysis is developed further in each of the sections about a transition. It is also included in the section on "Prioritisation" (below).

SUMMARY

Viewing ageing as part of the life course provides a much more comprehensive framework for understanding and analysing the ageing process. The notion of cohorts and trajectories allows for some of the patterns and groupings in life to be captured. Socio economic factors are key here, but there are others relating to ethnicity and gender which can play a strong part. The focus on life events replaces the narrow and artificial categorisation by age. Age can only provide a partial and very broad context for ageing; the idea of concentrating on life events on the other hand allows for the great variety in life whilst at the same time capturing the key issues in people's lives. The concept of life transitions provides a very rich and detailed lens through which to examine the key issues in people's lives. A transition often brings with it a change in identity and sense of purpose, which along with other domains helps us to understand the impact on individuals and groups. And an understanding of the varieties of transition processes allows consideration of the psychological and emotional stages that people often have to negotiate as they address the changes in their lives.

An overview of life transitions and their place within a life course approach can be summarised as follows:

Cohorts → Trajectories → Life events → Life transitions → Transition process

3
ANALYSIS OF TRANSITIONS

3.1
RETIREMENT

Retirement is the quintessential life transition. For many it is the milestone that truly signifies their entry into 'old age'. It is estimated that about 650,000 turn 65 each year, many of whom will chose that time, or sometime near it, to retire.

DEFINITION

The transition into retirement is commonly understood as the process of moving from active engagement in the labour market to exit from it, being supported instead through pension income. As we will see below, this definition is severely challenged by some of the social changes taking place. Interestingly, the term has its origins in the sense of '*to withdraw to a place of safety or seclusion*".

NATURE OF THE TRANSITION

Retirement is a developmental type of transition. It is inextricably linked to a certain developmental phase in life and is closely associated with a major change in identity.

The pattern of this transition varies. The traditional model is the 'cliff edge' where working life suddenly ceases, to be replaced by a period of economic inaction. However new models are emerging and becoming increasingly prevalent – i.e. a phased retirement, where paid work commitments gradually reduce over time. This appears to be an option for around a third of retirees [24]. Around 40% of these people want to exercise this

option because they like working, and around 44% do it to remain active and keep their brains alert. However it must be recognised that this fluidity is more available to white collar than blue collar workers [9]. (**Fig. 3.1.1**)

This fluid approach to retirement makes it increasingly difficult to identify a clear transition. With this new flexible approach to retirement one has to ask – when does the process start and when does it end? And it can be further complicated by those people who replace paid work with an almost equal volume of volunteering, civic duties or caring responsibilities. Has such a person 'retired'? They might be economically inactive, but they are clearly continuing to contribute hugely to society. This, along with the huge increases in longevity make it imperative that a new term and narrative for 'retirement' needs to be created.
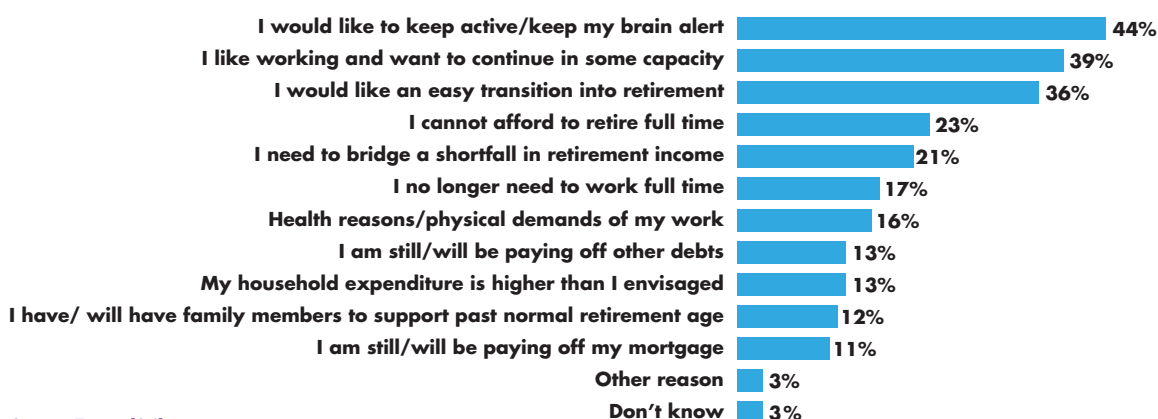
For most people retirement is known about, anticipated and planned for and for most people there is a degree of control about when it will occur (notwithstanding the changes to state pension ages – see below). It is also generally viewed as a desirable transition, although there are two possible scenarios for retirement:

- on the one hand it may promote a sense of wellbeing as workers move out of stressful and demanding career jobs
- on the other hand it may lead to diminished wellbeing as workers loose their occupational attachments, their work colleagues and a major anchor for their identities.

Couples
It is also important to note that this life transition is seldom experienced as an isolated adult. For most people, couples are undergoing two retirements – his and hers [25]. Retirement is a 'couple phenomenon'.

FIG. 3.1.1. Why have you moved from working full time into semi-retirement?

Reason	%
I would like to keep active/keep my brain alert	44%
I like working and want to continue in some capacity	39%
I would like an easy transition into retirement	36%
I cannot afford to retire full time	23%
I need to bridge a shortfall in retirement income	21%
I no longer need to work full time	17%
Health reasons/physical demands of my work	16%
I am still/will be paying off other debts	13%
My household expenditure is higher than I envisaged	13%
I have/ will have family members to support past normal retirement age	12%
I am still/will be paying off my mortgage	11%
Other reason	3%
Don't know	3%

Source: Twigg [24]

Many spouses retire at different times, which adds its own dynamic and complexity into how an individual experiences their retirement. Four patterns have been identified [26]:

- **traditional** (only the husband worked and retired)
- **dissynchronised husband** initially (both worked, husband retired first)
- **dissynchronised wife**, (both worked, wife retired first)
- **synchronised** (both worked and retired at the same time).

Researchers report that the effect of retirement varies across these retirement styles [27]. For example, in one study, ten percent of wives in the **traditional** retirement style complained about loss of autonomy and indicated that their marital happiness decreased after their husband retired, whereas 33% in **synchronised** styles reported increased happiness after they retired [28]. Another study found that husbands' retirement had a negative effect on their marital satisfaction and on the marital satisfaction of their working wives until the wives retired [29].

Long term married couples in the future will probably be faced with tougher decisions regarding the coordination of their retirement dates as more older couples will consist of two continuously employed partners. Moreover, many more of the wives will have an established career rather than sporadically assuming

different short-term jobs. How greater commitment and investment to career might affect the retirement decisions of married women relative to their husbands' decisions is unknown, but they may be less willing to follow the retirement timing choices of their husbands. When their older and possibly less healthy husbands are ready to retire, these women may resist because of their own career interests and attachments [27].

PROPERTIES

With regard to the properties of this transition experience, most people are all too aware of the impending nature of retirement, except those who are unlucky enough to experience a sudden redundancy. And most people are truly engaged in the process, at least on the level of thinking about their financial situation. However there is evidence of a lack of advance planning in this regard, with many experiencing financial shortfalls. Some research [24] suggests around 42% of retirees indicate that some of their retirement hopes and aspirations will not be realised as a result.

Individual's engagement with the retirement process seldom extends beyond the financial aspect and the idea of having a holiday and travelling. There is a lack of a modern vision for retirement in the current context where people retiring now can expect to live for another 20 to 30 years, most of which will be spent in good health. In particular there is very little discourse or engagement with the psychological or emotional aspects
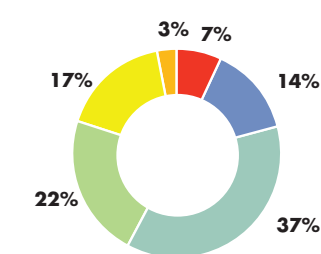
FIG. 3.1.2

Q: Thinking about your income in retirement, how does it compare with your income immediately before you retired? (Base: Fully retired)

- 4%
- 11%
- 19%
- 22%
- 23%
- 21%
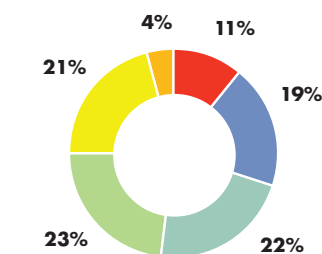
- 🔴 Greater
- 🔵 About the same
- 🟢 Up to 25% lower
- 🟢 26% to 50% lower
- 🟡 More than 50% lower
- 🟠 Don't know

Q: To what extent is your retirement income in line with your expectations before you retired from full time employment? (Base: Fully retired)

- 3%
- 7%
- 14%
- 37%
- 22%
- 17%

- 🔴 A lot more
- 🔵 A little more
- 🟢 About the same
- 🟢 A little less
- 🟡 A lot less
- 🟠 Don't know

Q: Thinking about your outgoings in retirement, how do they compare with your outgoings immediately before you retired? (Base: Fully retired)
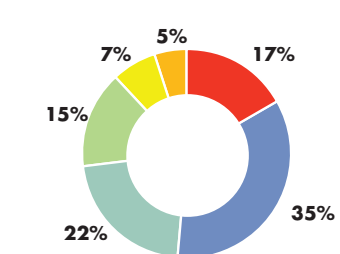
- 5%
- 7%
- 17%
- 35%
- 22%
- 15%

- 🔴 Greater
- 🔵 About the same
- 🟢 Up to 25% lower
- 🟢 26% to 50% lower
- 🟡 More than 50% lower
- 🟠 Don't know

Source: Twigg [24]

of retirement. This is particularly problematic as the scale of personal change occasioned by retirement can be extensive. (**Fig. 3.1.2**)

IMPACT

Retirement can affect all the personal levels identified by Dilts [21]:

- **Sense of purpose**: work provides many people with a significant element of what makes their lives meaningful. For most people it is second only to family in defining their sense of purpose in life. The end of work can therefore cause significant psychological disruption

- **Identity** – is hugely affected. Retirement is de facto an admission into 'later life' and is commonly associated with the marker of moving from an 'adult' to becoming an 'older person'

- **Beliefs** – although perhaps not affected as much as other elements, belief systems can undergo reappraisal, particularly as they relate to how the person makes sense of themselves and their place in the world

- **Capabilities** – can be hugely affected. Skills that were routinely deployed in the work place can become redundant. However this can also become a time when people relish the prospect of learning new skills and having the chance to learn things they have always been interested in.

- **Behaviour** – usually changes significantly, most obviously by the fact that former work activities become redundant and other behaviours usually replace them

- **Environment** – the workplace is substituted with another environment for the person to spend their time in.

So there is little doubt that retirement is a major life transition.

Health and wellbeing
The empirical evidence about the health and wellbeing outcomes of retirement is inconclusive. Some researchers have identified a significant negative association between retirement and life satisfaction [30, 31]. New research [32] suggests that retirement *decreases* physical and mental self assessed health:

- Retirement increases the probability of suffering from clinical depression by about 40%

- Retirement increases the probability of having at least one diagnosed physical condition by about 60%

- Retirement increases the probability of taking a drug for such a condition by about 60%.

Others have found a positive effect of retirement on health and wellbeing [33, 34].

FIG. 3.1.3
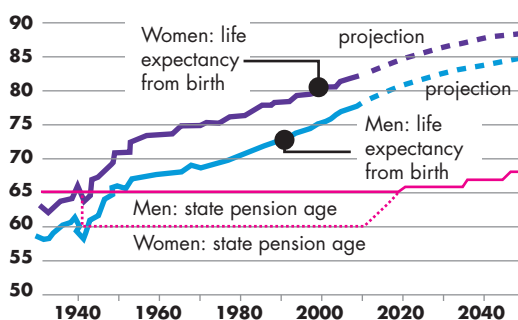
Source: Oxford Institute of Ageing

INFLUENCING FACTORS

There are a number of factors which influence how people experience this transition.

Time span and critical points
Age is becoming less and less of a determinant of retirement [9]. As noted elsewhere – it is becoming increasingly difficult to define the time span of retirement as the cliff edge model gets replaced with a more gradual approach. Some researchers [35] cite this change as "*a de-institutionalisation of the life course*" in that the major milestone that defines entry into old age is no longer standardised or predictable.

It is instructive to note from this graph that a proper period of average life expectancy post pension age did not really begin to appear until the late 1940s and 1950s. Prior to that retirement was not a real life transition for most people. The situation is dramatically different now with most people likely to live a further 20 years post pension age, most of it in good health. This demographic change alone obviates the need for a radically new concept and narrative for 'retirement'.

It is also important to note that, regardless of future raises in the state pension age, there has been a steady increase in the age of retirement since the early 1990s with the number of people over 65 in employment reaching 1 million in 2013 for the first time. For those over 65 the average employment rate in the UK is now 9.5%, though there are significant regional variations. (**Fig. 3.1.4**)

FIG. 3.1.4. Employment rate age 65+
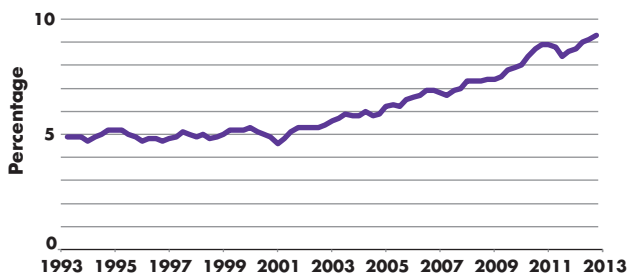
Class

There is a class dimension to this. People are more likely to remain in the labour market when they have worked in high status occupations such as managers and professionals, characterised by high social skills and low physical demands [36].

Gay and lesbian

Sexual orientation makes a difference too. Older gay, lesbian and bisexual people are more likely to be in work than heterosexual people [37]. 67% aged between 55-59 are in full or part time paid employment compared to 52% of heterosexual people of the same age. The trend continues as people get older (see **Fig. 3.1.5**).

FIG. 3.1.5. Over 70 in paid employment
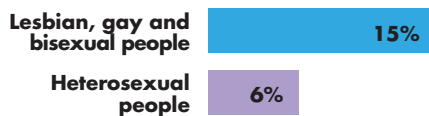
Source: Stonewall [37]

Financial issues are significant concerns for older gay, lesbian and bisexual people. Heterosexual people are more likely to rely on financial support from family and partners and are more likely to be able to rely on their home as a financial asset for the future. However, lesbian, gay and bisexual people are more likely to be reliant on personal or employer pensions and to be worried about their future housing arrangements [37]. (**Fig. 3.1.6**)

Ethnic minorities

There are particular challenges facing older people from Black and Ethnic Minority (BME) communities. While pensioners as a group tend to be poorer than other people in the UK, the evidence [38] demonstrates that BME older people are likely to have lower income than white people. In one study [39] for example, the average weekly income (2005) for white people between the ages of 65-69 was £191, while for BME men it was £132 and for women it was £90. White pensioners are also more likely to receive occupational pensions than older BME people and they (BME older people) are more likely to be dependent on means tested benefits. This financial background is likely to have a big impact on the decisions that older people from BME communities make about the transition into retirement.

Decision making

It is important to understand how people make decisions about when they will retire. Now that the default retirement age has been abolished the time of retirement is theoretically up to the individual to decide. As we have seen above however, there are already strong societal norms and patterns to the time in people's lives when they decide to retire. The state pension age is clearly a significant trigger as the following table illustrates:

For year 2011	Women	Men
In work, **pre**-retirement age	72%	70%
In work, **post**-retirement age	34%	11%

Note – retirement age for women in 2011 was 60; for men it was 65.

Whilst financial and health concerns are a major part of the retirement decision there are other issues which have an impact. Health issues and caring responsibilities are significant, but cannot account for even the majority

FIG. 3.1.6. Personal or employer pension as important source of future income

Source: Stonewall [37]

of the number of people who exit early from the labour market. Research in the areas of judgment and decision making and behavioural economics suggests that there may be a number of behavioural factors that have an influence [40].

When deciding to retire individuals very likely compare what they imagine life would be like if they retire now with what they imagine life would be like if retirement was delayed. People therefore need to have an accurate prediction of their future emotions. However the research evidence [41] shows us that people do not tend to make accurate forecasts of their emotional states (something which is called 'affective forecasting'). For example, prediction errors can result from 'impact bias' – that is, individuals' tendency to overestimate the intensity and duration of their emotions in reaction to positive and negative future events [40]. In other words they imagine that the event would be better or worse than it actually turns out to be. Inaccuracy in this aspect of decision making can lead people to make sub-optimal decisions.

Recognising the role that affective forecasting can play in the retirement decision can give important insights into why people retire when they do. Potential retirees are very likely to mentally simulate what retirement would be like before deciding to retire or not. There are a number of characteristics which often lead to a mismatch between mental simulations and actual experiences [40]:

- Mental simulations can be **unrepresentative**: which means that they are constructed from memories of past events that do not necessarily reflect how future events will unfold. Individuals tend to remember the best and worst aspects of any event, neglecting the instances which were simply average. On top of this there tends to be a negativity bias. This then means that when people are deciding whether to keep working or to retire, their mental simulations are likely to be negatively skewed, potentially leading people to leave the workforce sooner rather than later.

- Mental simulations can be **essentialised**: which means that they only contain the main features of the event but not the more minor details. Essentialised mental simulations of retirement may therefore lead people to focus on the major aspects of leaving the workforce, such as large amounts of leisure time, to the exclusion of the seemingly smaller details, such as possibly having few retired friends with whom to spend this newly acquired leisure time.

- Mental simulations may be **abbreviated**: which means that they are necessarily shorter than the actual event being simulated. Abbreviated projections generally contain only the earliest moments of the event in question. Therefore when mentally simulating how retirement might be, a potential retiree is quite likely

to consider only the early stages of retirement, and those early events tend to be the most positive aspects of retiring. They may therefore fail to consider some of the more long lasting effects of retiring, many of which might be more negative.

All the above characteristics of mental simulations may contribute to potentially inaccurate affective forecasts of retirement. Individuals may choose to retire early both because they think working longer will be worse than it is and because they think life in retirement will be better than it is [40]. Demonstrating that affective forecasting errors occur when individuals are thinking about when they should retire could be useful in developing interventions for overcoming, or de-biasing such prediction errors.

Theoretical models

There are a number of theoretical models for understanding retirement as a life transition:

Role theory [8] in conjunction with a life course perspective [42] provides the most commonly used explanations of adjustment to retirement [25]. From this perspective people who retire are vulnerable to feelings of role loss which can lead to psychological distress. Alternatively it can be a major 'role exit' that reduces stress and overwork. Clearly there are a lot of factors which will influence what each individual experiences, including the nature of the work role, timing and nature of retirement, personal and social circumstances etc.

Continuity theory proposes that people tend to maintain their earlier lifestyle patterns, self esteem, and values even as they exit their primary career jobs [25] . Therefore retirement need not lead to distress.

Life Course Ecological Model [25] proposes that the link between retirement and psychological wellbeing can best be understood through the lense of a life course, ecological perspective which focuses on process, the interdependency of linked lives, and context.

Correlates

Research indicates three possible factors which are likely to contribute to psychological wellbeing in retirement:

- **Economic resources** – it is pretty obvious that inadequate incomes and financial problems cause dissatisfaction in retirement. Research [25] indicates that income adequacy has a bigger impact on men's morale than that of women.

- **Personal resources** – these include socioeconomic status, health and personality. However the most important individual difference affecting the experience of retirement appears to be a **sense of personal control** in the retirement process. Evidence

from a range of studies suggests that a sense of personal control has a significant influence on retirement adjustment [43–45]. For example, a low sense of self efficacy has been found to be one of the best predictors of pre-retirement worry [43]. Other research [46] shows that those who stopped work and felt they had little or no choice reported lower levels of health and psychological wellbeing compared with those who voluntarily retired and worked the hours they preferred. This would suggest that there is a need to ensure that people have as strong a sense of control around the retirement process as possible.

● **Social-relational resources** – developmental processes such as retirement always take place in the context of ongoing social relationships [25]. Individuals' retirement decisions are often influenced by their spouse's personal and work circumstances. "*It is crucial to consider the work or retirement statuses of both spouses, given that each spouses's retirement transition represents an important life event for the couple, requiring adjustment on the part of both spouses.*" [25]. Strong emotional support from a spouse can be crucial to a person's experience of retirement. Note that research shows that women's psychological wellbeing is more heavily influenced by marital quality than men's.

Context

To fully understand the links between retirement and psychological wellbeing one must also consider the contextual factors within which retirement is situated - "*Retirement is not just a state but a complex process, embedded in prior psychological resources as well as gendered experiences*" [25]:

● **Gender** – because of the nature of their work histories and social roles, women appear to adjust to retirement differently from men [25]. In particular women tend to have more negative attitudes towards retirement than men and this is linked with greater levels of depression and loneliness [47].

● **Prior levels of psychological wellbeing** – are hugely influential, with a high baseline of wellbeing likely to continue into retirement. Research indicates that men tend to experience increases in their morale as they undergo the transition into retirement [25, 48]. There is also evidence of a "honeymoon" phase immediately after retirement [47]. It is suggested that right after the retirement event there is often a euphoric, busy, honeymoon phase during which retirees may feel more energetic, healthy, and satisfied as they pursue desired plans or experiment with new activities and roles. Research findings support the "reduced role strain" hypothesis – i.e. that in general, retired men feel released from the pressures of their career jobs, and thus retirement is

beneficial for their psychological wellbeing. Men retiring from jobs who have low morale tend to experience greater improvements in morale following retirement. However there appears to be a difference in the experience of those moving into retirement and those who have been retired for a while. Continuously retired men tend to report greater incidence of depressive symptoms, suggesting that being retired, as opposed to moving into retirement, may be a significant contributor to depression in later life [33, 49]. Baseline psychological wellbeing comes in here with those with higher levels managing to mostly maintain their wellbeing through and post retirement.

● **Attitudes** – Personal attitudes towards retirement have been found to be crucial in determining a successful transition into retirement. A ground-breaking piece of research [50] examined the impact of people's attitudes towards retirement on their health outcomes, particularly their longevity. The study involved nearly 400 people and found that participants with positive attitudes towards retirement lived significantly longer than those with negative attitudes. The study asked people approaching retirement – "*What best describes what you think about your life in retirement and how your life will be during your retirement?*". After following participants up to 23 years later the researchers found that participants with more positive ratings of retirement tended to live significantly longer. Those with positive attitudes had a 52% probability of surviving compared to 36% for those with negative attitudes, even after controlling for relevant variables. In other words positive attitudes towards retirement increased longevity by an average 4.9years! The findings were deemed to be statistically significant. Other factors could have contributed to the findings; however attitudes to retirement were found to have made a greater contribution to survival than all other co-variants, including functional health. (**Fig. 3.1.7**)

FIG. 3.1.7. Attitude towards retirement (ATR) predicts survival
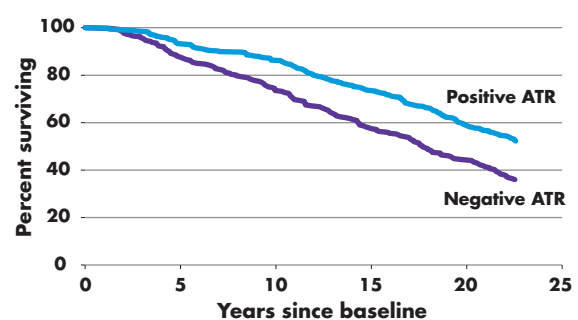
Source Levy, Lakra [50]

So what is it about attitudes towards retirement which are causing this kind of difference? The researchers think that it is largely explained by health behaviours and/or stress. Other research [51] has shown that people with negative attitudes towards ageing in general are less likely to engage in healthy behaviours such as adhering to prescribed medications or eating healthy diets. Research has also shown that negative attitudes generate stress by defining retirement in terms that are a threat to wellbeing. The researchers conclude – *"Traditionally, preparations for retirement have focussed on financial matters, but our findings indicate that psychological preparedness also deserves attention."*

SUCCESSFUL TRANSITION

The things which characterise whether the retirement transition has been successfully completed are to some extent contested. The mainstream narrative is minimalistic in its expectations. Retired older people are expected to have a holiday, generally keep out of the way, not get depressed and try not to use up too many health services. This old narrative is becoming replaced by two alternatives:

● **Successful Ageing** – On the one hand there is the emergence of a 'successful ageing' movement which is focusing on how older people can re-interpret their later life and make it into one of the most satisfying and productive times of their lives [52–59].

Here the characteristics of successful ageing include [52]:

 – Positive evaluations of one's past life (**Self Acceptance**)

 – A sense of continued growth and development as a person (**Personal Growth**)

 – Belief that one's life is purposeful and meaningful (**Purpose in Life**)

 – The possession of quality relations with others (**Positive Relations with Others**)

 – The capacity to manage effectively one's life and surrounding world (**Environmental Mastery**)

 – Sense of self determination (**Autonomy**).

● **Selfish Giant** – On the other hand, fuelled by an analysis which claims that older people have had a disproportionate share of the nation's wealth [60, 61], with claims that the baby boomer generation is a "selfish giant", there is the beginning of a trend to want older people to be forced to contribute to society – e.g. through undertaking voluntary work in return for their benefits [62]; vacating larger properties to enable families to live in them, and leaving paid work

early to 'hand over the jobs' to younger people. These ideas are by no means mainstream yet, but they do represent a different view of what a successful transition into retirement might constitute.

As with many other life transitions there is a risk of loneliness and isolation amongst retirees. For many people the heart of their social life is the workplace. Once they leave this then some people can experience real problems maintaining strong social connections.

INITIATIVES TO SUPPORT PEOPLE UNDERGOING THE TRANSITION INTO RETIREMENT

There are three main categories of initiatives – information, policy and training.

Online information

There are a number of online resources with information and advice about retirement. It is striking that nearly all of them focus exclusively on the financial planning aspects of retirement. There is very little on the wider dimensions, including the psychological or emotional aspects:

Retirement Reinvented
http://www.retirementreinvented.com/

Satisfying Retirement
http://satisfyingretirement.blogspot.co.uk
/2012/02/adjusting-to-retirement-being-together.html

Planning for retirement – **Age UK and Paul Lewis**
http://www.ageuk.org.uk/money-
matters/pensions/planning-for-retirement/

Pensions and retirement
https://www.moneyadviceservice.org.uk/en
/categories/pensions-and-retirement

Preparing for Retirement – **Citizens Advice Bureau**
http://www.adviceguide.org.uk/england/debt_e
/debt_pensions_e/debt_nearing_retirement_e/preparing
_for_retirement.ht

The Pensions Advisory Service
http://www.pensionsadvisoryservice.org.uk

My retirement: What do I need to know – **Which guide**
http://www.which.co.uk/money/retirement/my-
retirement-what-do-i-need-to-know/

Plan your retirement income – **Government website**
https://www.gov.uk/plan-retirement-income

Policy

With regard to policy, the Government has initiated a number of policy changes in recent years, in particular the removal of the default retirement age and the automatic enrolment of people into occupational pensions. The removal of the default retirement age is expected to have a significant impact on retirement as a life transition. It gives individuals additional control over when and how they want to retire. Some will still want to retire early, but for others there is an expectation that more people will delay their retirement date, and others will develop more flexible approaches (as already noted above). Another important policy development is that since 2006 individuals have been able to continue to work for an employer whilst being paid an occupational pension by that employer.

Training

The other potentially significant initiative is offer of pre-retirement courses to older employees.

There is very little research into pre-retirement courses or their effectiveness. In trawling what literature there is it is clear that the general focus of pre-retirement courses is on financial planning (including pensions and investment strategies), health, and leisure activities and volunteering. There is little if any evidence of the inclusion of the psychological or emotional dimensions of the retirement process. In that sense there is a clear mismatch or gap between the significance of retirement as a life transition (as outlined above) and the reality of the initiatives which are on offer.

There is some evidence of more progressive thinking emerging. A recent EU project [63] set out their ideas for an ideal pre-retirement course:

The objectives of the pre-retirement courses are that participants will:

- Be more conscious of their own strengths and competencies, and continually develop and use them as long as possible.

- Be better prepared to find his or her own goals and ways, both in the last part of their professional career on the job and in the years beyond.

- Be able to see through traditional images and stereotypes of ageing and retirement and not to let their new life be predicted by outdated prejudices

- Be able to create his or her own tailor made way to a meaningful and fulfilling life in the third age.

They also set out a list of possible content:

- Presentation of the group of participants and contents of the programme

- Retirement as a transition

- The dynamics of change (time, social relations, money, etc.)

- Histories of life

- The necessary resources (territory and environment opportunities and services, etc.)

- The necessary abilities to be developed (learning how to listen, self-empowerment, group work)

- To become aware of one's own potentials and weaknesses (a balance of competencies)

- Basics to design a project for life (what it is, what does it mean, etc.)

- How to build a project of life

- The pursuit of wellbeing (for him/herself, for neighbour, for other people)

- Social/political commitment.

EXAMPLES

Examples of training / educational programmes to support the transition into retirement include the following:

Ageing with Confidence

Although it is not a 'pre-retirement course' as such there is a very interesting example from Ireland that has the potential to be a more generic approach to preparing people for later life. **Ageing with Confidence** is a course designed to support people to make a positive transition into later life. It is a proactive attempt to build up the resilience of older people to deal with the challenges of later life, including the risk of loneliness and social isolation. It was developed by Age and Opportunity in 2001 as a community education programme. The impetus for the initiative arose from a perceived need for an educational/self-development course targeted at older people to counter negative perceptions of ageing, lack of confidence and to empower them to improve their health and wellbeing. As a means of achieving this goal Ageing with Confidence develops life skills and promotes positive mental health. The programme enables participants to explore their own ageing; challenge the myths and stereotyping that lead to ageism; and provide information on physical, psychological and social aspects of growing older.

The programme consists of 8 weekly two-and-a-half hour sessions. Each session is delivered by two facilitators trained by Age and Opportunity and consists of information on aspects of ageing such as:

- Self-Confidence and Ageism

- The Components of Self and Physical Ageing
- Psychological Aspects of Normal Ageing
- Self-Knowledge and Stresses in Later Life
- The Emotional Self
- Improving Self-Confidence
- Isolation, Loneliness and Sexuality in Later Life.

Importantly the course tackles some of the internalised negative thinking that can be a barrier to ageing well or to getting involved in the wider community [64].

My Life My Way

Another interesting example is "**My Life My Way**" which is a low cost, citizen empowerment model being introduced into Denbighshire, Wales from Sweden (where it is known as **Passion for Life**). **My Life My Way** provides a framework for older people which enables them to make incremental positive changes in their lives. It looks at where people are, where they want to be, and what the gap is in the middle between these two points. People are then asked "*what small steps can I make by the next meeting that will help me narrow the gap between where I am now to where I want to be*". In this way, **My Life My Way** encourages genuine citizen empowerment and enables the older person to take responsibility and identify their own small steps to change.

The vehicle used to enable older people to make these small steps to change is the Plan, Do, Study and Act tool, or PDSA.

Sweden's Passion for Life framework is based around four themes:

- Safety in the Home
- Social Networks
- Food & Drink
- Movement.

In Denbighshire's **My Life My Way** a fifth theme has been added – Creativity & Growth, which focuses on age discrimination, happiness, confidence, returning to work and learning.

Passion for Life is felt to be an effective initiative on a number of counts:

- Low cost
- Addressing ageism and commonly held negative stereotypes of older age
- Empowerment of older people through exploring new ways of working, with emphasis placed on small steps to change

- Educates and supports older people to maintain a full life at optimum health and maintain independence despite age or any other condition affecting them
- Provides a structure for people at pre-retirement stage, involving delivery of pre-retirement courses.

Retirement Transition Initiative

The **Retirement Transition Initiative** [65] is expected to be piloted in three areas in 2014. It is an initiative which will aim to equip people who are around the retirement transition with the information, networks, resilience and opportunities they need in order to continue purposeful activity post-retirement. It will aim to improve the economic outcomes, health, and wellbeing of both the individual and their community. Through attendance at a residential training weekend participants will have the opportunity to build social capital with networks of peers, while learning about the challenges of later life and exploring how they can use their existing skills – or new ones – to continue purposeful activity and connect with their communities [65].

VOLUNTEERING

Another key initiative to assist people with the transition into retirement is that of volunteering. The evidence shows that there are significant positive benefits for older volunteers. For example, a recent UK study [66] involving over 5,000 older people was able to conclude – "*there is strong evidence supportive of a causal interpretation of the relationship between volunteering and wellbeing in later life.*" This investigation of volunteering and older people looked at a number of indicators of wellbeing – depression, quality of life, life satisfaction, and social isolation – and how these were affected by people's involvement in volunteering over a two year period. A number of key points are worth noting:

- The wellbeing of older volunteers was greater than that of non-volunteers
- The strength of the wellbeing effect increases with the volume of volunteering undertaken i.e. there is a 'dose effect'
- Improvement in wellbeing is only present where people feel appreciated for the efforts they put into volunteering.

There is a growing body of research which demonstrates the vital importance of purposeful activity and meaningful engagement to health and wellbeing. For example, a recent comparative study [67] across a number of EU countries "*identified strong positive and statistically significant correlations between ratings for well being and for social participation. This indicates that the higher people, aged over 65, rated their wellbeing, the more*

Fig. 3.1.8. Volunteering activity by age group and gender
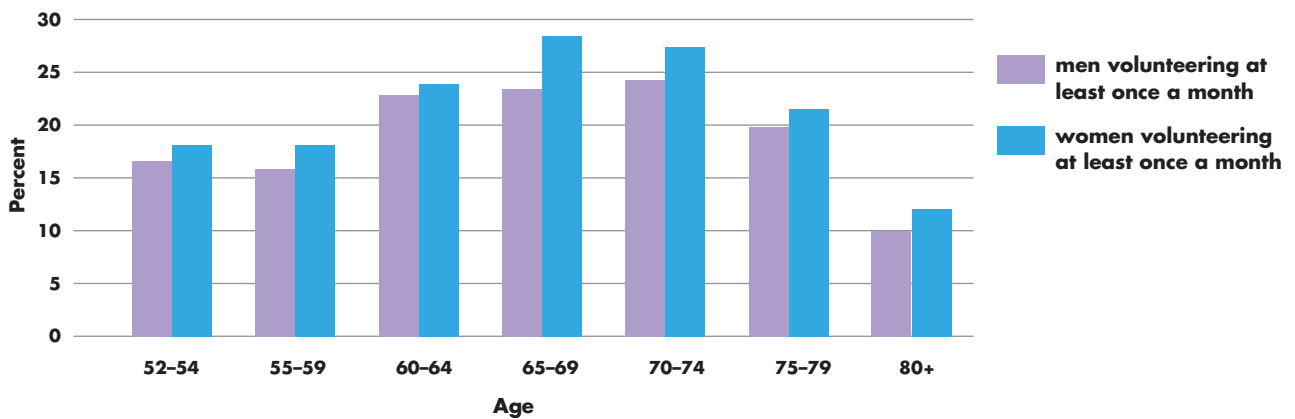
Source: Harries and Las Casas [68]

social activities they participated in." This is not just about volunteering, but volunteering is a key element.

It is clear, therefore, that regardless of when people leave paid employment it is crucial that they have a strong sense of purpose in life and remain socially engaged in one form or another. Volunteering and civic engagement have a huge potential to provide this. Engagement in volunteering can be very important once the 'retirement honeymoon' phase is over when many retirees feel a void in their lives and miss many aspects of working life. Volunteering can fill that gap and give them a new sense of purpose. (**Fig. 3.1.8**)

EMPLOYEE VOLUNTEERING

The transition out of paid employment is therefore a very important policy issue in the context of an ageing society. Employee volunteering has an important role to play in this. Much could be gained by re-focussing employee volunteering as a way of supporting older workers to make the transition into a fulfilling and healthy later life. Traditionally employee volunteering has concentrated on supporting younger employees to develop as individuals, learn new skills, build their confidence etc, and through this boost staff moral and improve staff retention within the workforce. As well as providing these benefits to the company it has largely been seen as a part of a company's 'corporate social responsibility' strategy of supporting their local community or wider society. This approach is worthwhile and laudable. However within the context of an ageing society there are good reasons to change this model and instead prioritise the developmental needs of older workers. In this model, releasing older workers to engage in volunteering can support them to make the

transition from paid work into civic engagement/ volunteering post retirement. Timing is important; engaging those coming up to retirement in volunteering is much more likely to result in their subsequent participation later on.

Refocusing employee volunteering on the developmental needs of older workers could:

- Support new 'post retirement' careers. Some forms of unpaid / part paid work after retirement are beginning to be conceptualised as a sort of second 'career' – which provides meaning, personal development, and a means of working in a field of activity which one is passionate about. The emergence of **Encore Careers** in the USA (see below) is one of the most developed examples of this trend. Employee volunteering could enable older workers to gain new skills and competencies in preparation for this.

- Support 'knowledge transfer' between the generations, within as well as outside the work place – e.g. mentoring /coaching of younger workers by their older peers.

- Support older workers to test out and get engaged in volunteering before they retire and thus become much more likely to remain actively engaged once they finish paid work.

EXAMPLES

Examples of volunteering programmes to support the transition into retirement include the following:

Encore Careers [69]

The 'baby boomers' make up the largest, healthiest, best-educated population in history. Those on the leading edge of the generation are pioneers in a new stage spanning the decades between middle and late life. Neither young nor old, they represent an extraordinary resource. Millions of them are determined to apply their experience to make a difference for others. Some are able to do so as unpaid volunteers. But most are looking to combine aspects of work – income and benefits – with elements of service through what some are calling "encore careers".

Such careers combine social impact, personal fulfilment and continued income – "*purpose, passion and a paycheck*" – enabling people to put their experience to work for the greater good. Unleashing this vast potential requires fresh attitudes, policies and practices that welcome the contributions of older people who want work with meaning, and who want to create a world that's better than the one they were given. **Encore.org** has set out to define this new stage of life and work – and to change policies and create new institutions that will help older people make the transition. People who plan to continue working say it is important that the work gives them a sense of purpose, keeps them involved with people and helps them improve the quality of life in their communities.

Retired and Senior Volunteer Programme

The **Retired and Senior Volunteer Programme (RSVP)** [70] encourages the growing number of over 50 year-olds to volunteer in their local area. Well over 14,000 elderly people now participate in community work throughout England, Scotland and Wales. Activities are organised and led by volunteers, with no limits in terms of project sector or type. Nor are there restrictions as to who can join in: disabled volunteers are welcomed, and there is no upper age limit. RSVP's policy is that "no one is rejected".

Staffed largely by volunteers, RSVP was set up in 1988 within **Community Service Volunteers** (CSV), the UK's leading volunteering and training charity. CSV had offered opportunities since the 1960s, but RSVP was its first programme dedicated to older volunteers. It aimed to address the isolation and sense of purposelessness often felt by the elderly and the retired, while harnessing their skills and experience for the benefit of local communities. This clearly reflects a basic principle of RSVP/CSV: that volunteering not only helps those at the receiving end, but also those who are giving their time. Many volunteers say their work is a reason to get up in the morning.

Community projects are initiated by volunteers themselves, meaning opportunities with RSVP are as diverse as the people running them, covering sectors from health to environment to education to cultural heritage. For example, a project in London matches senior citizens with medical students to help the latter understand the physical and psychological difficulties faced by older people. Another involves 1500 volunteer drivers throughout the UK who transport patients and carers to their appointments, offering not only practical help but also regular social contact – someone to talk to when doctors may be too busy to listen. Many more activities – knitting circles, cooking clubs for men, dance classes and telephone book clubs – take place around the country. Some RSVP projects benefit entire families. For example, the volunteers behind City Can Cycle, on a housing estate in the West Midlands, provide struggling families with refurbished bicycles that have been abandoned or damaged. On average two bikes find a new home each week – over 120 in total so far. The scheme also offers work experience to young people at risk of dropping out of school, giving them concrete skills and boosting their confidence. Another project places some 2000 volunteers in local schools, where they are paired with a student for one-to-one reading lessons. An independent evaluation indicated that when reading regularly with RSVP, children's reading age went up by an average of one year in under three months. Teachers further report that the time spent with a volunteer has helped kids' self-esteem and improved their concentration and performance in other subjects. Volunteers also benefit. Says Doreen, aged 90, who helps children with reading every week: "I love the idea that at my age, I still have a contribution to make to society."

Unlocking Potential Project

Volunteer Now in Northern Ireland works to promote, enhance and support volunteering across Northern Ireland. Its focus is to connect with individuals and organisations to build healthy communities and create positive change.

The '**Unlocking Potential Project**' [71] was a five year initiative which began in 2008. It was funded by The Atlantic Philanthropies and managed by Volunteer Now. The overall aim of the project was to encourage and support healthier ageing and civic engagement in Northern Ireland, by enabling and empowering older people to take part in volunteering. Over its life course the project was informed by ongoing pieces of primary and secondary research.

The first objective of the **Unlocking Potential Project** was to challenge attitudes and raise awareness of the contribution of volunteering (by those from older age groups). One of the findings from initial focus groups with older people was that many had a narrow understanding of what volunteering was or could be (working in a charity shop or collecting money were the two most cited examples). It was also very clear that media coverage and government messages in relation to older people tended to focus heavily on the cost of ageing and the negative aspects of growing older. To overcome this the **Unlocking Potential Project** developed marketing messages and promotional images that featured older volunteers to raise awareness and visibility of the role that older people already play in the community through volunteering The '**One Good Reason'** campaign took the form of a marketing campaign which included billboard, bus and radio adverts as well as a P.R campaign that showcased existing older volunteers and told their story to inspire and encourage others. A telephone survey of 350 older people commissioned after this marketing revealed that 28% of respondents had recently seen advertising of volunteering and 80% of those aged 60+ felt that it appealed to them.

The **Unlocking Potential Project** has also engaged with local councils to encourage them to recognise the impact made by older volunteers in their areas. This has taken the form of sponsorship of "older volunteer of the year" awards which have been adopted by a number of local councils across Northern Ireland [71].

Grandmentors

CSV's **Grandmentors** [72] initiative is a project which harnesses the energy and experience of older volunteers (50+) to support young people to find work, stay on in education or take up training. Many of the young people (age 16 to 25) do not have positive adult role models; others lack direction, some have been in trouble with the police and others have been homeless.

The **Grandmentors** scheme matches older volunteers with young people experiencing these kinds of difficulties. Mirroring the grandparent-grandchild relationship, "grandmentors" give practical advice, support and companionship, for instance helping a young person plan a career, get back into education, or make the transition from care to independent living.

Those participating are expected to commit for a minimum of one year. Mentors and mentees meet weekly for at least three hours. Activities undertaken together vary but may include chatting, playing sport, entertainment such as cinema or theatre, or working together on practical tasks such as job applications. RSVP covers travel expenses and small extras such as coffee.

Grandmentors receive a range of support:

- initial and on-going training
- individual support from the project manager
- regular group support from other mentors
- travel and out-of-pocket expenses

A Grandmentor:

- visits a young person regularly (once a week / fortnight)
- helps work towards goals
- builds relationships based on trust and mutual respect
- acts as a positive role model

Grandmentors have helped young people:

- find an apprenticeship
- get on a college course
- find work experience
- write application forms and CVs
- increase confidence & self-esteem
- try new things
- have fun.

SPICE Community Time Credits

Spice adapted the principles of time banking as a credit system for common purpose. **Spice's Time Credits** [73] are hosted by public and community services and their main function is to credit time that people give to their community. The credits acknowledge time given by local people to support their public service and to volunteering in their local community. Every hour given (Time In), is an hour which can be 'redeemed' against a menu of local recreational services (Time Out). People may give their time to community decision making processes, to local community projects or to organising community groups and events. The credits are low cost; because redemption uses 'spare capacity' (i.e. part empty cinemas, music venues and public sports facilities). The credits are a catalyst to move beyond engaging only the 'usual suspects' to involve a much more diverse range of people. The results are positive, levels of active engagement rapidly increase and the negative cycles of dependency and inactivity begin to unravel. Furthermore, as the credits are embedded within public and community services, they are sustainable and encourage a collective approach between public service professionals and community members.

Evaluation of the Spice initiative [74] has demonstrated some significant benefits:

- Increased self-esteem, confidence and wellbeing
- Improvement in health
- Increased skills development
- Increased motivation and access to paid employment
- A dramatic increase in social capital
- Many more people giving time to the community
- Improved relationships between professionals and members of the community
- Increased collaboration between voluntary and public sector organisations
- Improved relationships between community members and public service staff
- Indication that money is being saved as a result of the improved relationships within the community.

UpLift Time Credits

Spice is creating a new bespoke time credit scheme for health and social care called UpLift. **UpLift Time Credits** [75] engage people in communities who are socially isolated and in particular, older people, and those with long-term ill-health. The credits enable participants to contribute time as well as receive support, so that they are not cast as 'throw away' people but instead as valued assets in their communities and as co-deliverers of health and social care.

UpLift Time Credits enable citizens to connect with each other and to facilitate a care-based 'credit' exchange. UpLift provides individuals with opportunities to develop interests and utilise their, as yet unrealised, personal assets to build strong and connected communities. Uplift does this by seeking out and encouraging individuals with health and social care needs to both receive customised support, but also to contribute to the community by utilising their skills and interests. In reciprocation for giving in this way, individuals are thanked with credits that enable access to cultural and leisure services to develop new networks and improve wellbeing.

ISSUES

There are a number of key issues with regard to the transition to retirement:

- The whole idea of 'retirement' is ripe for challenge and the development of a new 'narrative'. It is important for people's health and wellbeing that current ideas about seeing retirement as a time of relaxation and holidaying is balanced by models and images which promote greater involvement in civic life and general engagement with the world.
- Life post 65 will be a significant period of time for most people, most of which will be in good health. It needs to be recognised as a new and distinct stage of life.
- More graduated approaches to leaving the labour market need to be developed and promoted, particularly for those in manual occupations.
- Little attention is currently paid to the emotional and psychological aspects of ageing. This aspect of preparing for later life needs to be addressed with new support methods being incorporated for example into 'pre-retirement' courses. Attention to people's attitudes towards retirement need to be included in this.
- There needs to be attention to the processes that people use to make their decisions about when to retirement. There is scope for work to 'de-bias' some of the decision making processes that people use.
- Retirement can be a trigger for increased loneliness and relationship breakdown. There is a case for providing more support to enable people to negotiate this transition more successfully. Some of the examples of 'resilience training' could be useful here.
- There are great potential benefits to people approaching the retirement transition to be gained from volunteering. Employee volunteering in an employee's later years could be hugely beneficial to the individual and the wider community.

3.2
MOVING HOME

The home environment becomes of greater importance to older people in later life, especially if their health or mobility deteriorates [76]. Furthermore, a suitable home environment can be crucial to independence, health and wellbeing in later life. The current pattern of housing tenure in later life is set out below (**Fig. 3.2.1**).

Older households (60 plus) are more likely than average to live in non-decent and energy inefficient homes [78]. Older people occupy nearly a third of the housing stock, and it is estimated that soon older people will account for nearly half of household growth [79]. The proportion of older people owning their own homes was about 68% in 2001 and is projected to rise to 75% in 2021 [80].

Lesbian and gay
For lesbian, gay and bisexual people over 55 the situation is rather different. They are much more likely to live alone than heterosexual people. (**Fig. 3.2.2**)

Ethnic minorities
Household composition of BME older people is rather different from the white population. Lone pensioner households in the white community account for a larger percentage of households than is the case for lone pensioners in the BME community (15.6% as opposed to 2.8%) [38]. In terms of individual minority ethnic communities, the Caribbean community has the largest

number of lone pensioner households. Asian older people have been shown to be more likely to live in larger households with relatives; this is especially the case for groups such as Pakistani or Bangladeshi families [38].

NATURE OF THIS TRANSITION

Moving home is generally the sort of transition that is voluntary and one that people can therefore anticipate and have some control over. The biggest exception to this is where people have to move because an impairment or health condition renders their environment inaccessible. The transition itself tends to have a long gestation period from first thoughts to actual completion and establishment in the new environment. It is a major transition in later life involving significant emotional energy and practical tasks. That having been said it only really affects one aspect of the Dilts framework significantly – that of environment. The other dimensions tend to be relatively untouched.

NUMBER OF PEOPLE LIKELY TO EXPERIENCE THIS TRANSITION

Many older people want to remain as long as possible in their own home. In the UK almost 90% of people stay in their own homes until they may have to leave because of illness or bereavement [81]. This figure is much higher than in many other countries where more people choose to move to a home more suited to support them as they age. At present, 1% of the UK's population of over 60-

FIG. 3.2.1. Tenure of older households (England)

Legend:
- private rent
- social rent
- own with a mortgage
- own outright

Source: NPI analysis of the *English Housing Survey*. Average for 2008–09 to 2009–10. *From*: Shelter [77]

FIG. 3.2.2. Living alone

Lesbian, gay and bisexual people: 41%
Heterosexual people: 28%

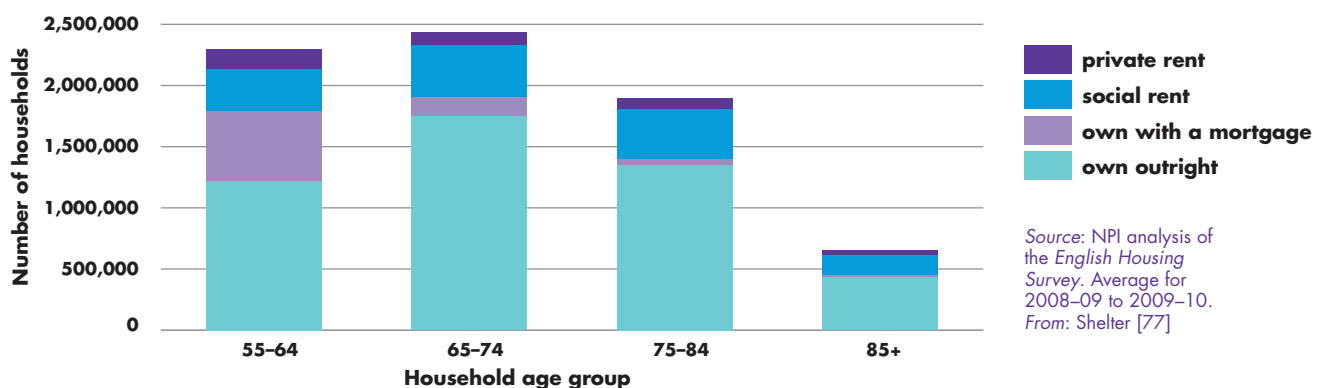*Source*: Stonewall [37]

year-olds live in dedicated retirement communities, in comparison to 17% in the USA and 13% in Australia and New Zealand [80] – there is clearly scope to increase the number here with appropriate schemes and effective communications strategies and marketing.

Older person households are much less likely to move than other households (28% compared with 66%) [82]. Around 2 million older person households have moved at least once within the last 10 years. This suggests that around 200,000 older person households move home each year, around 3% of all older person households [82].

The number of older person households that have moved within the last 10 years by age

Age of HRP	Households resident < 10 years (000s)	% of age group resident < 10 years
55–64	760	33%
65–74	700	29%
75–84	430	23%
85+	120	18%
TOTAL	**2,000**	**28%**

Source: English Housing Survey. Average for 2008–09 to 2009–10. From: Pannell, Aldridge [82]

Around 56% (110,000) move to owner occupation, 14% (28,000) to private rented, and 30% (60,000) to social rented. By tenure group this amounts to a turnover of 2% in owner-occupied households, 7% in private rented, and 4% in social rented among older person households [82].

REASONS FOR MOVING

The reasons for older people moving house are complex and various. The following table provides an insight from the 2009/10 English Housing Survey which asked people there reasons for moving home. (**Fig. 3.2.3**)

Key points to note here are [82]:

- the importance of the neighbourhood in motivating a household to move home regardless of age group

- (unsurprisingly) older person households are much more likely to want to downsize than other households – although this was still only a reason for 20% of older person households

- the most common answer was 'other family/personal reasons', which highlights the complex factors that influence an older person household's decision to move.

Older people can often face events in later life which impact on the suitability of their home for their needs. So for example, moving may be considered in response to bereavement, acquiring a health condition, the need to be nearer to family members, to free up capital, to live in a decent and energy efficient home etc. Moving in later life can therefore be associated with times of distress and uncertainty [83] rather than a simple preference for a nicer environment.

There are therefore many competing factors which influence who and how many people will consider to move home in later life or stay put. The following graphic illustrates some of these competing pressures:

FIG. 3.2.3. Reasons for moving of households that moved within the last two years by age group
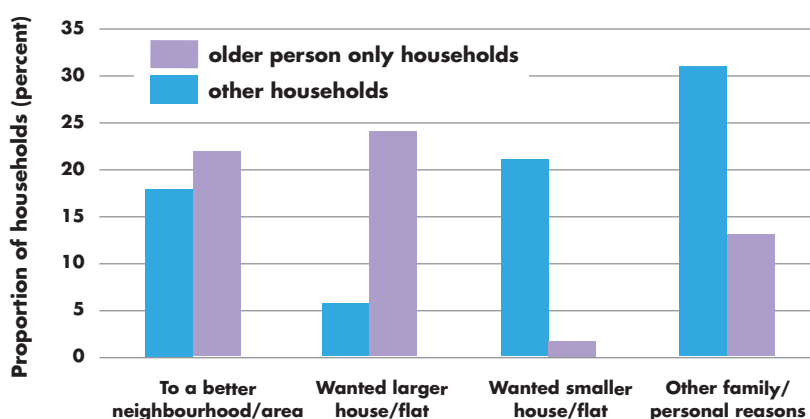
Source: Pannell, Aldridge [82]

Staying or moving – competing pressures

Factors that encourage older people to move home:

- financial/release of equity
- changing circumstances or needs
- availability of more suitable or attractive
- housing/neighbourhood
- good information and awareness of options

Factors that encourage older people to stay in their current home:

- emotional attachment to/satisfaction with home, neighbourhood and community
- fear of moving, costs and hassle of moving
- lack of other housing options or poor awareness of options
- wish to preserve housing wealth for inheritors

Source: Shelter [77]

There are broadly three types of 'movers' among older person households [82]:

- **'Lifestyle' movers** (typically the younger age range) may move to the coast or countryside, to a vibrant city centre, or even abroad, seeking a better quality of life.

- **'Planners'** (typically the middle age range) move before they need to, and while they still have the energy: factors influencing the **planners** include the onset of health problems and a realisation that their existing housing will become less suitable; in terms of quality of life, what is important is that they remain in control.

- **'Crisis movers'** (often the older age range) typically remain in their existing housing as long as possible, until they have to move, often because of accident or ill-health. They are less likely to have any choice and are more likely to end up in a care home even if that is not their preference and when other housing (e.g. extra care) would have met their needs better.

Pannell [82] assesses that there are trade-offs in terms of quality of life between the three groups: **lifestyle movers** make a choice based on (perceived) quality of life; **crisis movers** have been able to stay longer in their preferred housing and have in effect lost their 'bet' that they would not have to move; however if **planners** cannot find what they want, the risk is that they will have to move in a crisis.

Some of the barriers to moving have been identified [83]:

- The amount of time that finding and moving to a suitable property can take can impact as a barrier as older people can find it hard to think ahead because of the uncertainty around their health needs.

- Availability of a suitable property was a key issue. This included long waiting lists for rented warden-controlled properties. Homeowners mentioned the lack of affordability of bungalows and limited supply of owner-occupier property suitable for older people – some just did not like the idea of renting.

- Moving was seen as too daunting. Even where people recognised that living in a more manageable property made sense, they were put off by the upheaval of moving, having to sort everything out and physically packing, emotional ties to their home, not knowing where to move to or how to get the process started.

- There was a resistance to living in properties specifically designed for older people. Occasionally participants mentioned psychological barriers associated with living among 'old people', fearing it would make them feel older themselves and this was seen as a 'last resort'.

- Factors that contribute to wellbeing and quality of life include feeling in control and being able to manage uncertainty. Many owner-occupiers stay put because they are reluctant to move from the known to the unknown or at least to an alternative where they risk having less control [82].

- Research [81] by one specialist housing provider found that the potential stress involved in moving was a more important factor in people's housing decision making than cost.

Lifestyle moves

There has been a long-term trend of people "retiring to the countryside" in later life so that the population in rural areas is generally increasing, while that in urban areas is reducing [84]. This phenomenon has seemed to slow somewhat in the early 21st century [85], but may be predicted to be likely to persist, and likely population change in the rural population is about 15% compared to 8.8% in urban areas [86]. The notion of living in a rural idyll still appears to have a lot of traction. According to a survey by SAGA, 43% of over-50s plan to move away when they retire. Of course there is a class dimension to this with the overwhelming majority of those who move to the countryside being middle class.

Risks

There are risks for those who do move. Isolation in the countryside has been shown to increase the risk that problems are not recognised or are overlooked. People who move to the countryside chasing the myth of the

FIG. 3.2.4. Which three neighbourhood features would be the most attractive to older people if they were to move
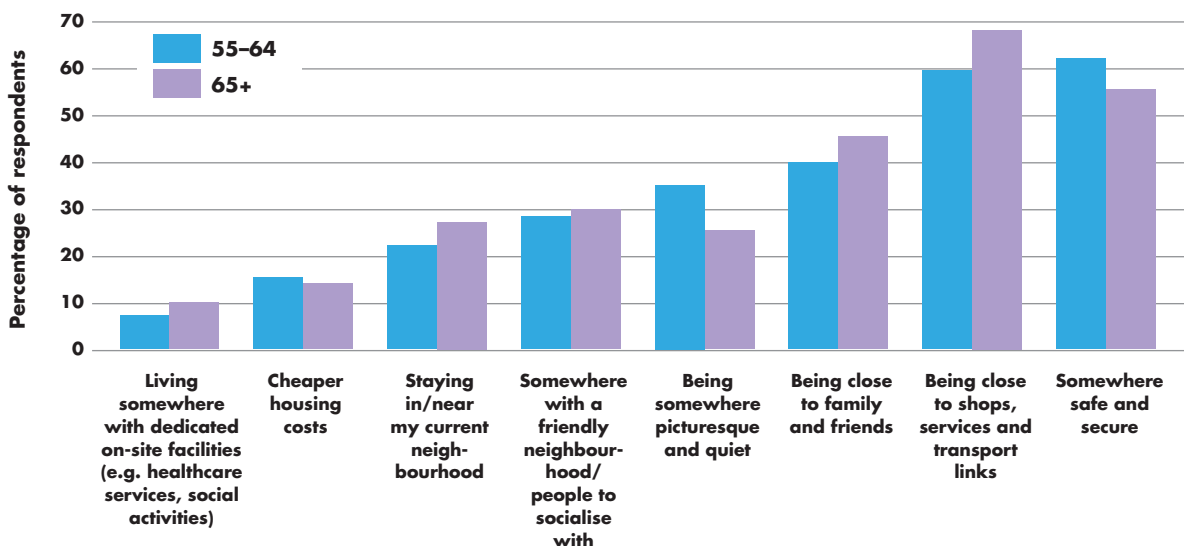
Source: Shelter [77]

rural idyll are in danger of "*ignoring the complex reality of modern rural living for a wide range of groups*" [86]. The rate of rural ageing is faster than in urban areas but the issues are quite different – for example, isolation, transport, access to financial services are all much more problematic for people who live in the countryside.

Illness and disability

One of the major reasons for moving in later life is because illness or disability renders a house inappropriate for someone's needs. Older person households that contain someone with an illness or disability are much more likely to require specific housing; for example, level access housing, or housing requiring a 'floating' support service.

FIG. 3.2.5. Proportion of older person households containing someone with an illness or disability by age

Source: Pannell, Aldridge [82]

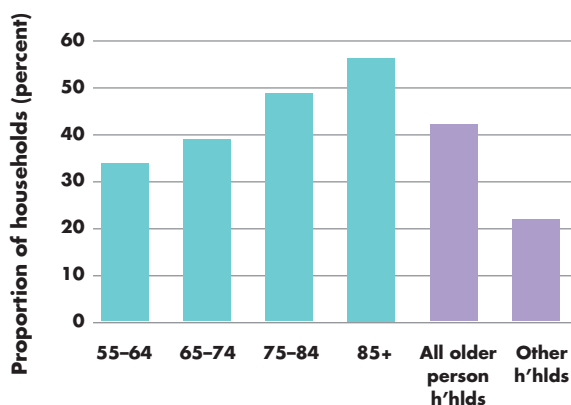As Pannell et al [82] have noted, sick or disabled older person households are notably more likely to live in social rented accommodation than other older person households. This could reflect limited financial capacity or, less likely, that it is better equipped to suit their needs. They are also less likely to be an owner-occupier; however owner-occupiers still make up the majority of sick or disabled older person households.

Supply side

There will always be a 'supply side' dimension to how many people will move home in later life. Research suggests that in the UK there may be an additional 10% of people who would consider moving if they had a choice of attractive homes in the right location [87]. Other survey research [77] suggests that over a third of older people are interested in the idea of retirement housing. Retirement housing currently makes up about 2% of the homes owned by people over 65 and it appears that the supply does not meet present demands.

However, there is very limited choice for older person households moving home to accommodate their support needs (in terms of tenure, location, size, affordability and type of care/support) [82]. And the market does not currently reflect older people's needs. For example, compared to older people's existing housing tenure (around 70% owner-occupation), there is much less specialist housing available for purchase.

Projecting how the demand for specialist housing will change with the growing number of older person households is subject to great uncertainty. Many 'known unknowns' enter including: how the length of stay in

specialist housing will change; how the health and housing needs of older people will change; and how these needs could be met through alternatives to specialist housing such as assistive technology. Nonetheless the number of older person households will increase and a proportion of them will require specialist housing. The analysis suggests that the size of the specialist housing stock will need to increase by anything between 35% and 70% [82].

It should be noted however that, whilst retirement housing is important, many older people reject the idea of age specific housing and are adamant that they want to stay living in a mixed-age community [88, 89].

Household projections

The number of households headed by an older person is expected to change as set out in the following table:

Age of HRP	2008	2033	Change	% 2008	% 2033	Change
55–64	3.6	4.0	0.3	39%	30%	-9%
65–74	2.8	4.1	1.3	30%	31%	1%
75–84	2.1	3.0	0.9	23%	23%	1%
85+	0.8	2.0	1.2	8%	15%	7%
All older HRP h'seholds	9.3	13	3.7	100%	100%	NA

Source: DCLG household projections

The key points are [82]:

- The number of households with an older HRP is expected to increase by 3.7 million, an increase of 41%.

- The 85+ group will experience the largest percentage growth (more than doubling). Households with a HRP aged 65–74 will increase by the largest amount (1.3 million).

- There will be a shift in the age distribution among older households. Households with a HRP aged 85+ will go up from 8% of the total to 15%, whilst those with one aged 55–64 will fall from 39% to 30%.

Downsizing

Some people chose to 'downsize' of their own accord, either to reduce maintenance or gardening responsibilities, and/or to release capital for other purposes. There is also a growing public policy lobby [77, 80, 87, 90] which is seeking to encourage and incentivise downsizing by older people in order to free up capacity in other parts of the housing ladder. It is recognised that downsizing is not the right solution for everyone and that it should be an informed choice; not an obligation.

It is estimated that the level of UK households which are 'under-occupying' their homes is thought to be 37%, of whom half are aged 50–69 (equivalent to 3.3 million homes) [91]. Or to put it another way, 57% of older person households under-occupy compared to 27% of other households [82]. The argument put forward by some is that if older people downsize to more suitable accommodation they will free up family sized homes for younger families who need them (see **Fig. 3.2.6**).

There is also an argument that downsizing will mean that older people can move to more appropriate housing which will support them to remain independent and healthy for longer, thus easing the pressure on health and care budgets [87].

FIG. 3.2.6. Illustration of market chain effect

First-time buyer moves to 2 bed house

Larger family moves to 3 bed house

Older people move to retirement community
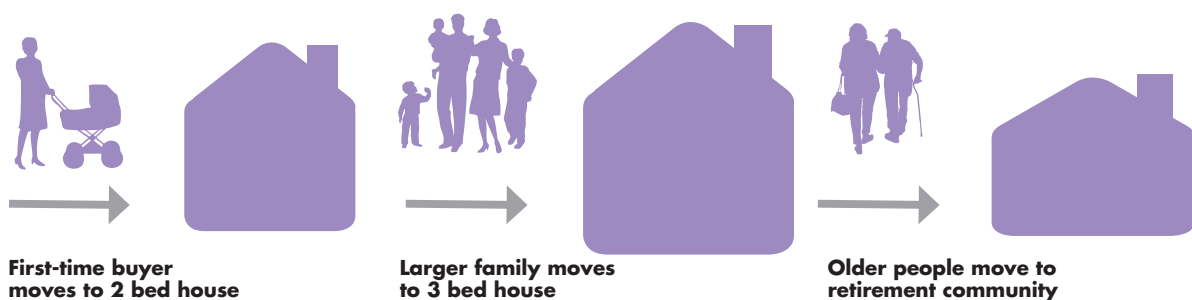
Source: Shelter [77]

HOMES FOR LIFE TOOLKIT

This Toolkit could be used by people across all tenures to assess their homes. Where it is used with professionals, the focus should be on empowering the householder to do the assessment and reach their own decision.

1. How accessible is my home? Slopes, steps, proximity to transport, amenities etc.

2. How many stairs? Could a stair lift be fitted? Is there room for a downstairs toilet or bathroom? Would adaptations be practical and affordable?

3. Will it be affordable to heat and repair?

4. Could it cause accidents? (high cupboards etc.)

5. Assess strength of tie to the home, neighbours, location, garden etc.

6. What are the realistic and affordable options for moving? – Where to get information?

7. Make a housing plan, and decide at what point it is implemented. To stay and adapt, or to split the home, or have a HomeShare, or to move at a certain time?

Source: Sutherland [87]

One of the proposals to support this move to greater number of people downsizing is to encourage people in their 50s and 60s to assess their homes through a "Homes for Life" toolkit. Evidence suggests that once people are in their 70s and beyond it becomes increasingly difficult to make decisions about moving home [87]. People who downsize do so mostly between their mid sixties and seventies.

However there is a strong critique of this 'simplistic' notion of capacity being freed up through older people downshifting. Pannell and others [82], in a rigorous market assessment, concluded that, for various complex reasons, the overwhelming majority of spare capacity released into the market comes from the death of the last older person in a household rather than from downsizing. It also appears that the official definition of unde-occupation is completely at odds with what older people actually chose themselves [82]. That is, older people nearly always want more bedrooms than the Government thinks that they should have.

There is some evidence [82] that the current discussion of downsizing and under-occupation (especially from the government) is upsetting, annoying and distressing, and reflects a lack of concern or understanding of wellbeing and quality of life issues from an older person's perspective.

THE IMPACT THIS TRANSITION CAN HAVE

The prospect of moving home can be very daunting for older people and they often see it as a 'last resort'. Research demonstrates how moving home is an incremental decision making process, often involving a combination of factors.

In terms of the Dilts framework [21], there is little impact on most of the domains (e.g. Sense of Purpose, Identity, Beliefs, Capabilities or Behaviours). The one element which is significantly impacted on is obviously that of Environment.

For those who complete the move successfully, people often report happiness and wellbeing. For example, research [92] with people who had moved into specialist retirement housing found that 92% of them were happy and contented with 83% saying that they were happier than in their previous home.

INTERVENTIONS TO SUPPORT THIS TRANSITION

Support for older people considering the transition to a new home can be crucial. The main initiatives are specialist housing information and advice, and the offer of practical help with a move. Research [83] with older people has established a number of the issues that older people face in moving and the things that helped them through the process:

- Having a friend or family to help was extremely important – from help with sorting and packing through to moving furniture.

- Physical health – mobility and the ability to manage the practical aspects of moving.

- Clearing out a lifetime of possessions was emotionally as well as physically exhausting. Seeing a move as a fresh start, buying new things and decorating helped them cope with the upheaval and sense of loss of continuity, familiarity and place.

- Being able to leave furniture behind for the incoming purchaser was useful when downsizing.

- Staggering a move eased the process – having the new property available before moving out of the old one enabled a more gradual move, although financially this meant paying additional rent.

FIG. 3.2.7

LOCAL AND NATIONAL ADVICE SERVICES

Advice on options · Case work and support · Information · Advocacy · Local policy initiatives

HOUSING ADVICE

NATIONAL ORGANISATIONS

Specialist training · Research and education · Funding for pilot projects · National policy initiatives and changes
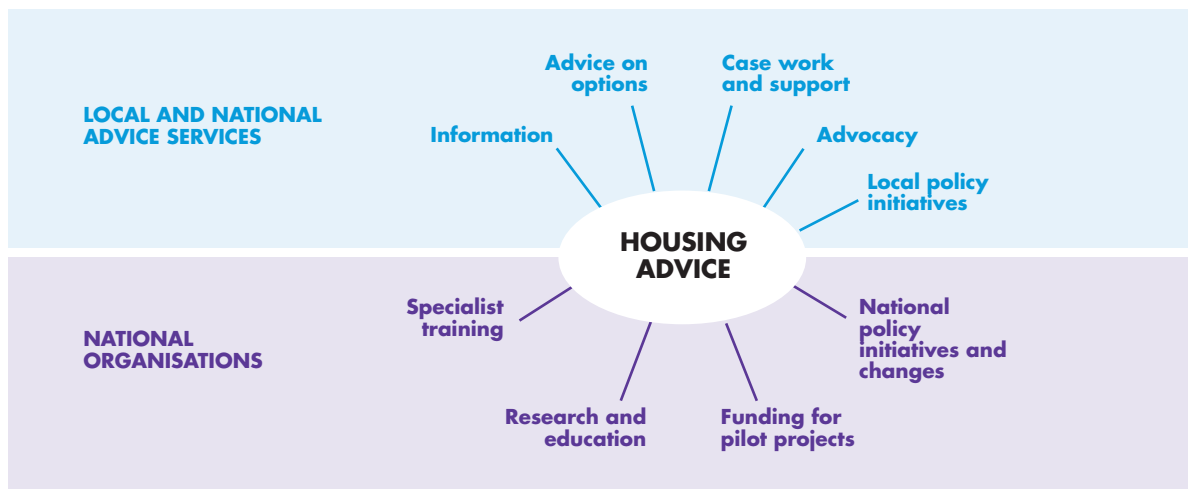
Source: based on Grant [95], as featured in Pannell [94]

Information and advice

Older people require information and advice about a range of things including the type and availability of accommodation appropriate to their needs. They also need information on housing improvement schemes and grants that are available.

Research [93] suggests that the main areas in which older people want information and advice on their housing are:

- Advice on moving – often around a crisis, such as a bereavement or a fall.

- Advice on staying at home , and being able to deal with disrepair, adaptations, benefits and finances.

- To know the options and their implications – "should I stay or should I go?"

- General housing issues – housing rights, housing benefit and income issues.

Housing advice for older people is provided by a range of statutory and voluntary organisations, as categorised below. As well as local providers and national helplines offering a direct service to older people (and to their advocates, friends and relatives, carers and professionals), there are also federations of agencies and national organisations with links to local groups [94].(**Fig. 3.2.7**)

As Pannell [94] notes, there is a problem in drawing the boundaries around 'housing' advice. If an older person has a housing problem to resolve, they are likely to need holistic advice covering issues wider than a narrow housing focus, extending to other related areas such as benefits and community care.This means that advice staff need a broad knowledge and the ability to refer

clients to, and/or work in partnership with, staff in other statutory and voluntary agencies. It is likely to take some time to get to the bottom of the problem; the more vulnerable or marginalised the older person, the more time and skill is needed to develop their confidence and build a relationship.

The overall conclusions from a number of research studies [94] into housing advice services is that general housing-related advice services (both statutory and voluntary) are underused by older people. There appear to be a number of reasons for this (taken from [94]):

- Older people rely mainly on informal support and advice, sometimes from their peers but most often from family members. However, family members are not necessarily well-informed and there may also be emotional or financial considerations that prevent them from giving impartial advice.

- Where older people seek advice from professionals, it is likely to be from people they are already in contact with, e.g. home care staff, sheltered housing wardens or day centre organisers. Again, these people may not be aware of the range of options, issues and services available, or of other sources for referral, and a service provider such as a housing association will not necessarily give independent advice.

- Older people have limited awareness of advice agencies and usually think of all-age services such as Shelter, Citizens Advice Bureaux and law centres as being for younger people. This is particularly so in the case of housing issues, due to the emphasis placed by the media on young homeless people.

- Older people are less likely to attend office appointments or use telephone helplines, preferring home visits or contact through existing links such as community groups (although attitudes to phone or web-based services may well change in the future).

- There is a reluctance to use local authority-based services, particularly where people have already experienced problems (e.g. with Housing Benefit claims). People from vulnerable or minority groups are especially likely to fear prejudice and misconceptions from mainstream services.

- There is a widespread need for emotional support and sometimes advocacy and for older people to develop a trusting relationship with advisers. This requires time and sensitivity, and may also prevent advisers referring their clients on or involving volunteers.

- Some older people need practical help in the short term (e.g. at the time of a move), while others require ongoing support (e.g. tenancy sustainment). Many do not have family members or friends to call on; and even those who do may not ask for help, through pride and the desire to safeguard their independence.

A review of the evidence [96] of the effectiveness of general information and advice services is pertinent to the effectiveness of housing services. The evaluation established the following key points:

- Information and advice services can be most effective when they are designed to target the specific needs of identified groups, such as older people.

- Although written information can be sufficient for many older people, those with the greatest needs may require information and advice delivered personally (face to face or by telephone), often with practical support to resolve their problems.

- The greatest demand for both information and advice is often linked to times of personal, medical or financial change/crisis, which is often when people are least able to seek the support they need.

- Older people find it difficult to access information and advice for a range of reasons, so services should be accessible through a range of access points and in different ways.

- Information and advice have a key role to play in improving access to public services and benefits for older people.

- A stand-alone information service is generally less effective than one that also provides advice, because many people will need support to fully understand and act on the information provided.

- Good-quality, accurate information can be provided from a range of sources but advice often needs to be independent, especially in cases concerning legal rights.

- It is good practice for information and advice providers to involve older people in the development of the content and design of their service to ensure that it meets their needs and is usable and accessible.

- Good local knowledge is essential for successfully targeting potential beneficiaries and harder-to-reach groups, for example black and minority ethnic elders and people living in isolated rural areas.

- Although information and advice for older people should be targeted at older people, information and advice aimed at professionals, carers and relatives can also be an effective way of meeting the needs of older people.

Evidence from research [97] suggests that advice services specifically targeted at older people are much more likely to reach them. A service in a London borough with a 10% older population had 1% of its client group being older people before a specialist service was established. Three years later 8% of its clients were older. It is also generally accepted that people seeking advice are lost in the signposting process and the more people are lost the greater the number of steps a person has to take between asking for advice and getting to the place that can give them the right advice. This is likely to be particularly true of older people who will have less mobility and therefore less capacity to pound the streets seeking the advice they need.

Housing options services

The definition of a **housing options service** is a scheme that provides information, advice, support **and practical help** to older people who are living in poor or unsuitable housing and/or considering options for moving on.

Research [89] into the operation of **housing options services** found that they were popular with older people and it appears that a housing options service employing one full time worker can potentially help between 90 and 100 older people each year by providing information, advice, advocacy and practical support. This would not necessarily meet the full extent of local need for housing options support but there are clear cost benefits if older people can be enabled to live independently in their own homes for a longer period of time. This has to be of interest to those involved in commissioning services from the health, housing and social care sectors and particularly for **Supporting People Teams**.

EXAMPLES OF INTERESTING PRACTICE

FirstStop

FirstStop [98] is an independent national web/telephone based service which provides information and support to older people on the related issues of housing, care and finance. There are three key services:

- **The FirstStop National Advice Line:** run by Elderly Accommodation Council (EAC) and in conjunction with several national partner organisation, and able to reply to emails as well as providing a telephone service. **FirstStop** can:

  - Provide a checklist "*How well does your home suit you?*" to help you weigh up pros and cons

  - Discuss options and ensure people are aware of all the opportunities available

  - Provide a copy of a "*Guide to Housing and Care Options*"

  - Prepare a personal *Housing Options Report* following a discussion with the person.

- **FirstStop Local Advice Services**, run by over twenty partner organisations including Home Improvement Agencies, Age UKs and in several cases, older people themselves.

- **First Stop Moving Home Service**: If people decide to move, FirstStop's Moving Home Service may be able to help. It offers a caring, independent and flexible service that includes as much or as little as people choose:

  - Help to find a new property

  - Preparing for moving – choosing what to take, packing, organising gas, electricity and other utilities

  - The removal itself

  - Preparing and settling in.

The key findings of an evaluation [99] of **FirstStop** were:

- The information and advice delivered by FirstStop is helping people to resolve their housing problems in ways that are more satisfactory and empowering to them.

- Customer satisfaction was high and the overwhelming majority of customers would recommend FirstStop to others.

- FirstStop's innovative use of the latest technology creates a seamless experience for customers. The system provides a 'one stop shop' for older people to access the information and advice they need on a broad range of subjects.

- It generates considerable business efficiencies saving time and money for service providers.

- FirstStop successfully launched a national 'housing options' training programme, delivered at the local level, which has received positive feedback.

- Has encouraged a shift to a culture of early preparation, prevention and self-help. The aim is to encourage older people to make necessary changes to their housing and care arrangements before they encounter a crisis.

HousingCare

http://www.housingcare.org – This site provides information. It contains:

- A large library of selected reading about housing, support and care services for older people

- Local directories of specialist accommodation for older people – retirement, sheltered and extra care housing; care homes, nursing homes and hospices

- Local directories of services for older people, covering everything from home repair services to day centres to transport services.

Moving Experience – McCarthy & Stone

- A professional advisor spends on average about 10 hours with each customer, from the first visit to being on hand when people move into their new home to help with any further requirements. A Handyman service is also provided if required.

- Change of address, transfer of utilities and meter readings: the advisor will help arrange all of the paperwork for notifying utility companies and other relevant organisations, and will run through a checklist to ensure nothing is forgotten. New address cards are also given.

- A free, confidential financial advice and health check can be provided, looking at potential entitlement to benefits, such as eligibility for pension credit. McCarthy & Stone Money also provides a direct service to customers (in partnership with other relevant parties) on annuities, later life planning including wills and powers of attorney, and equity release which is provided by Age Partnership.

- A decluttering service is offered at an agreed rate and provided by the company undertaking the removal.

My Ageing Parent

http://www.myageingparent.com/downsizing-or-moving-for-the-elderly/ – a site which offers assistance with de-cluttering, downsizing and moving.

Redbridge Council: Social Tenants' Service

Redbridge Council also offers support and advice to people in social housing who want to downsize to a smaller property. Of interest is that they have recently switched from offering a £2,000 reward for each bedroom freed up as a result of the move, to a £250 subsidy, plus a service which then provides practical help to move – from changing utilities, to identifying a new place to live. The impact on cost, from small samples, has been striking. The results of this programme suggest that the barriers to moving house for older people, is not necessarily just financial, but practical. By offering to take on the practical tasks, like organising moving companies and overseeing the move itself, the Council is saving an average of £1,050 per move [100].

EVALUATION

A recent evaluation [100] of a number of these type of housing advice and supports services concluded that overall, there is a good range of services delivering in this sector. However, there remains the longer-term problem of how to demonstrate outcomes, which needs to be overcome to make the case for sustained investment. A more strategic, whole sector approach to capturing delivery outcomes is needed to evidence this work.

ISSUES

There are a number of issues relating to the transition of moving home:

- There need to be realistic alternatives on offer to older people, including the support required to enable them to remain in their own homes should they wish to. The provision of aids and adaptations, as well as community services (including Supporting People services) is vital to this. Reductions in the provision of social care and housing support services are mitigating against this.

- The concept of moving home is a very challenging one for many older people and advice and support services need to recognise this. Support needs to be ongoing throughout the process and it needs to be recognised that there are usually significant emotional dimensions to the transition for older people. Whilst practice help is definitely required, so too is emotional support.

- There are supply side issues that need to be addressed. It is very questionable whether there is sufficient good quality and attractive housing (specialist or mainstream) to meet the needs of older people who would otherwise be interested in moving.

- Seeking to pressurise older people to downsize in order to free up capacity for younger people should be avoided. Providing incentives may be justified, but there are significant doubts about the efficacy of such policies.

3.3
BECOMING A GRANDPARENT

Becoming a grandparent is an important transition in later life. For many people it is a joyful one, opening up possibilities for the grandparents themselves, for the grandchildren and for the parents. It can provide a new focus for family relationships and can rekindle intimacy.

NATURE OF THE TRANSITION

This is a transition about which there is no control and very little warning. It is therefore not a transition which allows for much planning and preparation.

In terms of the Dilts framework [21] the largest impact is upon that of Behaviour – which relates to all the activities that grandparents get involved in with their grandchildren (i.e. child care and family support and engagement). There is some impact on Identity – being a grandparent has a recognisable and generally positive role within society. Sense of Purpose can also be impacted as grandparents begin to reassess their priorities as they engage with their new grandchildren.

NUMBERS OF PEOPLE LIKELY TO EXPERIENCE THIS TRANSITION

There are an estimated 13.6 million grandparents in Britain today (7.6m grandmothers and 6m grandfathers) [101]. By the age of 65, the majority of people are grandparents. (**Fig. 3.3.1**)

Further characteristics associated with this transition are that 45% of grandmothers and 19% of grandfathers are living alone without a partner (widowed, divorced or separated), and 55% of all grandparents are retired. There is bigger policy dimension; 28% of grandparents with grandchildren under 16 are in the "sandwich generation" with their own parents still alive.

The profile of grandparents has changed over time. Not surprisingly, grandparents are getting older – there are now more grandparents aged over 75 than in 1998.

FIG. 3.3.1. Proportion of adults with a grandchild under 16 by age and gender 2009
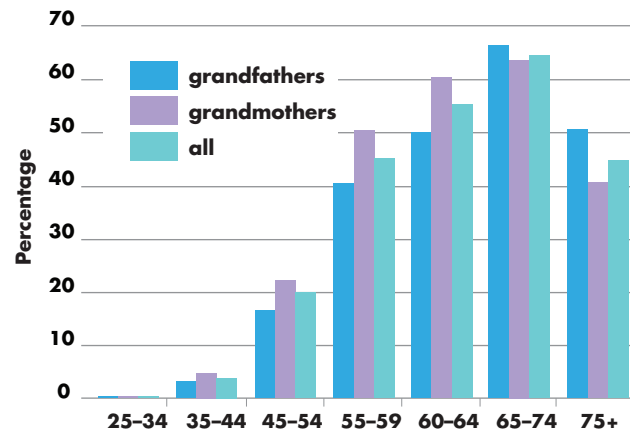
Source: Wellard [101]

LIKELY IMPACT OF THIS TRANSITION

Becoming a grandparent presents an exciting opportunity to grow and change and to experience a very special relationship. Many grandparents describe the sheer pleasure of spending time with their grandchildren without being burdened with the responsibilities of being a parent. The positive sides of the experience can be very far reaching. Having grandchildren can give grandparents a sense of continuity and reassurance that life goes on. It can therefore exert an important influence on their **sense of purpose**. Their life can have added meaning and purpose, giving them a renewed confidence in their usefulness and value. Perhaps one of the most important things about becoming a grandparent is the opportunity to have a 'second chance'. Through the relationship with their grandchildren, grandparents can try to do better some of the things they felt less happy about as parents.

Becoming a grandparent also changes one's **identity.** It is a role that is generally valued and respected in society. But the biggest impact is likely to be on **behaviours**. Spending time with the grandchildren is the major feature of this transition. Almost all grandparents are in contact with their grandchildren, and this is overwhelmingly positive and tends to enhance grandparents' quality of life [101]. However there can be challenges in situations where parents rely on the grandparents to undertake significant and regular amounts of childcare. Research [101] suggests that nearly two thirds (63%) of grandparents (with grandchildren under 16) look after their grandchildren.

FIG. 3.3.2. Age distribution of grandparents who look after their grandchildren, 2009
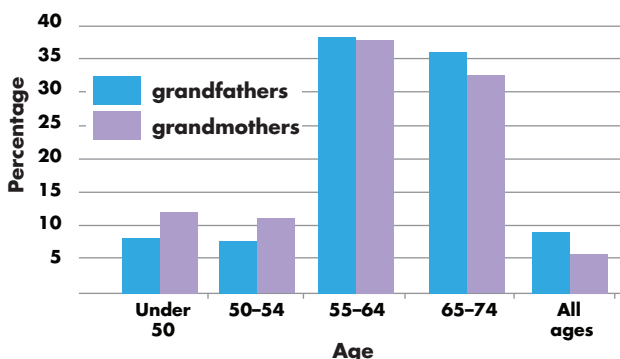
Source: Wellard [101]

The amount of time spent care can be significant. The data indicates that 19% of grandmothers providing high levels of care of at least 10hrs per week. Most childcare is provided by older grandparents aged 55–64, followed by those aged 65–75. Another study showed that more care is provided by grandparents who are retired than those still in employment [102].

The picture which emerges is that much of the informal childcare on which families and the economy depends is provided by older grandparents who are currently not working. As older people are expected to remain longer in th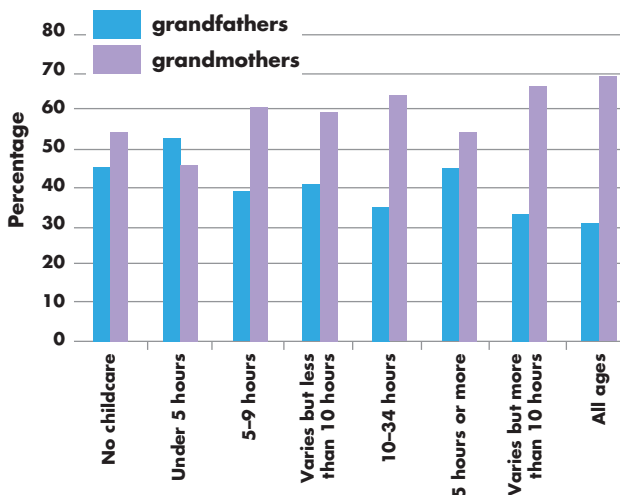e workplace, grandparents may be put under pressure to combine work with childcare. There is also a risk of, particularly grandmothers, becoming increasingly vulnerable to poverty if they leave work early to provide care [101]. Grandparents who actively contribute to care and support in this way generally

benefit from an enhanced sense of purpose in life, even when they feel emotionally drained by childcare demands. But there are dangers; grandparents raising their grandchildren may lack privacy and leisure time, have less contact with friends and be at the risk of social isolation [103].

There are particular risks for grandparents who end up raising their grandchildren in their own house. In these cases there is a greater probability of ill health and elevated depressive symptoms [104, 105].

Grandparents are involved in supporting people in other ways:

- Maternal grandparents are often an important source of support to families experiencing divorce or relationship breakdown [103]. Research shows that they are more likely to provide help with care of grandchildren if parents are separated than if they are together.

- Research indicates that grandparent involvement is linked to better emotional adjustment and fewer behavioural problems among adolescents [103].

- Grandparents contribute financially to their families through transfers of money and other assets passed through the generations [106].

- Research [107] indicates that there is a very considerable amount of informal care given by grandparents to adolescents and suggests that because grandparents may be filling the parenting gap for hard-working parents, there is a case for greater recognition of their role as family supporters.

There is of course a significant intergenerational dimension to the grandparent role and recent research highlights some of the benefits of this two way exchange. Researchers [108] have found that grandparents and grandchildren can have a significant beneficial psychological effect on each other. They found that an emotionally close grandparent-adult grandchild relationship was associated with fewer symptoms of depression for both generations. Grandparents who both gave and received tangible support had the fewest symptoms of depression over the course of the study. Giving or receiving tangible support, such as a ride to the shops or help with household chores, with their grandchildren led to significant beneficial psychological effects. Therefore, encouraging more grandparents and adult grandchildren to engage in this type of exchange may be a fruitful way to reduce depression in older adults.

Whilst becoming a grandparent is mostly a positive experience, tensions can arise between the generations. Typical problems include:

- A sense of interfering with parenting styles

- A feeling of being taken for granted

FIG. 3.3.3. Hours of childcare provided by grandmothers and grandfathers, 2009

Source: Wellard [101]

- Resentment at intrusion into family life
- Competitive behaviour regarding care of the children
- Judgemental attitudes.

Some of the key domains to "successful grandparenting" have been identified. Research [109] with grandchildren validated the following five elements as being associated with successful grandparent / grandchild relationships:

- a fairly high degree of closeness
- a strong sense of being known by the grandparent
- a strong sense of the young adult's knowing the grandparent
- a sense of the grandparent being a fairly strong influence in the life of the grandchild
- a sense of an authentic or independent grandparent/grandchild relationship not dominated by, but supported by, the middle generation.

INTERVENTIONS TO SUPPORT THIS TRANSITION

Becoming a grandparent is seen as a private affair with no formal input from the state. There are however a number of voluntary / campaigning organisations which provide information and guidance:

Grandparents Association
http://www.grandparents-association.org.uk/ – the national charity which supports all grandparents and their families.

Grandparents Plus
http://www.grandparentsplus.org.uk/ – the national charity which champions the vital role of grandparents and the wider family in children's lives – especially when they take on the caring role in difficult family circumstances.

Grannynet
http://www.grannynet.co.uk – the definitive website for grandmothers, providing advice and friendly chat, combining modern knowledge with traditional values.

The issues around this transition are not so much about the characteristics of the direct support to grandparents, they are more related to how wider changes in society may impact on grandparents and potentially add to their stress whilst reducing their incomes. The campaigning group Grandparents Plus argues [101] that as our population ages, increasing numbers of grandparents will be in the "sandwich generation" with both their own parents alive, and with grandchildren under the age of

16. A high proportion of grandparents in this group are both still working and providing childcare. Policy trends towards older people, especially women, staying in the workplace longer are likely to conflict with the role that grandparents, especially grandmothers, play in providing informal care, both for older relatives or partners and for their grandchildren. At the same time, cuts in state support for childcare and the declining availability of publicly funded social care, except for those with the highest level of needs, mean that there is an increasing role for the wider family to step in to provide informal care. At the moment, the bulk of informal childcare is provided by grandparents who are aged between 55 and 64, often retired grandmothers. This is the very group who will be increasingly expected to stay in the workforce and who are more likely to have elderly parents (often aged over 80) who may require care and support.

Grandparents Plus [101] go on to argue that there is an urgent need for policy agendas around employment, pensions, childcare and eldercare to be joined up. Changes in retirement and state pension ages need to take account of the vital role of grandparents in providing childcare, enabling parents to work. Requiring people to work through their sixties is likely to have profound implications for the supply of informal childcare, maternal employment rates and intergenerational relationships within families. If older people remain longer in the workplace, there is a risk of a serious "care gap" emerging in provision of informal care for children and older people.

ISSUES

There are a number of key issues involved in the transition to becoming a grandparent:

- Whilst becoming a grandparent is mostly viewed and experienced as a positive thing, there can be unwelcome pressures to provide extensive childcare placed on some people.
- Policies to extend the working lives of older people may place a lot of stress on grandparents (particularly grandmothers) who need to combine working with caring responsibilities for grandchildren.
- Special attention needs to be paid to the (small) number of grandparents who are required to have their grandchildren to live with them and look after them full time. Such situations can put people at higher risk of depression and poorer health outcomes.

3.4
RELATIONSHIP BREAKDOWN

Relationship breakdown can happen at any time in life but there are particular issues when it happens in later life.

DEFINITION

A relationship breakup is the termination of an intimate relationship by any means other than death. The term is less likely to be applied to a married couple, where a breakup is typically called a separation or divorce.

CURRENT CONTEXT

Good quality relationships are particularly important in later life. They are associated with happiness and wellbeing and have also been shown to protect against the negative consequences of stress. On a practical level, relationships are often a source of care in later life and good relationships can decrease the risk of wealth inadequacy [68]. A recent poll [68] found that 83% of older people thought that having strong personal relationships with friends and family was the most important factor for a happy retirement. (**Fig. 3.4.1**)

Lesbian and gay

Lesbian, gay and bisexual (LGBT) people over 55 are more likely to be single, more likely to live alone, less likely to have children and less likely to be in regular touch with their family [37]. The starkest contrast is with older men where 40% of gay and bisexual men over 55 are single compared with just 15% of heterosexual men [37]. LGBT people tend to enter their 50s with much more experience of shorter relationships compared to non LGBT people [110]. One research study showed just 19% had been in a relationship longer than 20 years compared to 60% of those with only opposite sex cohabiting histories [110].

THE NUMBER OF PEOPLE AFFECTED BY THIS TRANSITION

The trends in relationship breakdown appear to be changing as follows [68]:

- Whilst for the general population divorce rates have decreased in recent years, divorce rates amongst men and women aged 50–59 and 60+ **increased** between 1991 and 2011 as shown in the following table:

	Men 50–59	Men 60+	Women 50–59	Women 60+
2011	10.0%	2.3%	7.9%	1.6%
1991	7.1%	1.6%	5.1%	1.2%

From Harries and Las Casas [68]

FIG. 3.4.1. Current state of couple relationships at 60–64 and 80+
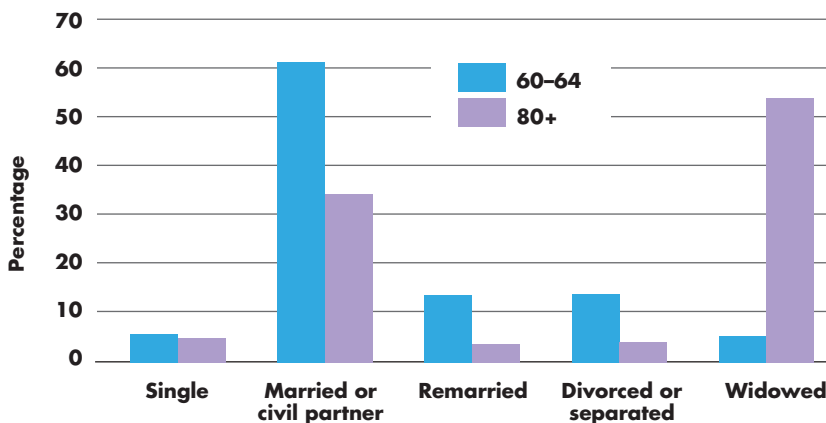
Source: ELSA Wave 5 2010–2011   From: Harries and Las Casas [68]

- There is some debate whether this growth in 'silver divorce' reflects the breakdown of long-term marriages compared with more recent marriages or remarriages.

- Amongst the baby boomer generation there has been a rise in unmarried cohabitation. Those who formed a relationship in later life were as likely to be in a cohabiting relationship as marriage. More than a quarter of a million people over the age of 65 in England and Wales were living unmarried with a partner at the time of the 2011 census – double the number recorded a decade earlier. Cohabiting unions tend to be stable and unlikely to culminate in marriage or separation. During later life cohabitation appears to operate as a long-term alternative to marriage[111]; three out of five older cohabitees are themselves divorced.

- The trend towards more cohabitation has contributed to a surprise fall in the **proportion** of older people living on their own – a drop from 43% to 31% in the last decade.

- There has been a rise in the **number** of people living alone. Current predictions [112] suggest that the number of people aged 65 living alone will grow from 3 million to reach 4.8 million by 2033.

- Older men are more dependent on their couple relationship than women [113]. Losing their partner was the most frequent worry for men (it was third for women).

- There is a class dimension. Whilst 75% of those in social grade AB are in a couple relationship, this drops to 59% of those in C1, 56% of those in C2 and 41% of those in DE.

Academic research has cited several possible reasons for the increase in the divorce rate among older people. These include:

- **Increasing life expectancy**. In 1991, men aged 60 in England and Wales were expected to live a further 21 years. This increased to 26 years for men aged 60 in 2012. Similar rises have been observed for women. This means that even with a small chance of divorce during each year of marriage, marriages are now more likely to end in divorce and less likely to end in the death of one spouse than they were in 1991.

- **A loss of stigma in being divorced**. In 1991, there were 404,000 divorced people aged 60 and over in England and Wales, a figure which increased three-fold to 1.3 million by 2010. As it becomes more common to be divorced, there are fewer stigmas attached.

- **Increasing participation in the labour market by women**. The employment rate of women aged 16 to 64 rose from 53% in 1971 to 66% in 2012. This means that women have become more financially independent and are more likely to have built up their own pensions. Therefore in general women are now more able to support themselves outside of marriage than in the past.

NATURE OF THE TRANSITION

Relationship breakdown is a developmental transition in that it is the outcome of a period of change over time in a relationship. It is generally anticipated and usually both parties have an element of control in the situation. As with most transitions in later life it can happen concurrently with other transitions. It is probably most closely related to 'empty nesting' and 'retirement', both of which can change the dynamics in a relationship quite

FIG. 3.4.2. Percentage of over 50s married in 2002–03 still married in later years
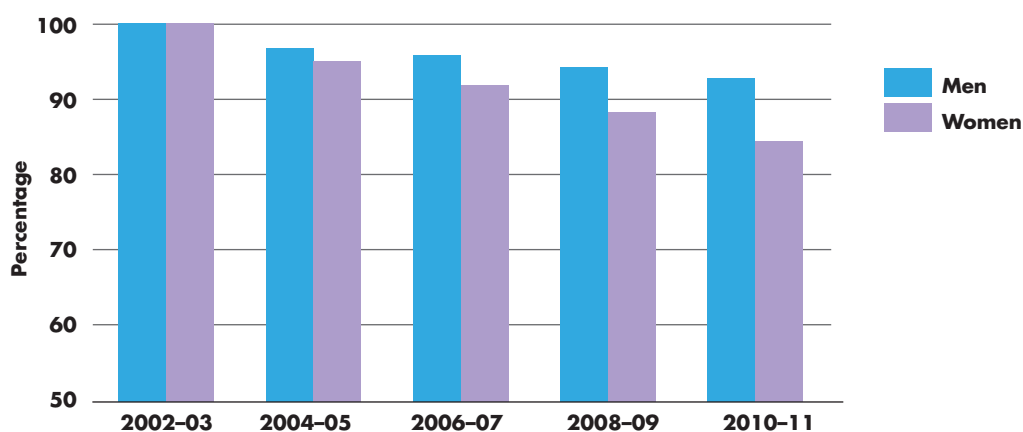
Source: ELSA Wave 5 2010–2011   *From*: Harries and Las Casas [68]

significantly [114]. The internet is full of articles with 'top tips' on how to help a relationship 'survive retirement'. There clearly seems to be a recognition that retirement can be a major threat to couple relationships. There is however very little research on the subject of relationship breakdown in later life itself. A review of what research literature there is [115] shows that research is largely based on US populations, leaving a lack of recent empirical evidence on the marital relationships of couples living in the UK.

IMPACT

Relationship break up is generally viewed as producing significant distress, although for many it can also be a positive release from an undesirable situation. It is not just the break up of a marriage that is important — some [116] have argued that the dissolution of dating and cohabiting relationships can be just as painful as or more painful than divorce because these non-marital relationships are less socially recognised.

In terms of the Dilts framework [21], relationship breakdown is likely to have greatest impact on people's **environment** (i.e. separation and moving into different accommodation), and **identity** (i.e. not being part of a couple any more). **Behaviour** is also likely to be impacted upon as the person has to do most things on their own, rather than as part of a couple.

The impact of divorce and relationship breakdown has probably changed over the years as divorce has lost some of the social stigma it once had. For example, research [117] in Holland found that divorcees are less socially lonely in 2009 than in 1992. Previous studies had shown that divorce increases the risk of loneliness, but as society changes divorce is increasingly becoming a more normal life event. Marriage and partnerships have not become less attractive but the social position of divorcees has improved and this may have had a positive impact on loneliness.

It is not possible to see divorce as simply a 'desirable' or 'undesirable' event. For some the change is a welcome break and opportunity to forge a new life; for others it can be a trigger into depression and loneliness. A number of key points about the impact of relationship breakdown include:

- Older individuals appear to adjust to divorce less well than younger people do [118].

- Women who divorce later in life may experience financial difficulties.

- Isolated older men are one of the highest risk groups for suicide.

- Many second marriages can end in divorce.

INFLUENCING FACTORS

People go through a number of transitions in later life and this can affect their relationships. Life transitions are likely to place pressure on individuals and intimate relationships. As already noted above, 'retirement' and 'empty nesting' are common triggers of relationship breakdown. Both bring about changes in the amount of time people in couples spend together and this can cause tensions and expose unsatisfactory aspects of a relationship which were previously kept in the background.

One of the few studies that there is [115] examined the 'anticipatory thoughts' about retirement. The most frequent focus of their hopes and fears was potential change in the marital relationship after retirement. Three times as many wives as husbands referred to their marriages as they speculated about retirement. A content analysis revealed four major themes. The most frequent was change in the emotional quality of the relationship followed by the conflict between spending time together and the loss of personal space. There was less emphasis on the implications for household management and the possibility of widow(er)hood.

Gay and lesbian
Gay and lesbian people have been unable to marry (until 2014), and civil partnerships have only relatively recently been instituted. There is therefore little official data on gay and lesbian long-term relationships. What research there is challenges some of the old stereotypes that gay males and lesbians are lonely and devoid of close contacts. In reality the support networks of gays and lesbians in later life are comparable to the rest of the population, but that the composition of support groups differ in that older gay males and lesbians tend to receive support from their families of choice composed of selected relatives, close friends and current or former lovers who provide support, including caregiving [27, 119]. The adjustment of older gay males and lesbians has probably been shaped by the socio-historical context in which they came of age [27]. The heterosexism and homophobia that existed during most of their adulthoods and the lack of role models have probably affected them. Many older gays and lesbians concealed their sexual orientation to conform, fearing loss of job, family and friends and some may even have married to hide their homosexuality [120].

It has to be noted that significant changes are likely to take place given the scale of change in social attitudes towards homosexuality — culminating with entitlement to 'marriage'. Participation in public commitment ceremonies and recognised unions and for some, access to same sex partner benefits are experiences unavailable to earlier cohorts that may ultimately affect later life

wellbeing and long-term relationships. Along with these new opportunities, however, current cohorts of gay and lesbian adults are likely to be faced with new challenges to maintaining relationships that older counterparts may have largely avoided [27].

SUCCESSFUL TRANSITION

A successful transition is generally assumed to be characterised by the development of another partnership. For many this is the case and the data set out above regarding cohabitation is an indication of this. Following relationship breakdown, not all older people feel confident to form new relationships. One in five people over 50 in a recent survey [113] said they lacked confidence to form new friendships and relationships – equating to 4 million people across the UK. There was a strong social gradient to lack of confidence, with those on lower incomes finding it much more difficult.

However it has to be recognised that this is not the only positive outcome of relationship breakdown. Many people are very happy to live outside of a relationship in their later life and this is particularly true of the baby boomer generation of older people.

Although there is very little research data on the experience of divorcees in later life, some of what there is points to some differences between men and women. A study examined life satisfaction among individuals who had undergone a transition in marital status and those whose marital status remained stable over a 7-year period among 2,180 men and women between the ages of 67 and 102. Among those individuals whose marital status remained stable over the 7 years, women's life satisfaction declined and men's remained constant. Among those who experienced a transition—in particular, the loss of a spouse—a decline in life satisfaction was found for both men and women, the decline being more dominant for men. In addition, mens' life satisfaction increased over the 7-year period if they gained a spouse, whereas the same was not true for women. Generally, these findings imply that the relationship between marital status transitions or stability differs for men and women.[121]

INTERVENTIONS TO SUPPORT RELATIONSHIP BREAKDOWN

There are very few if any initiatives specifically targeted at older people at risk of, or having experienced relationship breakdown, apart from the following online offers:

Relate have a section on their website for older people. http://www.relate.org.uk/life-channel-retired /index.html

Relate and Gransnet have joined together to produce online support for relationships in later life http://www.relate.org.gg/relate/Welcome_files /RelateGransnetTips.pdf

Saga also provide some advice http://www.saga.co.uk/money/work-and-retirement /retirement-and-your-relationship.aspx

ISSUES

Policy
One of the biggest 'gaps' in the support for this transition is that "*relationships are central to people's lives but are all but absent from current policy debates*" [68]. There is very little public debate about how to nurture a relationship through the transitions in later life.

Provision
Older people are also under-represented in relationship support services. Less than 1% of the 100,000 people that Relate supports each year are aged 70+ [68]. There has however been a very slight rise in the number of 'baby boomers' (50–70) who use Relate services – a rise from 12.9% in 2009/10 to 14.6% in 2011/12.

Structural problems
Relate [68] feels that there is a need for some significant development work to address relationship breakdown in later life. As far as it is concerned:

- It is not an issue that local authorities take sufficiently seriously. It proposes therefore that older people's relationship health should be part of the work of Directors of Public Health.

- The services that are currently in existence are on the periphery and are therefore not easy for people to access when needed. It proposes that relationship support should be embedded in the local service landscape.

- There is a need for new service offers. It proposes an 'innovation fund' to stimulate new thinking.

- There is a lack of engagement by the wider third sector in supporting relationship strengthening. It proposes that third sector organisations should be more involved and use volunteering as an effective offer.

Insight

The following 'report card', although based on US data, nevertheless gives an interesting insight into some of the relationship issues in later life:

Retirement Tango | A report card on later life

When Retirement Works...

84% of retired spouses* ages 55 to 75 say they now spend more time doing things together

78% are happier now than when they were working

76% feel less stressed

41% say their relationship is stronger

30% argue less

12% are more romantic

*In a household where both spouses are retired
Source: AARP based on Opinion Research Corp. survey of 1,064 people ages 55-75; margin of error: +/- 3 to 6 percentage points, depending on sample size

And When It Doesn't

29% worry more about money

22% sometimes get irritated that their spouse is now around them more

21% now wish they had continued to work longer

19% experience more tension in their relationship

14% now wish their spouse had continued to work longer

Ready or Not

Many couples approaching retirement haven't settled some basic issues

73% disagree on whether they have completed a detailed retirement income plan

62% don't agree on their expected retirement dates

47% don't agree on whether they will continue to work in later life

41% make investment decisions for retirement together

33% either don't agree or don't know where they plan to live in retirement

17% are confident that either spouse is prepared to handle their joint retirement finances

Source: Fidelity Investments based on Richard Day Research Inc. survey of 648 married couples; margin of error: +/– 4.7 percentage points

Getting Out, Staying In

Spouses ages 55 to 75 on how often they engage in these activities

BEFORE RETIREMENT

Activity	Before	SINCE RETIREMENT More	Less	Same
Eating out	97%	40%	17%	40%
Travel	95%	47%	17%	32%
Exercise	95%	37%	15%	43%
Hobbies	94%	38%	10%	46%
Sex	91%	7%	22%	62%
Involved with children	90%	24%	18%	47%
Attending church	89%	19%	8%	62%
Volunteering	83%	33%	14%	37%

Source: AARP based on Opinion Research Corp. survey of 1,064 people; margin of error: +/– 3 to 6 percentage points

The Bloom on the Rose

What men and women age 45-plus say they do to keep romance in their relationships

	MEN	WOMEN
Make a point of telling each other "I love you"	63%	65%
Recognise birthdays and anniversaries	61%	53%
Take a getaway together at least once a year	33%	24%
Set aside a day or evening each week just to be together	27%	25%
Bring each other surprises, presents or flowers	24%	28%
Romance? What's that?	16%	23%

Source: AARP based on Knowledge Networks survey of 1,670 people age 45-plus; margin of error: +/- 2.4 percentage points

Old Roles, New Roles

Trying to figure out what kind of relationship you want with your partner in retirement? Start with these questions.

◆ **How do we** each define happiness at this stage of life?

◆ **How supportive** are we of each other? How critical? To what extent do we accept each other as we are?

◆ **From 1 to 10** on the togetherness scale, what level feels most comfortable for each of us? Why?

◆ **Where do we** each prefer to be on a scale of 1 to 10 from isolation to frenetic activity?

◆ **In what ways** do we practice parallel play? Do I (you) want more or less of this? Why?

◆ **Do you** or I need better communication skills? A sense-of-humor tuneup?

◆ **How many** interests do we share? Have any been forced on either of us?

◆ **How do we** rate our levels of rigidity, and how can we become more flexible?

◆ **What were our** hopes and dreams as children? As young adults? What are they now?

◆ **How would we** describe our financial personalities? Is our parallel play either constrained or encouraged because of our financial resources?

Source: Maryanne Vandervelde, "Parallel Play: Necessary New Skills for Happy Retiree Couples"

The Wall Street Journal

Source: Wall Street Journal

3.5
BECOMING A CARER

NATURE OF THE TRANSITION

Becoming a carer is a transition which is related to the health and illness of a relative. It is generally something which is unforeseen, not able to be planned for and something over which the person has little if any control.

Becoming a carer is a transition which is commonly linked to other transitions, most notably acquiring (their own) health condition, entering a care environment (by their relative) and ultimately bereavement. It can also be interacting with retirement and many of the other transitions in later life. Becoming a carer can seldom be planned for or controlled.

PREVALENCE

Becoming a carer is a very common transition in later life. More than 20% of people aged 50–59, and 11.5% of people over 65 are providing some form of unpaid care [122]. The number of carers over the age of 65 is increasing more rapidly than the general carer population. Research has shown that whilst the total number of carers increased by 9% from 2001–2011, the number of carers over 65 increased by 15% in this period [123].

Older people also provide a lot of care and support to grandchildren – this issue is dealt with in the section on 'Becoming a grandparent'.

Gay and lesbian
Getting older can be much more complex for lesbian, gay and bisexual people as they are more likely to face the prospect either alone or without as much personal support as their heterosexual counterparts [37]. As a result, many lesbian, gay and bisexual people over 55 experience an increased sense of vulnerability and are more anxious about ageing. Given that they are more likely to live alone they are less likely to be able to rely on the support of a partner who will care for them. For those without close family, support from friends is very important and 'my family is my friends' is a common response from gay, lesbian and bisexual people when asked about personal support [37]. (**Fig. 3.5.1**)

Lesbian, gay and bisexual people are nearly twice as likely as their heterosexual peers to expect to rely on a range or external services as they get older, including GPs, health and social services and paid help [37]. That having been said, research [124] has shown that mutual care with partners was the preferred source of support should it be required in later life, even amongst those who were not in established couples. Those who are in couples do not appear to fully escape the anxieties prompted by the issue of care in old age and in times of frailty. In one study [124] coupled participants generally agreed that they had no guarantee that partners would be able to provide care, and they expressed a degree of ambivalence about the extent to which partners should expect to care.

Ethnic minorities
The pattern of caring in later life has some differences for BME communities. Studies suggest that multi-generational households may still be the norm for most BME communities, but it should not be assumed that they are either a source of support for BME older people or able to provide for the care needs of these people. The evidence appears to suggest containment rather than care and certainly undermines the old adage that 'they look after their own' [38]. There are however similarities with the white community; just as in the white community, carers in BME communities tend to be unsupported and isolated and women provide the bulk of the caring. The lack of support for isolated BME carers is often exacerbated by communication difficulties [38] .

FIG. 3.5.1. Would turn to a friend if ill and needing help around the home

Lesbian and bisexual women	52%
Gay and bisexual men	42%
Heterosexual women	19%
Heterosexual men	14%
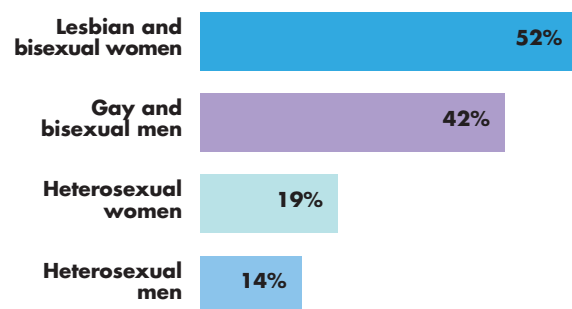
Source: Stonewall [37]

IMPACT

Following the Dilts' framework [21] the impact of the changes involved in becoming a carer can be characterised as follows:

- **Sense of Purpose** – is likely to be changed to focus on the needs of the other person. The cared for person's wellbeing can become the main meaning or sense of purpose in the carer's life, resulting in them suppressing or postponing other things that were once important to them.

- **Identity** – a carer's identity can become quite wrapped up in that of the person they are caring for as they become involved in undertaking tasks and advocating on their behalf.

- **Beliefs** – there is little that is likely to change in the belief systems of carers.

- **Capabilities** – carers are likely to need to learn new skills related to the care and support of their loved one. If they are to cope with their caring responsibilities they should also learn new skills on how to ensure their own wellbeing.

- **Behaviour** - becoming a carer is likely to have the biggest impact on people's behavior – how they spend their time and the tasks that they perform. The amount and type of care provided varies considerably. Across all carers (not just older carers), the frequency of different tasks includes [122]:

  – 82% providing practical help, such as preparing meals, doing housework or shopping

  – 38% providing personal care, such as help with bathing, feeding and going to the toilet

  – 38% providing physical help, such as getting in and out of bed and up and down stairs

  – 35% administer medication

  – 49% helping with financial matters and other correspondence.

  Carers providing 20 hours or more care a week are more likely to provide all manner of care tasks, from personal care, to housework and keeping the cared for company. Of these carers:

  – 57% provided personal care

  – 54% provided physical help

  – 57% helped with finances and paperwork.

- **Environment** – for many, becoming a carer severely restricts their ability to get out and about. Many feel constrained to remain at home with the person they are caring for.

For people in the 50-59 age band the person being cared for is most likely to be a parent, and for those 65+ it is most likely to be a spouse.

For many, becoming a carer can be a major transition involving significant levels of caring and having many different impacts on their lives, including:

- **Loss of income**. Caring often means that people are unable to continue working and therefore suffer a drop in income. Research [125] indicates that 62% worry about their finances and 53% believed this had an effect on their health.

- **Poor health.** Caring can take a toll on carers' physical and mental health. A survey by Carers UK indicated that 83% of carers say that caring has had a negative effect on their physical health, including injuries as a result of manual handling; and 87% say that caring has had a negative impact on their mental health, including stress and depression.

- **Relationship breakdown and isolation**. When asked in a survey [126] about the impact of caring on their relationships with friends and family, 66% said that their caring responsibilities had a negative effect on their friendships. A further 58% said that caring had also had a negative effect on their relationships with other members of their family.

POSITIVE OUTCOMES

For some carers researchers [127] have identified that there are positive aspects of caring, including:

- Giving pleasure to the person cared for

- Maintaining the dignity and maximising the potential of the person cared for

- Experiencing an enhanced relationship

- Meeting perceived responsibilities

- Sharing mutual love and support

- Developing personally.

In other research [128] the overwhelming majority (84%) of carers indicated that they received a great deal of satisfaction from caring.

INFLUENCING FACTORS

It is known that the impact of caring on carers' mental health is different for individual caregivers. Some carers experience a substantial negative impact while others are less affected by the caring role. This variation in the impact experienced is not simply related to the extent of caring provided [128].

Factors associated with the impact of caring include:

● **The relationship between the carer and the person being cared for**. Being a spouse is associated with lower levels of wellbeing. This is especially the case where the person being cared for has dementia; resulting in increased depression for the carer [127, 128]. The quality of the relationship is important too. Where there is a level of intimacy and love in the relationship this is often associated with better mental wellbeing [129].

● **Nature of cared for person's disability**. The impact of caring responsibilities on mental wellbeing can be affected by the nature of the disability of the person being cared for. Caring for a person with a mental illness or dementia may involve for the carer:

  – a lack of control

  – a degree of uncertainty

  – 'loss' of the person they once knew

  – witnessing the gradual decline of their loved one

Research [128] has shown that carers of people with physical impairments who are intellectually intact express a greater sense of wellbeing than carers of people with mental health problems. Family carers of people with dementia experience more burden than family carers of other people with chronic illness [130], and they are at greater risk of developing depression [131]. Carer burden is associated with patients' behavioral problems [132, 133].

● **Stage in the care giving process**. Where carers are in their 'caring career' influences the impact of caring on their mental health [134]. For example in the case of caring for someone with dementia Nolan [127] described various stages that the carer may go through, including:

  – Noticing

  – Discounting / normalising

  – Suspecting

  – Searching for explanations

  – Recounting

  – Taking it on

  – Going through it

  – Turning it over.

The carers' mental wellbeing can be expected to be different according to which stage of the process they were going through

● **Financial wellbeing**. Financial worries can compound the other stresses associated with caring and produce significantly reduced mental wellbeing among carers. Money greatly increases the coping options available. Put simply, financial difficulties are associated with poorer wellbeing of carers [128].

● **Social support.** The amount and quality of support available from family, friends and neighbours is an important factor in moderating the stresses associated with caring. Research [128] has shown that those carers with large informal support networks reported greater life satisfaction, less resentment and less anger than carers with smaller networks. It is not just about quantity, the quality of the support is also important [135].

● **Coping strategies**. These can be defined as the things people do (acting or thinking) to increase a sense of wellbeing in their lives and to avoid being harmed by stressful demands. The literature [127] shows that carers use a broad range of coping strategies and that some strategies are more successful than others. The nine most popular strategies found [127] to be helpful by over 50% of carers were:

  – Realising that the person you care for is not to blame for their position

  – Taking life 'one day at a time'

  – Finding out as much as you can about the problem

  – Keeping a little free time for yourself

  – Realising there is always someone worse off than yourself

  – Realising that no one is to blame for things

  – Keeping one step ahead of things and planning in advance

  – Getting as much help as you can from professionals and service providers

  – Talking over your problems with someone you can trust.

SUCCESSFUL TRANSITION

It is quite difficult to characterise when the transition to becoming a carer has been undertaken successfully. Positive outcomes are most likely to be associated with carers retaining their physical and mental wellbeing and remaining connected with family and friends. These things are all severely challenged by caring responsibilities. In many cases the transition to becoming a carer will be completed by the death of the person being cared for; which in turn takes the person into another transition in later life – that of bereavement.

INTERVENTIONS TO SUPPORT PEOPLE IN THE TRANSITION TO BECOMING A CARER

There is a distinction to be made here. The focus of this report is on supporting the 'transition' to becoming a carer, rather than supporting people in the ongoing task of caring over time (where for example, carers' breaks are so important).

The key interventions to support people becoming a carer are:

- information
- assessment
- carers support groups
- self care education programmes
- counselling / talking therapies
- mindfulness training.

Information

General advice and information for all carers is provided by a number of national organisations:

Carers Trust
http://www.carers.org/

Carers UK
http://www.carersuk.org/

Carers Direct
http://www.nhs.uk/carersdirect/Pages
/CarersDirectHome.aspx

Age UK – advice for carers
http://www.ageuk.org.uk/home-and-care/advice-for-carers/

Independent Age – carers guide
http://www.independentage.org/media/231475/10_carers_what_support_is_available.pdf

Advice and information for carers of people with particular conditions is provided by organisations specialising in supporting people with the condition. Examples include:

Alzheimers Society – carers support
http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1710

Mind – carers support
http://www.mind.org.uk/information-support/helping-someone-else/how-to-cope-as-a-carer/#.Uqg6R02yMoY

MacMillan Cancer Support – carers support
http://www.macmillan.org.uk/HowWeCanHelp
/Carers.aspx

Stroke Association – guide for carers
http://www.stroke.org.uk/about/support-carers

Many local authorities have dedicated webpages to support carers; for example:
http://www.bristol.gov.uk/page/health-and-adult-care/advice-and-information-carers

Effectiveness

There is very little evaluation material available on the provision of information services for carers. The Department of Health however conducted an evaluation [136] of Carers Direct. Carers Direct was set up and funded by the Dept of Health in 2009 to provide a focused information and advice service to carers. It comprises two separate, but interrelated, service components;

● The Carers Direct information website

● The Carers Direct contact centre and telephone helpline.

These two distinct approaches to providing advice and information has been provided by two separate suppliers. The Carers Direct website is provided through NHS Choices and forms a component of their wider advice and information provision. The delivery of the Carers Direct helpline is contracted through 'bss' (a charity that specialises in information provision for the statutory and third sectors).

The number of callers to the Carers Helpline service were below expectations from the outset. The level of calls has usually been within a range of 1,400 to 1,900 per month. Over 60 percent of callers were between 40 and 69 years of age. Content of the calls and their outcomes are set out below (**Fig. 3.5.2**).

The use of the Carers Direct website has grown in each year of its operation. Current usage of around 1.3 million hits a year remains well below its potential target audience of all carers in England, which is judged to be around 5.2 million. It is recognised that many carers do not label themselves as such, so the linkage between Carers Direct and the wider NHS Choices information website remains crucial for many individuals who will begin looking at condition specific information and via that enquiry, be alerted to advice on carers.

FIG. 3.5.2

Top six subjects for calls	Top six outcomes from call
● Carers Allowance	● Signposted to local organisations
● Community care assessment	● Signposted to local authority
● Disability benefit	● Signposted to national organisaton
● Means-tested benefits	● Information provided on assessments
● Carers assessment	● Signposted to carers assessments
● Help in the home	● Directed to website

Feedback from cares is provided by the Carers Direct Website User Satisfaction Survey [136]. This indicated the following key issues:

● 46% of carers tend to look for information on help, advice and support about being a carer and 35% look for information related to financial assistance.

● The majority of Carers Direct users, 79%, agreed they found some or all of the information they wanted on Carers Direct.

● 81% of users thought the site was easy to use.

● 76% of users thought information was clear and easy to use.

● 68% of users thought the information was accurate and up to date.

● 80% of users would use the service again.

● 79% of users would recommend it.

● The services have been less successful in integrating and securing the linkages between the national and local perspectives.

Overall, this represents a high level of satisfaction with this service for carers.

Assessment

Carers have a right to an assessment of their needs, which should be undertaken separately from the 'cared for' person. Carers UK argue that "*substantially fewer assessments and reviews are taking place than there are carers who need them*" [122]. For those who are assessed, 94% go on to receive a service, although for nearly half of these people the only support offered is information [122].

Counselling/talking therapies

With regard to counselling, research has [137] found that it as an effective measure to relieve carer distress. Research [138] into a range of interventions concluded that the most consistent positive support to carers were found for psychotherapy and psycho-educational interventions, which produced improvements across practically all outcome domains. However, only a minority of carers in England and Wales are likely to be offered counselling or any other talking therapy.

There is also evidence that 'cognitive reframing interventions' (such as Cognitive Behavioural Therapy) for family carers of people with dementia are effective [133, 139]. Cognitive reframing is intended to reduce carers' stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do. It was found that cognitive

reframing has the potential to reduce anxiety, depression and stress. This review concluded that cognitive reframing might be useful to improve the mental health of informal carers of people with dementia.

Mindfulness Based Stress Reduction (MBSR)

Although mindfulness meditation is not a 'talking therapy', there are a number of cross overs with Cognitive Behavioural Therapy (CBT), in that MBSR seeks to change people's relationship with their thoughts. In particular it focuses on reducing 'rumination' and repetitive negative thought patterns. Mindfulness has been described as a life-enhancing skill and approach to living which can deepen a person's sense of wellbeing and fulfillment. It involves learning to notice what is occurring in one's present moment experience, with an attitude of openness and non-judgmental acceptance. It is defined as:

"…the awareness that emerges through paying attention in a particular way, on purpose, in the present moment, and non-judgementally, to the unfolding of experience moment by moment" – Kabat-Zinn [140]

There is a growing body of research indicating the effectiveness of mindfulness meditation in supporting the reduction of stress and improved quality of life for carers [141–147]. For example, research [148] has shown that mindfulness based stress reduction (MBSR) was more effective at improving overall mental health, reducing stress, and decreasing depression in carers carer education programmes. Both mindfulness and education interventions decreased the self-rated caregiver stress compared to the respite-only control.

Research [149] has also found that with MBSR self-reported depression, perceived stress, and carer burden decreased during the 8-week intervention with further reduction demonstrated after a 1-month follow-up. Further research [150] of a brief MBSR programme for caregivers indicated that it was successful in significantly decreasing substantial stress symptoms and mood disturbance.

Carers support groups

With regard to carers support groups, research [137] found that there is no conclusive evidence regarding the effectiveness of support groups, nor is there any evidence that they produce direct improvements in the wellbeing of carers or in their ability to continue caring. Support groups are valued by those who attend, but not all carers wish to attend. Research [138, 151] found that group interventions are less effective at improving caregiver burden and wellbeing than individual and mixed interventions (i.e., combinations of group and individual programs) .

Carer education/self care programmes

Becoming a carer is a transition which often requires new capabilities and can affect the person's life in a number of significant ways. Mostly the person has little choice or control over their situation. Skills and knowledge training is therefore a very important intervention to support people through this transition. Evaluation of skills and knowledge training courses (Caring with Confidence) and (Looking after Me) [152–154] found that the carers who participated in the programmes were very positive about them and benefited in a number of ways, including:

END OF LIFE CARE SERVICE

The Looking After Me carers course, provided by the Expert Patients Programme CIC, is about carers making time to look after their own health and wellbeing. It aims to help them develop self-management skills to take more control of their situation and make a difference to their lives. The course looks at:

- Relaxation techniques
- Dealing with tiredness
- Healthy eating
- Coping with feelings of depression
- Communicating with family, friends and healthcare professionals
- Planning for the future.

It is aimed at and free to any adult who gives help to a relative or friend who is ill, disabled, elderly, or in need of emotional support and is aimed particularly at adults caring for other adults. The sessions are delivered by trained and accredited tutors who have experience of being a carer themselves. Benefits include:-

- Learning new skills to help people to cope with their caring situation
- Developing the confidence to take more control of their lives
- Meeting with others who share similar experiences
- Developing more effective relationships with health and care professionals
- Having access to a wider support network through contact with others in similar situations.

The course is run over 6 weekly sessions, each lasting about 2 hours 30 mins.

CARING WITH CONFIDENCE COURSE THROUGH CARERS DIRECT

The Caring with Confidence programme gives carers a better understanding of the problems carers face and helps people find new ways to tackle them. The course is a free online interactive learning programme and as a series of courses that carers can download and complete in their own time. Local group sessions may be available.

- greater confidence in their caring roles
- learning new skills
- improved health and wellbeing
- better knowledge of support services
- improvements affecting those they cared for.

The courses were recommended to be made widely available.

In a wide ranging meta review [155] of the evidence of effectiveness of services to support carers it was concluded that there is evidence to support the use of well designed psycho-educational or multi-component interventions. Factors that appear to positively contribute to effective interventions are those which:

- Provide opportunities within the intervention for the cared for person as well as the caregiver to be involved
- Encourage active participation in educational interventions for caregivers
- Offer individualised programs rather than group sessions
- Provide information on an ongoing basis, with specific information about services and coaching regarding their new role
- Target the care recipient particularly by reduction in behaviours.

Approaches which do not appear to have benefit are those which:

- Simply refer caregivers to support groups
- Only provide self help materials
- Only offer peer support.

These results were substantiated by another systematic review [156] which concluded that individualised interventions that utilised problem solving and behaviour management demonstrated the best evidence of effectiveness in supporting carers. Research [157] found that training carers in coping skills was effective in improving carer quality of life, reducing burden related to patients' symptoms, and caregiving tasks. Structured carer skill-training interventions are promising even in the difficult environment of end-of-life care and for families already receiving benefits

ISSUES

A lot of national work has been undertaken under the auspices of the Carers Strategy to increase the provision of assessments, information and carers breaks. Access to ongoing support services are clearly important. For example, research [158] has indicated that those not receiving respite care were far more likely to suffer from mental health problems: 36% compared to 17% of those getting time off from caring.

However there are serious questions about the level of support for carers. For example, although most of the carers who were caring for at least 50 hours a week in a Carers UK survey had a GP who knew of their caring responsibilities (84%), of these carers, most (71%) said that their GP didn't do anything differently to accommodate them. Very few had a GP who gave regular carers' health checks or did home or telephone appointments [126]. In the same survey, 37% of carers providing substantial levels of care said that they cared without any support from services or from family or friends, and a further 29% cared with support from family and friends, but not with any support from services. This meant that 4 in 10 carers said they had not had a full day off from caring in over a year and half and had not had a holiday away from home in the last five years.

Government figures would appear to substantiate this picture. A Government study [159] indicates that of the estimated 1 million carers who are over 65 in England, just 93,000 of these received any carer specific support.

With regard to some of the counselling / talking therapy /mindfulness interventions found to be effective above, there is very little provision for this kind of intervention, except by those who can afford to pay themselves.

3.6
BEREAVEMENT

DEFINITION

Bereavement is a transition which starts with the loss of someone close to the person through to the point in their lives where the feelings about the loss are no longer centre stage in their lives. They are still there, but do not dominate the emotional landscape of the person. Grief is the emotional reaction to loss and involves a process over time during which the nature and content of the emotional reaction changes.

NATURE OF THE TRANSITION

Bereavement is one of the most significant life transitions in later life, principally affecting married or cohabiting couples through loss of a spouse/partner. Sibling loss is another major feature in later life as is the loss of friends. Bereavement is a developmental type of transition in that it is closely associated with ageing and ill health. The risk of experiencing a bereavement in later life increases exponentially with time.

Bereavement is experienced by nearly everyone and when the person who has died is a close family member or friend it can have particularly distressing effects and lead to physical and mental health changes, and social readjustment [160].

Older people are likely to experience multiple bereavements, usually sequentially rather than concurrently. The loss of a spouse or a sibling will be a relatively unique transition, but overlaid on top of this will be the common experience of multiple bereavements of friends. Whilst each of these individually may not have the same intensity as the bereavement associated with a spouse or sibling, they can combine to increase the sense of vulnerability, loss and mortality which can accumulate to have a powerful negative emotional impact.

This particular life transition can often interact with others. For example, it is quite common for one partner in a marriage to be caring for the other before they die – so bereavement and caring can be inextricably linked. And bereavement can impact just at the time that the couple are undergoing the retirement transition.

IMPACT

People react to bereavement in diverse ways. While the majority experience short grief reactions and remain stable or resilient during their journey through bereavement, some experience more long-term grief effects and recover slowly during the first 1-2 years. Others (10–15%) suffer distress and depression in the long term [161], often referred to as 'complicated grief'.

Although the reaction is primarily an emotional response, there are also physical, cognitive and behavioural dimensions. Whilst the terms are often used interchangeably, bereavement refers to the state of loss and grief is the reaction to loss. Mourning involves actions and expressions to share feelings of grief [162].

Using the Dilts framework [21], the impact of bereavement can be understood in the following way:

- **Sense of Purpose** – bereavement can severely challenge one's sense of purpose in life, particularly when it involves a spouse or other family member.

- **Identity** – becoming a 'widow' or 'widower' can have a significant impact on one's sense of identity, although the impact has probably diminished in recent years as social attitudes and conditions have changed.

- **Beliefs** – bereavement can have some impact, particularly in how people consider and address existential questions and philosophical or religious beliefs.

- **Capabilities** – there can be some impact, particularly when it is a spouse who has died. The remaining partner may have to learn how to undertake tasks and responsibilities which were previously shouldered by the other partner.

- **Behaviours** – can be significantly impacted, particularly when it is a spouse who has died. The remaining partner is likely to have to undertake many activities on their own and this can affect what things they continue to do. One common impact of bereavement is a higher risk of loneliness – which can manifest through a reduction in undertaking social interactions (see more below).

- **Environment –** the death of a partner can often be the trigger for 'downsizing' of accommodation and moving house.

Loneliness
The hardest thing to cope with can be isolation. Forming new friendships in later life is not easy and bereaved older people can find themselves alone for days at a time with no obvious way of doing anything about this.

Loneliness may be a dominant emotion experienced by older people who are bereaved. Studies of older widows and widowers find social isolation and loneliness to be key themes [163–166]. More intense social loneliness was found [167] where there was:

- slower disease progression in the person who died

- poor physical or mental health

- more importance attached to receiving support

- social anxiety

- less support during the marriage

- more opportunities to talk about the death

- less importance attached to contact with others.

Predictive factors for emotional loneliness were:

- having been unable to anticipate the death

- poor physical health.

Loneliness can be heightened by reminders of the dead spouse or partner, anniversaries of the death, having to learn to do tasks previously carried out by the partner, and socialising as a single person. Costello [168] explored older people's perceptions of loneliness following loss of their spouse or partner and found that feelings of loneliness begin with the realisation that the lost person will not return. In addition, loneliness and social isolation were part and parcel of the social experience of ageing, and loss often meant being socially disenfranchised. Loss of a life partner in particular often means that the bereaved are also at risk of losing their place in their social network [169]. Providing meaningful support consequently challenges the wider social network and health and social care service providers.

Health outcomes

Bereavement in general is associated with poorer health outcomes. There are increased risks for stress related illnesses in the first six months following a death [170]. Studies based on longitudinal data able to control for prior physical health status show worse outcomes for physical health and health behaviours, such as higher levels of perceived poor health and self reported medication use, among bereaved spouses compared to the non-bereaved [171]. Others have noted increased mortality risks [172, 173]. With complicated grief the situation produces significantly worse outcomes including higher mortality, worse physical and mental health and greater utilisation of health services [174]. A review of mood and anxiety disorders in widowhood suggests that the relative risk of developing a mood or anxiety disorder is between three and ten times that of non-widowed controls [175].

Poverty

Several studies have shown that losing a spouse has a significant association with poverty in later life [176, 177]. For example, one study [178] showed that being newly widowed was associated with higher poverty risks for those aged 55 and over even when work history variables (including years in full time work since age 18) and current socioeconomic circumstances were taken into account.

GRIEF

Grief is the emotional response to loss, particularly to the loss of someone or something to which a bond has been formed. The bereavement period can be confusing and involve a lot of very powerful emotions. These emotions can grow, fade and shift as people move across different stages of bereavement.

Models of the grief reaction

As with any transition, grief takes place over a period of time (though there is no standard timescale). And as with transitions in general, the grieving process is thought by some to involve a number of distinct stages. There are a number of theories about the stages of bereavement.

The first major theoretical contribution on grief was provided by Freud in his paper 'Mourning and melancholia' [179], and profoundly shaped professional intervention for nearly half a century. For Freud, 'grief work' involved a process of breaking the ties that bound the survivor to the deceased. This psychic rearrangement involved three elements: (1) freeing the bereaved from attachment to the deceased; (2) readjustment to new life circumstances without the deceased; and (3) building of new relationships. Freud believed that the separation required the energetic process of acknowledging and expressing painful emotions such as guilt and anger. The view was held that if the bereaved failed to engage with or complete their grief work, the grief process would become complicated and increase the risk of mental and physical illness and compromise recovery. Freud's grief work model stresses the importance of 'moving on' as quickly as possible to return to a 'normal' level of functioning.

Grief stages

Several later grief theorists conceptualised grief as proceeding along a series of predictable stages:

- **Phases of grief [170, 180]**
  Parkes argues that many people who are bereaved will experience the following stages at their own pace:

  – Shock, which may show itself in many different ways for example numbness or disbelief

– Separation and pain, which may show in waves of distress, intense yearning for the person who has died and feelings of emptiness

– Despair, which may show itself in depression, difficulties with concentration, anger, guilt and restlessness

– Acceptance.

● **Five stages of grief [181]**
One of the most dominant stage models of grief is that of Kubler-Ross which, as the title suggests, has five stages: (**Fig. 3.6.1**)

It is argued that every step of this process is natural and healthy, and it is only when a person gets stuck for a long period of time that the grieving can become unhealthy or destructive. Going through the grieving process is not the same for everyone, but everyone has the same common goal – acceptance of the loss and to keep moving forward.

● **Critique**
One of the drawbacks of the stages of grief model is that many people view the stages as being absolute and linear, and that individuals should always progress through the stages in the exact same order. This misinterpretation can lead people to believe in a 'right way' to grieve and may cause bereaved individuals to compare their personal experiences of grief to an assumed 'norm'.

Stage theories have a certain seductive appeal – they bring a sense of conceptual order to a complex process and offer the emotional promised land of 'recovery' and 'closure'. However they are incapable of capturing the complexity, diversity and idiosyncratic quality of the grieving experience. Stage models do not address the multiplicity of physical, psychological, social and spiritual needs experienced by the bereaved, their families and intimate networks. Since the birth of these theories, the notion of stages of grief has become deeply ingrained in our cultural and professional beliefs about loss.

Newer models
The early stage theories of grief became unpopular because they were considered to be too rigid. There are, however, new models that succeed in identifying definite patterns and relations within the complex and idiosyncratic grief experience. Two of the most comprehensive and influential grief theories are:

● **Dual Process Model [182]**
The Dual Process Model of Grief, describes grief as a process of oscillation between two contrasting modes of functioning. In the 'loss orientation' the griever engages in emotion-focussed coping, exploring and expressing the range of emotional responses associated with the loss. At other times, in the 'restoration orientation', the griever engages with problem-focussed coping and is required to focus on the many external adjustments required by the loss, including diversion from it and attention to ongoing life demands. The model suggests that the focus of coping may differ from one moment to another, from

FIG. 3.6.1. Five stages of grief

Stage	Interpretation
1 – Denial	Denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. It's a defence mechanism and perfectly natural. Some people can become locked in this stage when dealing with a traumatic change that can be ignored. Death, of course, is not particularly easy to avoid or evade indefinitely.
2 – Anger	Anger can manifest in different ways. People dealing with emotional upset can be angry with themselves, and/or with others, especially those close to them. Knowing this helps keep detached and non-judgemental when experiencing the anger of someone who is very upset.
3 – Bargaining	Traditionally the bargaining stage for people facing death can involve attempting to bargain with whatever God the person believes in. People facing less serious trauma can bargain or seek to negotiate a compromise. For example "Can we still be friends?.." when facing a break-up. Bargaining rarely provides a sustainable solution, especially if it's a matter of life or death.
4 – Depression	Also referred to as preparatory grieving. In a way it's the dress rehearsal or the practice run for the 'aftermath' although this stage means different things depending on whom it involves. It's a sort of acceptance with emotional attachment. It's natural to feel sadness and regret, fear, uncertainty, etc. It shows that the person has at least begun to accept the reality.
5 – Acceptance	Again this stage definitely varies according to the person's situation, although broadly it is an indication that there is some emotional detachment and objectivity. People dying can enter this stage a long time before the people they leave behind, who must necessarily pass through their own individual stages of dealing with the grief.

Based on the Grief Cycle model first published in On Death & Dying, Elisabeth Kübler-Ross, 1969.
Interpretation by Alan Chapman 2006–2013.

one individual to another, and from one cultural group to another.

The model explains how bereaved individuals can alternate between having a loss orientation at times and a restoration orientation at other times. The individual can also oscilate between dealing with and avoiding the grief, which are both natural and healthy coping strategies at different times in the grieving process. This oscilation may be influenced by external factors such as work or caring responsibilities.

● **Tasks of mourning [183]**

Worden suggests that grieving should be considered as an active process that involves engagement with four tasks:

– to accept the reality of the loss

– to process the pain of grief

– to adjust to a world without the deceased (including both internal, external and spiritual adjustments)

– to find an enduring connection with the deceased in the midst of embarking on a new life.

Worden also identifies seven determining factors that are critical to appreciate in order to understand the client's experience. These include:

– who the person who died was

– the nature of the attachment to the deceased

– how the person died

– historical antecedents

– personality variables

– social mediators

– concurrent stressors.

These determinants include many of the risk and protective factors identified by the research literature and provide an important context for appreciating the idiosyncratic nature of the grief experience. Issues such as the strength and nature of the attachment to the deceased, the survivor's attachment style and the degree of conflict and ambivalence with the deceased are important considerations. Death-related factors, such as physical proximity, levels of violence or trauma, or a death where a body is not recovered, all can pose significant challenges for the bereaved.

● **Meaning reconstruction [184]**

Neimeyer's model is based on the fact that bereaved individuals are faced with the task of reconstructing their understanding of how the world works and their personal identity without the presence of the loved

one. There are three core dimensions to the process of meaning reconstruction. The first dimension is sense making, or the ability to find an explanation for the death and make sense of the occurrence. This is particularly important early in the grieving process, although it is an ongoing process for most individuals. The second dimension is benefit finding, where individuals are able to identify benefits to the bereavement in order to aid in their adjustment, whether the benefits are personal, spiritual, or philosophical. The third dimension is identity reconstruction, which requires the bereaved individual to change and adjust their sense of self after experiencing the loss of a loved one.

Synthesis of grief reactions

Regardless of what model of bereavement one subscribes to, it is clear that there are a range of different emotions associated with grief, including:

● Sorrow

● Longing

● Guilt

● Numbness

● Anger

● Hopelessness

● Loneliness

● Despair.

Many people compare grief to waves rolling onto a beach. Sometimes these waves are calm and gentle and sometimes they are very intense, such that it leads to people to:

● Not wanting to get up in the morning

● Neglecting themselves

● Not eating properly

● Feelings that they cannot carry on living without the other person

● Not feeling able to go to work

● Taking their feelings out on other people.

All of these feelings are normal parts of bereavement – unless they go on for a very long period of time. Sometimes grief can turn into depression. One of the key differences between grief and depression is that grief comes in waves whilst depression is like a cloud that hangs over everything. Key signs that grief has turned into depression include:

● Feelings of guilt unrelated to the recent loss

● Feelings of worthlessness

● Feeling sluggish, drained or confused

● Finding it difficult to speak coherently

● Difficulty in carrying out everyday tasks.

PREVALENCE

Office for National Statistics figures show that there are now 2.7 million widows or widowers in England and Wales. Of the 484,367 people who died in 2011 in England and Wales, 83% were aged over 65, and 54% were aged over 80 [185]. Consequently many of these deaths would have left spouses and partners, other family members and friends bereaved. More specifically, a larger number of older women than men become bereaved of a spouse or partner due to common diseases affecting men at a younger age [186]. This gender dimension is reflected in the fact that 1.7 million women over the age of 65 are widowed and live alone in the UK; three times the number of men [187].

INFLUENCING FACTORS

There are a number of circumstances which influence the way a person moves through the bereavement experience. Other losses in an older person's life will affect their ability to undertake the bereavement process successfully:

● existing health conditions

● communication and cognitive difficulties

● reduced social support

● changed living arrangements i.e. moving to sheltered housing

● financial difficulties.

Relationships
As has already been noted, the relationship between the deceased and the bereaved is a critical factor in determining the grief reaction. Where the deceased is an acquaintance or a distant friend the grief experience may be relatively minor, though again as already noted, the accumulation of a number of deaths of friends can produce a more significant reaction.

In later life the most significant deaths are likely to be that of a spouse or a sibling:

● **Death of a spouse**
Within the context of later life, death of a spouse is a very common transition that older people have to address. Although death of a spouse may be an expected transition, it is a particularly powerful loss.

A spouse often becomes part of the other in a particularly unique way; many widows/widowers describe 'losing half of themselves'. After a long marriage older people may find it an extremely difficult transition. And the manner of the loss will be important. The survivor of a spouse who died by an act of violence will experience a very different form of grief from that of a survivor of a spouse who has died of an illness. Furthermore, most couples have a division of labour which means that bereavement can bring with it significant challenges to the remaining partners capabilities and behaviours.

Death of a spouse is associated with particular risks to longevity. Helsing [172] found a much higher risk of mortality amongst widowed males, particularly those who did not go on to re-marry. Continuing to live alone is another significant risk factor for both men and women – social networks are therefore very effective at ameliorating stressful life events such as bereavement. The continual availability of even one person for conversation or assistance can be even more effective than a large number of friends or relatives who visit less frequently.

It is worth noting that where there is a caring relationship between spouses, a positive experience of care giving results in greater loss and grief when one of them dies. In addition to the loss of their loved one they lose an important personal role [188].

● **Death of a sibling**
Death of a sibling in later life is a common experience for older people. This can be one of the most devastating life events, but sibling grief is one of the most overlooked forms of grief. It can be such a significant event because of the fact that such relationships are often the longest significant relationships, especially for twins. Overall, with the loss of a sibling, a substantial part of the sibling's past, present, and future is also lost. If siblings were not on good terms or close to each other, then intense feelings of guilt may ensue [189, 190].

Gender differences in grieving
Gender differences play a big role in how individuals deal with grief and experience bereavement. Women are generally socialised to display emotions more than men, so it is more common for women to grieve more overtly and longer than men. Women tend to openly express their feelings, process their feelings with others, and grow more after the loss. Men, on the other hand, may want to grieve privately, be alone more frequently, and preoccupy themselves with other activities such as work or a hobby. These differences may be better explained by differences in coping styles by the two genders. Women tend to be more emotion-focused while men tend to use

rational problem-solving coping. Women may seek others to talk to in order to deal with their emotions while men prefer to focus on the tasks that need to be accomplished, such as planning the funeral, and generally keeping themselves busy. Generally, two patterns of grieving have been identified, with one being more intuitive, or affective, and stereotypically feminine, and the other being instrumental, or physical or cognitive, and stereotypically masculine. These stereotypical differences in grieving may help explain why being female is often considered a protective factor when it comes to being resilient as well, since women tend to seek out help and support more often and process their feelings openly.

Cultural differences in grieving

Each culture has its own values, beliefs, expressions, and rituals regarding death and loss. Some cultures mourn privately and discourage public displays of grief, while other cultures encourage open displays of emotion and grief. For those directly working with people experiencing bereavement it is important that they employ a generic approach to multicultural counseling, which combines culture-specific and universal perspectives, stressing both differences and similarities across cultures [191]. Tramonte [191] offers a variety of factors that need to be considered when working with bereaved clients from different cultures: communication, values, family concepts, religious beliefs, attitudes toward the body, attitudes toward death, bereavement, grief, and mourning practices, and funeral practices.

Gay and lesbian

The death of a loved partner is devastating for anyone regardless of sexual orientation, but gay men and lesbians can face unique challenges. For example, the stress of bereavement can be increased if the surviving partner has concealed his or her sexual orientation and/or the true nature of their relationship so that open grieving is not possible. Inheritance laws and employment policies about bereavement leave designed for married couples can add to the burdens faced by gay men and lesbians.

Many local councils have dedicated resources as the following examples indicate:

Lesbian and Gay Bereavement Project – Royal Borough of Kensington and Chelsea
http://www.rbkc.gov.uk/az/az.asp?OrgId=2016

Lesbian and Gay Bereavement Project – Manchester City Council
http://manchester.fsd.org.uk/kb5/manchester/fsd/organisation.page?record=246bADyhEEM

Other national / regional helplines are also in existence:

London Friend
http://londonfriend.org.uk/get-support/helpline/

COMPLICATED GRIEF

Bereavement is a normal part of life and for most people is undertaken satisfactorily. However approximately 10%–15% of people have severe reactions [192] [193]. Complicated grief remains poorly defined and without formal diagnosis, but is described as ' unresolved grief with symptoms related to bereavement that are distinct from those of depression and anxiety' [194].

Characteristics

These kinds of severe reactions appear to mainly occur in people with depression present before the loss event [192]. Prolonged Grief Disorder or Complicated Grief is a pathological reaction to loss with a number of symptoms which have been associated with long-term physical and psycho-social dysfunction. Complicated grief is characterised by an extended grieving period. The signs and symptoms are listed [195] as:

- extreme focus on the loss and reminders of the loved one
- intense longing or pining for the deceased
- problems accepting the death
- numbness or detachment
- bitterness about the loss
- inability to enjoy life
- depression or deep sadness
- trouble carrying out normal routines
- withdrawing from social activities
- feeling that life has no meaning or purpose
- irritability or agitation.

Predisposing factors

Research has identified some predisposing factors that may help professionals to recognise who may be at risk of experiencing complicated grief or bereavement [162]:

- Losing a spouse has an increased risk for complicated grief compared to losing a parent or a sibling [196].
- If the individual had a relationship with the deceased that was close, dependent, and/or confiding, then he/she has a higher risk for poor adjustment to the death [193, 197]. In contrast, widowed individuals who were in a conflicted relationship have lower levels of yearning for the deceased, leading to lower prevalence rates of complicated grief.

FIG. 3.6.2. The Bereavement pathway

HEALTH CARE SECTOR
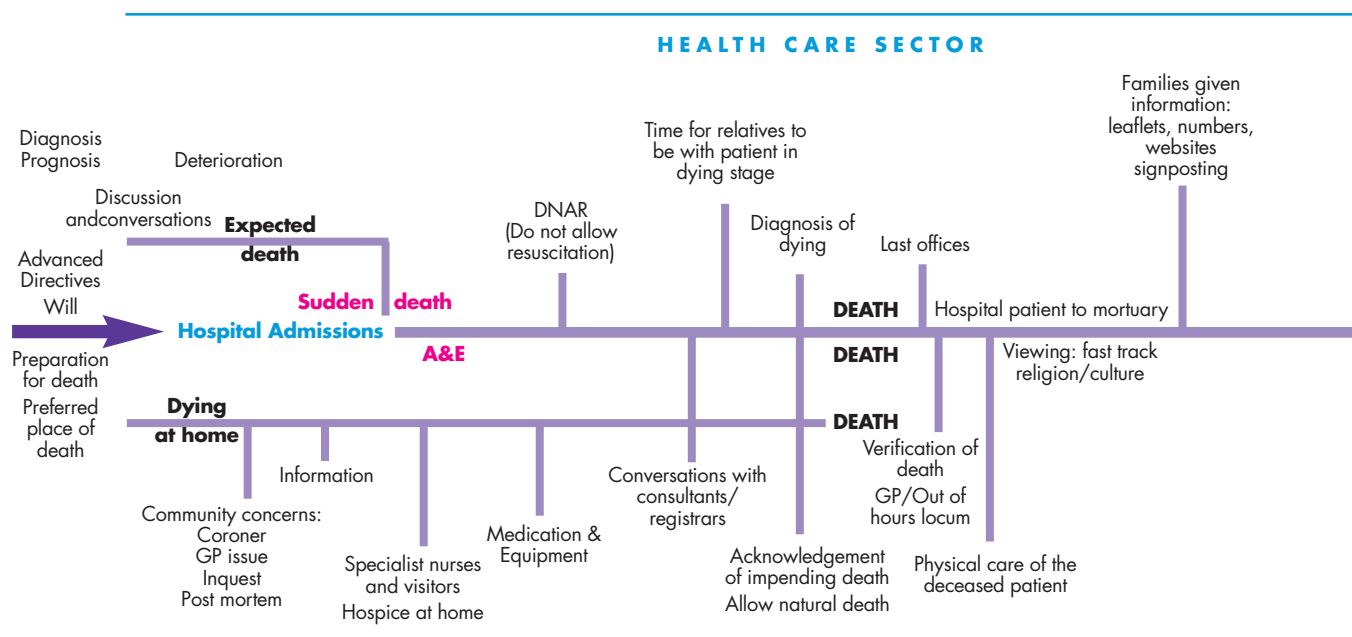
Source: © The Bereavement Pathways Project. A partnership beween the
Bereavement Services Association and Cruse Bereavement Care, 2007–2010

- Individuals who feel unprepared for the death or experience a sudden or tragic loss have a higher risk of developing complicated grief [193].

- Studies have shown that individuals who have lost a loved one due to a stroke or heart disease are more likely to experience complicated grief compared to those who have lost a loved one due to cancer [196]. This is likely due to the unexpected nature of the death for strokes and heart disease, which increases the risk of developing complicated grief.

- If an individual believes that he or she has a good support system, it is less likely that he or she will develop complicated grief. An individual's perceived level of support is more influential than the actual received support in determining his or her adjustment to death [198]. Friends appear to provide more encouragement and reinforcement for the individual to overcome their grief than do family. This may be because family members may end up encouraging pathological dependency which leads to less motivation to overcome grief.

Overall a number of significant factors have been identified [199] as being associated with the onset of complicated grief:

- A close relationship with the deceased

- Marital closeness and dependency

- Feeling unprepared for the death

- Perceiving the death as violent or traumatic

- Perceived social support.

INTERVENTIONS TO SUPPORT THIS TRANSITION

The purpose of bereavement care is "… to benefit the bereaved individual, to help him or her to deal with the emotional and practical problems following the loss of a loved one" [200]. Bereavement care covers a wide spectrum from informal through to specialist health and social care services (see Bereavement Pathway overleaf).

Tiered approach
National guidance advises on the need for a tiered approach to bereavement services [201]:

Component 1
Grief is normal after bereavement and most people manage without professional intervention. Many people, however, lack understanding of grief after immediate bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of

VOLUNTARY/COMMUNITY SECTOR

SOLUTIONS

Deaths overseas
and repatriation
Burial abroad –
coroner's agreement

Registration
of Death

Appointment
at Bereavement
Office

Signposting & information
Networking (links cross-sector)
Training/Education (staff cross-sector
Co-ordinated services
Assessment
Onsite bereavement services
Cross-sector referral

Support groups
Specialist groups

Access to
bereavement
services in the
community

Health services
(if required)

Family
Friends
Social circles
Faith communities
GP

CONNECTING

SERVICES

Empowerment
Resilience
Self-help
Normal life

Questions
asked/answered
Appointment with
consultant

Contact established with
bereavement support

Medical Certificate of
the Cause of Death
Scrutiny of MCCD
Cremation papers (if
required)
Hospital PM consent
HTA – donation

Joint core literature
Bereavement forums
Bereavement volunteers
Improved NHS follow-up
Joint services delivery
Bereavement services protocol
Bereavement services standards
Bereavement services quality markers

Email support
Telephone support
One-to-one support
Home visits
Information & signposting

Coroner's courts
Inquests
Inquiries

support. Family and friends will provide much of this support, with information being supplied by health and social care professionals providing day-to-day care to families.

Component 2
Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver Component 3 interventions.

Component 3
A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist need of bereaved children and young people.

Voluntary sector
Voluntary sector services are most likely to become involved in Components 1 and 2. Some will carry out bereavement care as a continuation of their involvement with the family, for example the Alzheimer's Society. Others like Cruse, a national charity for bereaved people, will only provide a service at a much later stage in the bereavement journey. (**Fig. 3.6.2**). The voluntary sector provides a huge amount of bereavement support – estimated at around 80% of all bereavement care [202], with over 600 bereavement organisations across the UK [174].

NEED FOR SERVICES

The literature is clear that bereavement support is only required for a small proportion of bereaved people, those who are already experiencing complications in their grief. Unsolicited help based on routine referral of everyone shortly after loss is not likely to be effective [203]. Schut and Stroebe [204] summarise their review of the literature with the conclusion that:

Routine intervention for bereavement has not received support from quantitative evaluations of its effectiveness and is therefore not empirically based. Outreach strategies are not advised and even provision of intervention for those who believe that they need it and who request it should be carefully evaluated. Intervention soon after bereavement may interfere with 'natural' grieving processes. Intervention is more effective for those with more complicated forms of grief. (p. 140)

The general pattern emerging from this is that bereavement interventions are only appropriate for those with complicated grief symptoms. About 85% do not go on to develop 'complicated grief' [197]. As outlined in the tiered model (above), only a small proportion of people will require specialist and professional services. The overwhelming majority will only require some information and acknowledgement and some of them will benefit from low level interventions such as support groups. These elements are looked at in more detail below.

EFFECTIVENESS

A recent national overview [174] of effectiveness of services found the following:

● The strongest evidence is for targeted and specific intervention for people with more complex grief reactions.

● There is no evidence to support the use of intensive bereavement interventions universally.

● There is some evidence that motivation on the part of the bereaved is required for bereavement care interventions to be effective.

● The acceptability and appropriateness of support groups is largely dependent on bringing together people with similar attributes and grief experiences.

TAKE UP

Even when people are offered support most people do not go on to seek any form of professional help. For example one study [205] showed that after a contact letter and bereavement booklet were sent from the bereavement service, only 25% of those surveyed contacted the service further and only 7% went on to seek professional help.

There appear to be a number of reasons why most bereaved people do not seek professional help. Most appear to feel that they do not need assistance or that services offered would not meet their needs [206, 207]. Factors associated with the uptake of services [174] include:

● Greater personal resources such as higher self esteem and life satisfaction, had fewer depressive symptoms and grief adaption problems.

● Uptake of services is more likely if:

 – the relationship to the deceased is spousal

 – the bereavement is due to a sudden death rather than a death that was expected

 – the bereaved person has been providing significant levels of care over a long time.

● Social networks are the main source of support for most people and many report that they do not need formal bereavement support services. Need for formal bereavement support is associated with the availability of social support and nature of the death. Evidence shows that post bereavement support is affected by the quality of social networks, i.e. family and friends [208], although it is also important to note that a person's role in a social network may change after a bereavement.

ASSESSMENT

If interventions are to be targeted at those experiencing complicated grief then it is important to identify who these people are. The approach to assessing the risk of people requiring support with complicated grief is very mixed. There is a level of agreement about the need for assessment of the bereaved to identify those most at risk of having complicated grief reactions although no clear evidence exists for how this should be carried out [209]. There is no standard assessment tool. Horrocks [210] compiled a list of grief assessments and found a total of 63 instruments to assess bereavement and grief! Some approaches involve case discussions rather than an assessment tool.

And to add to the confusion, opinions are mixed about the value of undertaking any form of risk assessment [202]. Not all services carry out a formal screening or risk assessment for complicated bereavement. Indeed studies of the hospice movement identified that only 43% of these services formally assessed the need for bereavement support.

Although many generic and bereavement specific assessment tools are available they often confound coping with loss with other symptoms i.e. psychological distress. The main focus of measurement should be on the ability of the person to cope with their loss in terms of grief as a normal process and most risk assessment tools do not reflect this clearly [211].

However, there will be some benefit for the bereaved if in some way their risk is measured and appropriate action taken when risk factors are identified. Age, type of death, previous bereavement experiences, social support, characteristics of the bereaved person, and relationship with the deceased are key criteria that may be useful in identification of those who may require additional follow up and support [209].

INFORMATION

There are a range of websites with information for people who have been recently bereaved. The NHS main site is reasonably comprehensive http://www.nhsinform.co.uk/bereavement. There are others which focus on more practical information http://www.bereavementadvice.org, and others which focus on the more emotional aspects http://www.moodjuice.scot.nhs.uk/Bereavement.asp

Some simple statements about grief can also be very helpful. The following set of 'myths and facts about grief' are an example:

Myths and facts about grief

MYTH: The pain will go away faster if you ignore it.
FACT: Trying to ignore your pain or keep it from surfacing will only make it worse in the long run. For real healing it is necessary to face your grief and actively deal with it.

MYTH: It's important to be "be strong" in the face of loss.
FACT: Feeling sad, frightened, or lonely is a normal reaction to loss. Crying doesn't mean you are weak. You don't need to "protect" your family or friends by putting on a brave front. Showing your true feelings can help them and you.

MYTH: If you don't cry, it means you aren't sorry about the loss.
FACT: Crying is a normal response to sadness, but it's not the only one. Those who don't cry may feel the pain just as deeply as others. They may simply have other ways of showing it.

MYTH: Grief should last about a year.
FACT: There is no right or wrong time frame for grieving. How long it takes can differ from person to person.

Source: Center for Grief and Healing

ACKNOWLEDGEMENT

If it is accepted that bereavement is a natural process which the overwhelming majority of people manage successfully then it needs to be recognised that the only intervention usually required by the bereaved is for someone to validate a range of feelings that they are experiencing to enable them to adapt and move on through their grief [202]. Evidence shows that bereaved people want some kind of recognition or acknowledgement of the death. A card of sympathy or phone call is most valuable. Studies [212] have shown that the majority of bereaved people would have appreciated a letter of sympathy but that this was not always given. GPs often appear to fail to mention a recent bereavement during a routine consultation.

BEREAVEMENT SUPPORT GROUPS

One of the most common treatment options for bereavement (Tier 2) is the use of support groups. Typically, support groups are found to be useful for those individuals who are going through an "uncomplicated" grieving process, or those who possess the resources necessary to naturally proceed through the grieving process [162]. Individuals who are referred for support groups may be experiencing some current difficulties dealing with the loss, but they can be expected to work through their grief in time. The rationale for this form of intervention is that receiving support from a group leader or fellow group members may help the individual to get back on track in the grieving process.

Support groups can act as a surrogate system, especially for bereaved individuals whose other family members and friends are dealing with their own grief and may not be emotionally available.

Five main purposes of bereavement support groups have been identified [213], including:

- support
- sharing one's feelings
- developing new coping skills
- education
- exploring existential issues.

By participating in a support group, individuals are able to both receive and give support. Most participants in support groups already possess the resources to overcome their grief in time. However, by participating in a support group, individuals are exposed to some of the coping skills that other members have which they do not possess. It can also be helpful for participants to

obtain more information and education on the grieving process and how to go about making some of the life adjustments required with the loss of a loved one. The perception that others in the group have gone through similar experiences helps to lessen one's feelings of isolation and loneliness, and receiving support and feedback from others in the group helps to promote hope as well [214].

While support groups are helpful for most bereaved individuals, one question regarding support group participation is when is the appropriate time after experiencing the death of a loved one for an individual to join a support group. Some people believe that bereaved individuals need only a couple of months to grieve on their own before joining a support group while other people think that it is appropriate to wait at least six months. There is some research [215] to suggest that early intervention may be important in order to provide support and potentially prevent prolonged grief.

Evidence shows that peer support groups are most effective when they bring together people with shared characteristics in terms of the nature of the bereavement and the trajectory of the loss [174]. However, support groups can be perceived as intimidating to some and participants needed to be informed as to what to expect for these to be successful. There is evidence that some participants in bereavement groups have difficulty with the sense of obligation to help others while going through their own process of healing or that others' grief can often amplify their own. By definition a peer support group is about both receiving help and providing support for other members of the group. Only a very small minority of participants believe they give more than they receive with a large majority believing that their contribution is small in comparison to the benefit they gain, suggesting individual contributions tend to be underestimated.

INTERNET SUPPORT GROUPS

Support groups can even be helpful for individuals over the internet, although there will be issues here regarding older people's use of new technology. Individuals can seek support for bereavement on the internet in a variety of ways, through message boards, e-mail groups, chat rooms, and even online memorial web sites [216]. Internet bereavement support groups are growing in popularity. Multiple internet support groups are available and range from helping others who are grieving to specifically focusing on the type of loss or the relationship of the individual to the deceased. Many advocates of internet support groups argue that individuals who do not have a strong support system can greatly benefit from accessing the internet for support.

The internet can be especially useful for individuals who are hesitant or ashamed to seek help face-to-face. Results of an evaluation of an internet-based therapeutic intervention found lower dropout rates compared to face-to-face counselling, suggesting that individuals may feel more comfortable discussing sensitive issues over the internet [217]. Some research on internet support groups has been conducted, but due to poor methodology the results fall short of acceptable research standards and generalisability.

GRIEF THERAPY

For individuals who are having more significant difficulties (Tier 3), support groups may not be as beneficial. For this reason, individuals who are experiencing complicated grief or whose grief process is prolonged are encouraged to engage in some form of grief therapy [162]. Grief therapy implies that further interventions are needed for the individual to overcome the barrier they have encountered, whether the barrier is cognitive or emotional. These treatment interventions can range from formal counselling groups to Cognitive Behavioural Therapy (CBT).

A meta-analysis of the efficacy of grief therapy [218] found it to be relatively small compared to the effectiveness of therapy for a variety of other mental health problems found in other meta-analyses. This may be due to the improvement of participants in control groups, since grief naturally improves over time, not just for those participants in grief therapy.

The one intervention which does have an evidence base for effectiveness is Cognitive Behavioural Therapy (CBT). A review of studies using CBT for bereavement has shown that, overall, CBT interventions outperformed the non-CBT interventions both at post-treatment and follow-up [219]. The review also found that CBT interventions were more effective at reducing symptoms in grief, depression, anxiety, trauma, and general distress post-treatment compared to the non-CBT interventions. At follow-up, symptoms in depression and anxiety were reduced more in clients who received CBT-based interventions than those who received non-CBT interventions. However, the outcomes at follow-up revealed that there were no significant benefits for CBT interventions compared to non-CBT interventions. The efficacy of CBT is still under review, but so far the results of treating bereavement with CBT seem comparable to the initial studies examining CBT interventions for clients with depression, for which CBT is now empirically supported.

The internet is another channel for delivering CBT and one study of its effectiveness has been carried out [217]. The results of the study showed that symptoms significantly decreased in the treatment group compared to the control group. There was an overall improvement in psychological functioning (including depression and anxiety) between the treatment and control conditions, but no difference in physical symptom complaints. There were no significant differences at the three- month follow-up, which means that the treatment condition maintained symptom improvement after the intervention. The results suggest that CBT conducted over the internet is effective for individuals suffering complicated grief.

There has been the development of specific treatments for complicated grief. Shear et al [220] developed a complicated grief treatment (CGT) using the framework of interpersonal psychotherapy (IPT). CGT incorporated IPT and CGT techniques. The results showed a significantly better outcome for CGT participants.

ISSUES

Service provision issues

Bereavement care services are traditionally well developed in palliative care but there is little evidence of replication in generic healthcare settings where deaths are more likely to occur [221]. In addition, previous research has identified a lack of clarity about care provided to the bereaved in general hospital wards, care homes and in community settings, and that there is no particular provision for older people [222].

Research shows that bereavement service provision is very variable with little evidence of any standardisation across different parts of the UK [174, 202]. There are a variety of approaches at both national and local levels. What is seen as missing is some form of co-ordination, networking or linkage between the different facets [202]. Service providers are often unaware of what else exists for the bereaved in their local area or on a national basis. And provision contains significant anomalies. For example, bereavement service provision is largely embedded in hospice provision; however in the UK it is estimated that only 4% of people will die in a hospice. Another example is the fact that whilst it is mostly older people that die, there is very little evidence of services being specifically designed to meet their needs.

Two comprehensive attempts to review and map bereavement services [174, 202] highlighted a number of priority gaps:

- Bereavement can have health consequences

- There is a need to raise awareness and be much more open about grief as a normal process

- Education of care staff on bereavement needs development

- Research is required on many bereavement related issues

- There is a need to develop national policies and guidelines

- There is no co-ordinated approach to bereavement nationally

- Follow-up of the bereaved is often not available

- There is not enough awareness of multicultural issues

- Assessment of risk factors for complicated grief is lacking

- There is a dearth of evidence relating to bereavement support in care homes.

- Bereavement pathways are in their infancy and general practitioners and community staff are likely to play a key role in ensuring links between hospital provision and longer term care provided by the voluntary sector.

Other literature identifies a number of issues about the delivery of bereavement services:

- A major issue is the difference in the level of bereavement support that is provided to relatives of those who have died in palliative care services (including hospices) than is provided to others. "*If you have cancer you are sorted*" (Hospice Chaplain). This raises the question as to whether there are many people missing out on bereavement support because they are not seen by the palliative care services.

- Social class and deprivation are also recognised as major sources of inequality in people's access to services [202].

- There is a recognition of a lack of service provision for older people. "*It is incongruous that we are creating services for children and yet not for older people, who are the majority of the people who die*". [202]

- There is the paradoxical situation that some staff involved in bereavement support may seek to extend their role and function to become involved with people who in fact would do perfectly well without any bereavement support.

- Cruse recognises the importance of the need to normalise bereavement and as a result operates an 'in-reach' service i.e. it relies on people to contact it rather than going out to proactively contact people, nor to take referrals from other agencies. This policy is based on research which shows that there are better outcomes when the person self refers to services i.e. when they have recognised their own need for help.

User experiences

A national survey of users of bereavement services [223] indicated the following:

- The overall quality of care across all services in the last three months of life was rated by 44% of respondents as outstanding or excellent.

- Respondents of those who died of cancer in their own home rated the quality of care most highly (63%).

- Being shown dignity and respect by staff was highest in hospices and lowest in hospitals.

- For those who expressed a preference, the majority preferred to die at home (81%), although only half of these actually died at home (49%). The most commonly reported place of death was a hospital (52%).

- Two-thirds of respondents (64%) reported that no decisions had been made about care which the patient would not have wanted. However, 17% of respondents said yes to this question.

Public attitudes

It is essential to recognise that grief, loss and bereavement are normal processes that everyone will experience. Many argue that there is a great need for normalisation of behavioural and emotional responses to death and that there should be a resistance to pathologising grief. They argue that a culture has arisen where social norms make it difficult for people to cope with grief as a normal process. People are now protected from involvement with death, dying and the bereaved and with this limited experience are less able to accept loss and more likely to consider their grief 'abnormal' and in need of treatment. In some cultures where death is very commonplace there is a great deal of 'matter of factness' about it, which is rarely evident here.

There is a need to encourage discussion of how death and dying can be absorbed into life in a way that makes them more acceptable [224]. For some this raises questions about whether grieving and bereavement should be addressed in school curricula and in public health messages. There is certainly a view that there should be a strategy, drawing on previously successful culture changing campaigns [202] to raise the profile of bereavement issues. A survey of public attitudes on death and bereavement may be a helpful starting point.

Outcomes

Paradoxically, although it is mostly older people who die, there is a lack of good research evidence about the outcomes of the bereavement process for older people and their consequent need for bereavement services, even with regard to palliative care [225]. There are few support services which specifically focus on the needs of this group.

SUMMARY

- There is little indication of a lack of service provision but many commentators note a significant lack of co-ordination.

- Bereavement is a significant trigger for loneliness and isolation. There is a lack of provision to address this, principally in the form of befriending and/or community development (neither of which are specialist bereavement services). Lack of transport for frail or housebound older people can be a compounding factor.

- There is an argument for a public health campaign, along the lines of the 'five ways to wellbeing', to appraise the general public of what to expect and how to deal with their feelings around bereavement.

- There remains a huge mismatch between where people say they want to die (i.e. home) and where they actually do die (i.e. hospital).

- Talking therapies (e.g. CBT) are effective in supporting those with complicated grief.

3.7
ACQUIRING A LONG-TERM HEALTH CONDITION

DEFINITION

Acquiring a long-term health condition refers to the situation where someone develops an illness which, whilst not terminal, is nevertheless not amenable to 'cure'. It is a state of ill health that they will live with for a long time and where the purpose of medical intervention is to enable as good a quality of life to be lived as possible, regardless of the illness. The most common health conditions being referred to here are diabetes, chronic obstructive pulmonary disease, stroke, heart disease, arthritis etc.

For the purposes of this paper the focus is on the early stages – i.e. the first year or so of acquiring the condition. Thereafter, it is not so much a transition, but rather a process of maintaining as good a quality of life as possible with the illness. The transition focuses on what it means for someone to change from being "healthy", to someone who has an illness which cannot be cured. So the focus is on the emotional journey that people have to go through as they acquire a health condition and the interventions which support them to remain as independent and in control of their lives as possible. Medical interventions and clinical support do not feature in this analysis.

NATURE OF THE TRANSITION

Self evidently this transition is related to a change in health status. Acquiring a long-term health condition is largely unforeseen and unplanned for. It is clear that for some long-term conditions lifestyle can be a significant contributing factor. In these cases it is possible to argue that people have a degree of control over whether they acquire a long-term health condition. That having been said there are also life course trajectories which come into play here (i.e socioeconomic factors) which rather undermine the idea of control in this area. Having acquired a long-term health condition, there is then the option for people to take significant levels of control over their situation and the management of their condition (see below).

Acquiring a health condition is inextricably linked to many other transitions in later life – e.g. becoming a carer (for their partner), moving home, entering institutional care, planning for end of life, bereavement (for the partner). It is therefore one of the most critical transitions in later life.

IMPACT OF THIS TRANSITION ON PEOPLE'S LIVES

Acquiring a health condition is a very particular transition as it brings with it significant concerns about pain, discomfort and mortality. The onset of a debilitating long-term condition often thrusts the individual into a strict medical regime that involves regular check ups and complicated treatment processes. As well as these medical tasks, long-term illnesses also carry social, emotional, spiritual and vocational ramifications [226]. As a result people are generally faced with the prospect of having to adapt to significant losses that may impact several areas of their lives and affect their emotional equilibrium, their perception of life's meaning and their own self image.

In other words, "*patients are oft times reduced to being helpless witnesses to the collapse of some or every part of their existence.*" [226].

The transition involves accepting a change in **identity** – i.e. one transitions from a 'healthy person' to someone who is 'ill'. This in itself can bring about changes in one's **sense of purpose** in life – particularly where there are issues of disability and mortality. There also tend to be big changes in people's **capabilities and behaviours**. In order to live with their new condition people usually have to learn new ways of living and make various changes to their lifestyle. Past experience, coping strategies, emotional resilience and health related behaviours all influence the response to diagnosis and the impact of living with physical symptoms and resulting disabilities [227].

*"Supporting people to self care should start by supporting them to understand and accept their condition. By acknowledging that they have a LTC, individuals can begin the journey of developing knowledge, skills and confidence that can help optimise their quality of life and even slow the progression of their underlying clinical condition."*

Dr Alf Collins,
Consultant in Pain Management, Somerset

This is a transition which is usually unanticipated and is generally undesirable. That having been said it does not mean that people don't have the opportunity to take some control. Indeed the most important way of supporting someone through this transition is to empower them to do just that. Self care and peer support are vital elements of a portfolio of supportive interventions and are the bedrock of Government policy regarding long-term conditions.

Long term conditions are complex and can present substantial challenges for every individual living with one, including for their family and carers. Effective self management is crucial to the achievement of a healthy and satisfying life. This may require psychological acceptance of the illness, managing symptoms, personal motivation, adherence to treatment regimes, managing stressful medical procedures, adjustment of expectations and changes in behaviours and routines [227].

FIG. 3.7.1. Proportion of people with LTCs by age, England 2009
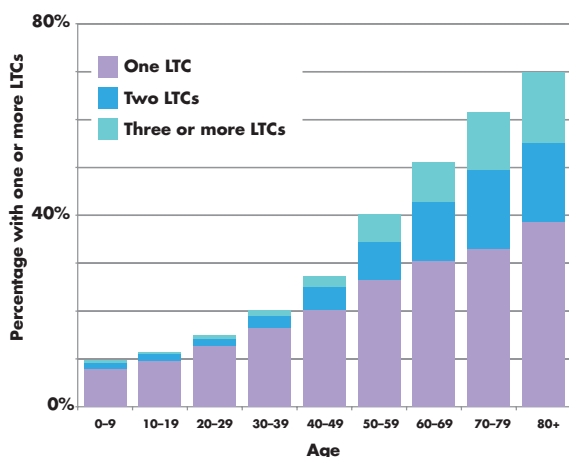
Source: Department of Health [228]

NUMBERS OF PEOPLE ARE LIKELY TO EXPERIENCE THIS TRANSITION

Acquiring a long-term health condition is a transition that increases exponentially with age. Long-term conditions are more prevalent in older people (58 per cent of people over 60 compared to 14 per cent under 40). (**Fig. 3.7.1**)

The Department of Health [228] estimates that the overall number of people with at least one long-term condition may remain relatively stable until 2018. However, analysis of individual conditions suggests that the numbers are growing, and the number of people with multiple long-term conditions appears to be rising.

There is a strong socioeconomic bias to the prevalence of long-term conditions. Most individual long-term conditions are more common in people from lower socioeconomic groups – people in the poorest social class have a 60% higher prevalence than those in the richest social class and 30% more severity of disease [228]. General Household Survey data (2006), analysed by the Department of Health below, shows that those from unskilled occupations (52 per cent) suffer from long-term conditions more than groups from professional occupations (33 per cent). (**Fig. 3.7.2**)

FIG. 3.7.2. Link between socioeconomic group and long-term conditions prevalence and severity

KEY

— **Severity – affects activities**

— **Prevalence**

Socioeconomic group:
I Professional, etc, occupations
II Managerial and technical occupations
III Skilled occupations
(N) Non-manual
(M) Manual
IV Partly skilled occupations
V Unskilled occupations
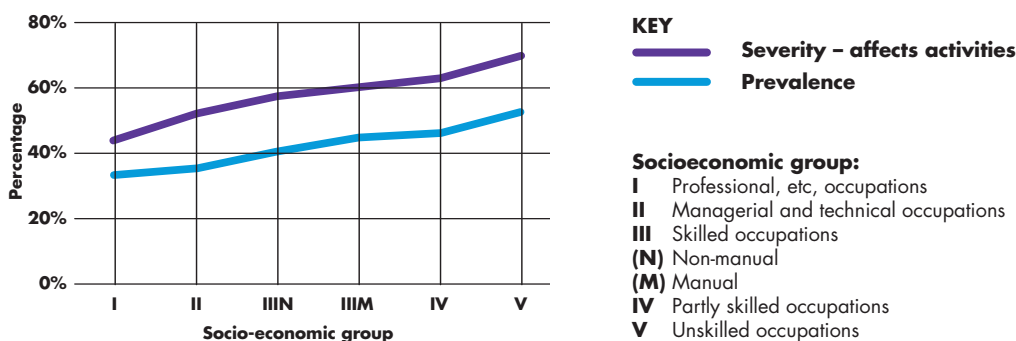
Source: Department of Health analysis of General Household Survey 2000

Geographical variation

These socioeconomic factors probably go some way to explain the significant geographical variation in the prevalence of long-term conditions: (**Fig. 3.7.3**)

FIG. 3.7.3. Prevalence of long-term conditions in England

Source: Department of Health [228]
Note: England average is 50% for this survey (GP patient survey 2010–11). Covers adults only and uses different method from that of other estimates

Gay and lesbian

There is a substantial body of evidence demonstrating that lesbian, gay, bisexual and trans (LGB&T) people experience significant health inequalities, which impact on both their health outc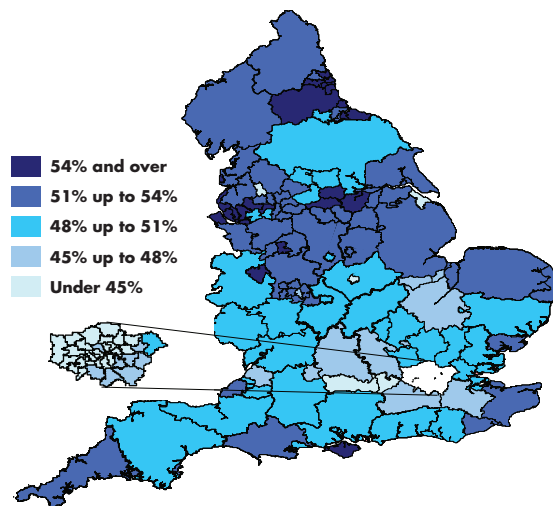omes and their experiences of the health care system [229]. While the smoking pattern of older lesbian, gay and bisexual people broadly follows that of heterosexual people – lesbian, gay and bisexual people over 55 drink more alcohol, are more likely to take drugs, have more concerns about their mental health and are more likely to have been diagnosed with anxiety or depression in the past [37]. There is also a lower uptake of screening programmes [229]. It is reasonable to extrapolate from the data that LGB&T populations will have a shorter life expectancy than their heterosexual counterparts due to their increased risk of cancer, coronary heart disease and suicide [229]. However research indicates that gay and bisexual men are less likely than men in general to have diabetes, which is consistent with a population which is less likely to be overweight or obese [229]. Lesbian and bisexual women aged 50–79 are more at risk of breast cancer because of a lack of early diagnosis [229].

Ethnic minorities

The evidence suggests that there is a higher incidence of ill health amongst minority ethnic communities [38]. In particular:

● higher rates of coronary heart disease for Pakistanis and Bangladeshis

● higher levels of hypertension amongst the Caribbean population

● higher rates of diabetes for all black communities.

Overall the data shows that older people from BME communities are more likely to report poor health 'over the last year' and more likely to report that an illness or injury has restricted their activity in the last two weeks [38].

IMPACT OF ACQUIRING A LONG-TERM CONDITION

Acquiring a long-term condition can affect people's lives in a variety of ways.

Quality of life

As the graph below shows, quality of life can be undermined .(**Fig. 3.7.4**)

One of the particular effects of acquiring a health condition is a tendency for a decline in older people's participation in activities outside the home, which in turn can reduce their opportunities to sustain friendships and meet new people. As people get older there is a marked increase in the amount of time they spend in their homes, often as a result of a health condition. It is estimated that those over 65 spend 80% of their time at home on average, increasing to 90% for those over 85 [230].

FIG. 3.7.4
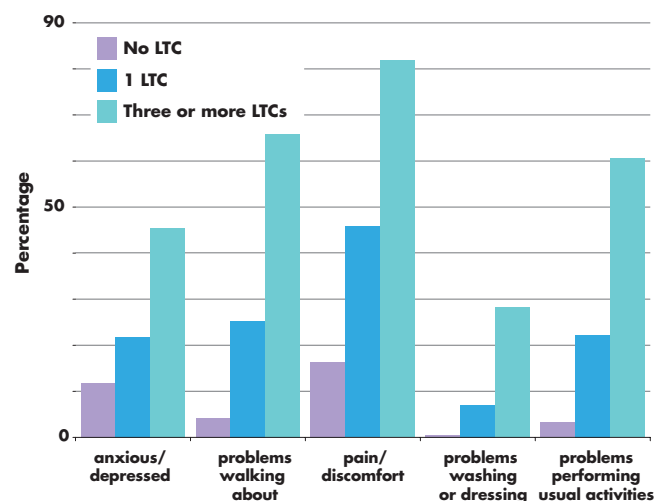
Psychological and emotional aspects

Acquiring a health condition can bring with it some significant emotional reactions. The diagnosis of a long-term condition can be a trigger for psychological distress. It is estimated [231] that 20% of people with a long-term condition are likely to suffer from depression with depression and anxiety being two to three times more common than in the general population. People with three or more conditions are seven times more likely than the general population to have depression [227]. With timely effective support many psychological problems can be dealt with or avoided altogether; however a well coordinated and collaborative pathway between physical, psychological and mental health components of disease specific pathways is required [227]. Psychological support is available from the NHS and from a number of the voluntary organisations supporting different conditions (e.g. Macmillan Cancer Care, Diabetes UK etc), although there is a significant mismatch between need and supply.

Cancer

Psychological distress in cancer patients is a significant and ongoing problem [232]. Emotional and psychological long-term side effects of cancer and its treatment include depression, anxiety, memory problems, difficulty concentrating, sexual problems and reduced social skills [233]. Although a certain amount of emotional distress is common, particularly around the time of a diagnosis, approximately 50% of patients (150,000 people per year) experience levels of anxiety and depression severe enough to adversely affect their quality of life. Although psychological issues are more common in the first year after treatment, one third of patients continue to report significant levels of distress well after treatment has been completed. Even 10 years on, 54% of cancer survivors (over one million people alive in the UK today) still suffer from at least one psychological issue [234]. It is also not just cancer patients who suffer psychologically; 67% of carers experience anxiety and 42% experience depression. Dealing with psychological distress is not just an adjunct to good care – it is fundamental. Evidence from 25 independent studies shows that mortality rates can be up to 39% higher in cancer patients with depression [235].

Diabetes

It is estimated [236] that about 60% of adults with diabetes report at least one troublesome concern or emotional difficulty related to diabetes and some 40% of adults with diabetes suffer from poor psychological wellbeing. There is evidence of disproportionately higher prevalence rates of generalised anxiety disorder, panic and depression amongst people with diabetes and the rate of common mental health disorders is some three times greater than in the general population [227].

Chronic Obstructive Pulmonary Disease (COPD)

The experience of breathlessness can be distressing and difficult to understand and control. Psychological factors can create a vicious cycle with escalating breathlessness.

Coronary Heart Disease (CHD)

People who have suffered a heart attack have a 30% chance of developing depression [237] and depression in people with CHD predicts further coronary events and greater impairment in health related quality of life [238]. People who develop depression following an acute coronary episode may be at particularly higher risk of worse cardiac outcomes. Depressed individuals with CHD are more than twice as likely to die than those with CHD alone [238].

Stroke

Three quarters of strokes happen to people over 65, who may be suffering from a range of other health conditions [239]. Stroke is a sudden, life changing event and stroke survivors often grieve for the life and identity they have lost so suddenly and expectedly. They often feel intensely frustrated and angry at being unable to carry out the simple, everyday tasks they used to take for granted. Anxiety and depression can also result from the damage caused by the stroke itself [239]. Stroke survivors presenting with depression are more likely to have another stroke [240]. There are also impacts on family; 64% of carers reported that the emotional impact of stroke was by far the hardest thing to cope with [241]. Two thirds of stroke patients responding to a survey had experienced difficulties in their relationship with their partner as a result of the stroke. Of these, one in ten had broken up with their partner or considered doing so.

COPING

Adjusting to acquiring a long-term illness is a critical aspect of the transition. As with all other transitions, some people adjust better than others. This is clearly related to the idea of 'resilience' (see more below), but there are also various theoretical constructs in the field of health psychology [226, 242]. It is not possible within the confines of this report to go into the depth of this field of study, suffice to say that the psychological and emotional aspects are fundamental to successful outcomes in this transitions. The medical side is well addressed by doctors – the emotional and psychological sides, which are equally important, are often left unaddressed, except when the patient displays issues which warrant the intervention of specialist psychology staff. There is little consensus about an overarching theoretical paradigm for understanding the process of

adjusting to acquiring a long-term health condition. Moss-Morris [242] has recently proposed the following overarching model which includes the following factors which are deemed to be helpful for adjustment:

Cognitive factors

- self efficacy / sense of control regarding disease management

- self efficacy regarding generic life situations

- benefit finding (positive reinterpretation)

- acceptance of illness

- high perceived social support.

Behavioural factors

- coping by using problem focussed strategies, planning and/or seeking social support

- engagement in good health behaviours

- adherence to medical and self management regimes

- maintenance activity levels in the face of illness

- appropriate expression of emotion.

Alongside these are a number of possible ongoing illness stressors which the patient has to deal with:

- managing social relationships and relations with health professionals

- an uncertain future

- preserving their autonomy

- acknowledging their limits

- managing stressful / ongoing treatments, lifestyle changes, disability, and symptoms.

The above indicates the range of psychological and emotional factors which come into play.

INTERVENTIONS TO SUPPORT THIS TRANSITION, AND THEIR EFFECTIVENESS AND COVERAGE

There are three key interventions to support people to successfully undergo the transition of acquiring a health condition:

- Provision of information

- Supporting self management

- Psychological support.

Information

The provision of good quality and timely information is fundamental to supporting people to make this transition. For example, it has been found that patients who have a better knowledge and understanding of their cancer and treatment are found to be more positive and less depressed. Conversely, research has found that patients who are dissatisfied with the information they receive are much more likely to be depressed and are potentially more likely to be anxious [243]. Patients with long-term conditions who are well informed are better able to understand and participate in their health care plan, experience less anxiety and are more likely to cope with their illness. They are also better equipped and prepared with questions for consultations with health professionals [243].

Providing information to patients helps maintain a sense of control. It helps with treatment compliance and self management because patients can weigh up the pros and cons of different options, make decisions, and know what to expect. It also leads towards a more collaborative relationship between patients and health professionals resulting in greater satisfaction with care [243]. Informed patients take a greater degree of ownership and responsibility for their care and are better equipped to manage their own symptoms. With the right information and support patients can look after themselves more efficiently and their quality of life is much improved.

There is a large amount of online information about the various long-term conditions:

NHS Choices
http://www.nhs.uk/Pages/HomePage.aspx

Stroke Association
http://www.stroke.org.uk

British Lung Foundation
http://www.blf.org.uk/Conditions/Detail/COPD

Diabetes UK
http://www.diabetes.org.uk

British Heart Foundation
http://www.bhf.org.uk/heart-health/conditions/heart-failure.aspx

However there can still be a mismatch between need and provision. For example, 52% of stroke survivors did not receive any information, advice or support with anxiety and 56% reported a similar lack of help with depression.

MACMILLAN SUPPORT LINE

The Macmillan Support line is a free, multilingual service available from Monday to Friday from 9am to 8pm and is free to call from UK landlines and mobiles. People affected by cancer particularly value the anonymity and confidentiality offered by the Macmillan Support line. The phone line is manned by cancer specialists who are trained to offer practical, medical, emotional and financial advice and who have immediate access to high quality and up to date information on cancer information and support. Callers to the Macmillan Support line are also signposted to appropriate local Macmillan and non-Macmillan services. The provision of effective cancer information and support can make a real difference to a patient's quality of life by helping to improve their physical and mental health, their financial situation and their ability to manage living with cancer. There is evidence linking improved quality of life to faster recovery, earlier discharge from hospital and to a reduction in the use of statutory services.

Self management

Self management refers to the practices undertaken by individuals towards maintaining health and wellbeing and managing their own health needs. Supporting self management involves educating people about their condition and motivating them to care better for themselves. Self-management support can be viewed in two ways: (a) as a portfolio of techniques and tools that help patients choose healthy behaviours; and (b) as a fundamental transformation of the patient–caregiver relationship into a collaborative partnership [244].

Self management is an approach with significant support. People with long-term conditions consistently say [228]:

- They want to be involved in decisions about their care

- They want to be listened to

- They want access to information to help them make those decisions

- They want support to understand their condition and confidence to manage

- They want joined up, seamless services

- They want proactive care

- They do not want to be in hospital unless it is absolutely necessary and then only as part of a planned approach

- They want to be treated as a whole person and for the NHS to act as one team.

There is growing evidence to show that supporting people to self care improves their health and wellbeing.

Key benefits to patients include:

- Better symptom management, such as reduction in pain, anxiety, depression and tiredness

- Access to relevant information

- Feeling empowered to take an active role in one's own health

- Increased self confidence and self-esteem

- Opportunities to give as well as receive help

- Learning new practical ways of managing problems

- Gaining inspiration and support from others' experiences

- Feeling more in control and less isolated and alone

- Opportunities to increase social circle

- Opportunities to develop new skills.

There are seven principles of self care [245]:

1. Ensure individuals are able to make informed choices to manage their self care needs

2. Communicate effectively to enable individuals to assess their needs and develop and gain confidence to self care

3. Support and enable individuals to access appropriate information to manage their self care needs

4. Support and enable individuals to develop skills in self care

EXPERT PATIENTS PROGRAMME (EPP) SELF-MANAGEMENT COURSES

The EPP self-management courses provide tools and techniques to help people to take control of their health and manage their condition better on a daily basis. They are free, but have not been commissioned in all areas. They offer the confidence, skills and knowledge to manage any chronic health condition such as arthritis, asthma, diabetes, epilepsy, heart disease, multiple sclerosis, cancer, irritable bowel syndrome, lupus, high blood pressure and many more. The majority of Expert Patients Programme courses are delivered by trained tutors who have personal experience of living with a long-term health problem. Courses usually run over six weekly sessions and include topics such as dealing with pain, extreme tiredness, coping with feelings of depression, relaxation techniques, exercise, healthy eating, communicating with family, friends and health care professionals and planning for the future.

5. Support and enable individuals to use technology to support self care

6. Advise individuals how to access support networks and participate in the planning, development and evaluation of services

7. Support and enable risk management and risk taking to maximise independence and choice.

Self care is not just one type of intervention. There are a range of interventions which operate across a broad spectrum, as set out in **Fig. 3.7.5** below.

General components that have been found to work well to support self management include [244]:

- involving people in decision making

- emphasising problem solving

- developing care plans as a partnership between service users and professionals

- setting goals and following up on the extent to which these are achieved over time

- promoting healthy lifestyles and educating people about their conditions and how to self-manage

- motivating people to self-manage using targeted approaches and structured information and support

- helping people to monitor their symptoms and know when to take appropriate action

- helping people to manage the social, emotional and physical impacts of their conditions

- proactive follow up

- providing opportunities to share and learn from other service users.

Psychological support

There is good evidence [247] to show the effectiveness of psychological support in reducing depression, anxiety and pain, and improving self management and coping skills, all of which help patients to feel more in control:

- One study [248] of newly diagnosed cancer patients found that in high risk patients, those who received a brief psychological intervention were less likely to develop anxiety or a depressive disorder compared with those who received usual care.

- A study [249] by the Centre for Economic Performance estimates that the overall gain to society of treating psychological disorders in patients with 10 sessions of Cognitive Behavioural Therapy (costing £750) is £4,700.

- CBT has also been shown to be effective in the support of people with COPD – being used in psycho educational breathlessness and health promotion groups delivered in primary care [250] and secondary care settings, with positive impact on psychological wellbeing, coping strategies and health care usage.

- Cognitive Behavioural Therapy (CBT) has been successfully delivered in identified cases of anxiety and depression following initial screening. Respiratory-focused CBT packages, delivered by a CBT-trained respiratory nurse, have delivered improvements in anxiety and depression scores and hospital admissions [251].

- Psycho-educational interventions significantly reduced angina frequency and medication use [252]. NICE-approved psychological therapies have been shown to improve the psychological, symptomatic and functional status of patients newly diagnosed with angina [253].

FIG. 3.7.5

Information	Skills and knowledge training)	Tools and self-monitoring devices	Support networks	Healthy lifestyle choices

• About services
• About conditions and treatments
• Health literacy services
• Access to IT services for information and support e.g. through libraries/community centres
• Information prescription
• Care plans
• Shared decisionmaking
• Access to GP electronic health record
• Social marketing
	• Health promotion, self-management and rehabilitation courses such as:
	  – Self Care for You
	  – EPP
	  – Cardiac rehabilitation
	  – Pulmonary rehabilitation
	  – DESMOND/ DAFNE
	• Health Trainers
	• Medicines use review
		• Medical devices e.g. home oxygen units
		• Telehealth/ telecare
		• Early warning systems e.g. weather watch
			• Local support groups
			• Patient support groups
			• Voluntary services
			• National support groups
				• Screening
				• Immunisation
				• Smoking cessation
				• Weight management
				• Exercise on prescription
				• Healthy eating
				• Drinking safely

FIG. 3.7.6. The NICE approved four-tier model of psychological support

Level	Who should provide it?	What should be assessed?	What is the intervention?
1	All health & social care professionals	Recognition of psychological needs	Effective information giving, compassionate communications and general psychological support
2	Health & social care professionals with additional expertise (including CNS)	Screening for psychological distress	Using standardised screening tools e.g. the Distress Thermometer, HADS etc.
3	Trained and accredited professionals	Assessments for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit therapeutic framework
4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy

The model for the provision of psychological support is set out in **Fig. 3.7.6**.

Interventions with an evidence base, and recommended by NICE [231] in the treatment of long-term conditions include:

● Psychological education

● Group based skills training

● Individual and group Cognitive Behavioural Therapy.

MINDFULNESS

Mindfulness is a form of psychological support which warrants special attention. Mindfulness is an integrative, mind-body based approach that helps people change the way they think and feel about their experiences, especially stressful experiences. It involves paying attention to thoughts and feelings so that people become more aware of them, less enmeshed in them, and better able to manage them [254]. There is increasing recognition that effective health care requires engaging patients in looking after their own mental wellbeing. Much, if not all, illness is influenced by stress, mental attitude and behaviour choices. Mindfulness courses not only help people deal with illness; they are by nature a health promotion and illness prevention tool [254]. As Grossman and colleagues put it in their 2004 review of Mindfulness-based approaches: "*A single, relatively brief and cost-effective programme that can potentially be applied to a wide range of chronic illnesses and is able to effect a positive shift in fundamental perspectives toward health and disease should be of great interest.*" [255]

Mindfulness and wellbeing

Research [254] suggests that mindfulness confers significant benefits for health and wellbeing and quality of life in general. People who are more mindful are less likely to experience psychological distress, including depression and anxiety, have greater awareness, understanding and acceptance of their emotions, and recover from bad moods more quickly. More mindful people have less frequent negative thoughts and are more able to let them go when they arise. They have higher, more stable self-esteem that is less dependent on external factors.

Effectiveness of mindfulness in supporting long-term conditions

Mindfulness approaches have been proven to be effective in a wide range of mental and physical health applications:

● Trials of Mindfulness Based Stress Reduction (MBSR) courses have shown that they can reduce stress and mood disturbance, improve mood regulation and increase perceptions of control [256].

● In a study of people with long-term anxiety disorders, MBSR participants had less anxiety during and after completing the course, with improvements maintained at three-year follow-up [257].

● MBSR participants with mood disorders have shown reduced negative thinking (rumination) [258].

● Compared with controls, patients with chronic pain attending an MBSR course reported less pain at the end of the course. They also said they were less restricted by pain, used less medication, and were less anxious and depressed, with most effects maintained at 15-month follow-up [259].

- More than half (65%) of a group of patients with chronic pain who had failed to respond to standard medical care reported marked reductions in pain after MBSR [260].

- MBSR led to a 65% improvement in mood and a 35% reduction in stress symptoms in a group of people receiving treatment for cancer [261].

- MBSR has also been found to reduce sleep disturbance and increase sleep time among people with cancer [262].

- People with cancer using MBSR report fewer medical symptoms and fewer physiological signs of stress (lower cortisol levels).

- Psychological changes have included less tension, depression, anger, concentration problems and instability, fewer stress-related neurological and gastrointestinal symptoms, and increased energy and quality of life [262].

- On the basis of research evidence the National Institute For Health and Clinical Excellence (NICE) recommended mindfulness to prevent relapse in patients who have experienced more than two episodes of depression and who are currently in remission.

Despite the efficacy of mindfulness, research [254] suggests that few of the people who might benefit are currently being offered mindfulness courses, despite for example the recommendation by the National Institute for Health and Clinical (NICE) of the use of mindfulness for depression (as above).

ISSUES

Delivery of self care

Whilst there is a consensus on the need to transform the model of care for people with long-term conditions to one where 'self care' becomes mainstream practice, there is still a view that not nearly enough has been achieved. Few of the initiatives which have taken place over the years have succeeded in transforming the situation. The management of long-term conditions still tends to be seen as the clinician's responsibility rather than a collaborative endeavour with active patient involvement and effective self management support [263]. That having been said, a recent extensive research study [264] found that self-care services were available in most areas (i.e. accessible advice and information, generic self-care support training and disease specific self-care support training). But it is not clear how well this approach to self care is implemented. A study by the Royal College of General Practitioners [265] for example states that while 95% of people with diabetes are seen annually only 50%

discuss a plan to manage their diabetes and less than 50% discuss their own goals for self management. This is similar to the situation uncovered in 2006 by the Healthcare Commission. Despite considerable efforts to tackle the most important area, namely the effectiveness of consultations between patients and clinicians, the most significant problem is the reluctance of clinical staff to provide active support for patient engagement. Shared decision making for example, is less common in the UK than in many other countries. Uptake of patient education, even when offered is often poor.

On average 79% of people in England report having enough support to be in control of and manage their condition. However the picture across the country is variable. The following map indicates the variation in the percentage of people who say that they "feel supported to be independent and in control of their condition". (**Fig.** 3.7.7)

FIG. 3.7.7

Legend:
- 82% and over
- 80% up to 82%
- 78% up to 80%
- 76% up to 78%
- Under 76%
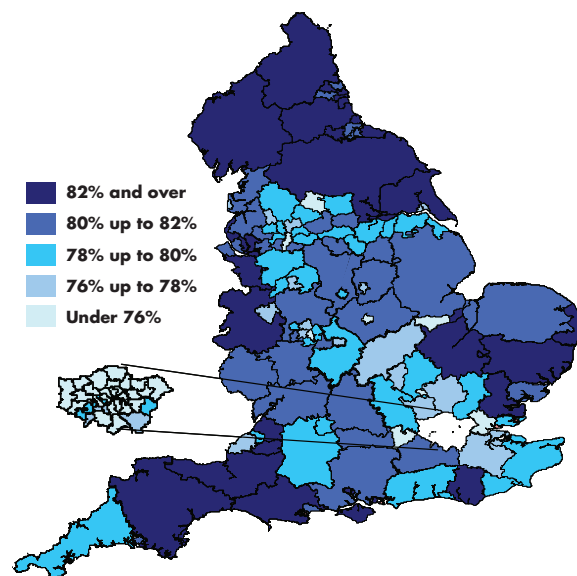
Source: GP patient survey, Jan–Mar 2011

Delivery of psychological support

Current provision does not appear to meet demand.

- One recent study [233] found that 40% of cancer patients with emotional problems had not sought help.

- Only half of the cases of depression in diabetes are detected [266].

- Data from a survey [267] of Diabetes UK members who had indicated a want or need for psychological support were not always able to access it.

- Only two in ten stroke survivors and one in ten carers received the support they needed to cope with the emotional aspects of stroke [239]. 67% of those surveyed had experienced anxiety and 59% felt depressed – over half of those did not receive any information, advice or support to help them. The Stroke Association's services offer emotional support but currently are only commissioned to see around 40% of stroke survivors in the UK.

- Over half the stroke units in England, Wales and Northern Ireland have no access to any psychological services.

- Three quarters of cancer carers experiencing anxiety or depression do not receive any support [268].

Whilst the interventions can be effective many people do not receive support during this transition to address their psychological needs. The reasons for this, whilst complex, include [227]:

- The continuing stigma of mental health.

- Commissioning structures and provider organisations which separate physical and mental care.

- The fact that many people see unhappiness as an inevitable side effect of their long-term condition, not recognising it as depression.

- health and social care professionals often lack appropriate assessment skills to identify mental illness and may underestimate the benefits of psychological support.

There is little systematic screening of patients for emotional problems by health staff. The Royal College of General Practitioners and the Royal College of Psychiatrists have jointly argued that all primary care staff require psychological awareness training, in order to increase the targeting and delivery of such interventions.

3.8
ENTERING INSTITUTIONAL CARE

Entering institutional care is one of the most feared transitions in later life. It is unlikely that any one in their earlier years looks forward to going into a care home when they are older. In a recent survey [269] of UK adults, 70% said they would feel scared about moving into a care home in the future.

That having been said, some people who are in care homes report being very happy and having a good quality of life.

DEFINITION

For the purposes of this section institutional care is defined as any form of communal living situation such as a residential or nursing home. It does not apply to 'extra care housing', which, although having some communal areas, is nevertheless a form of independent living i.e. people have their own front door. The transition involves the process from the first consideration of such a move through to the period when the person is living in the new situation and is considered to be 'settled' (whatever that might mean).

NATURE OF THE TRANSITION

Entry into a care home is a major transition which often happens in an unplanned way and in which the older person concerned, and their relatives, often feel that they have little if any choice and control. It is largely associated with some form of ill health or increased level of functional impairment.

Entry into institutional care is largely an unplanned transition and is usually associated with sudden ill health. As the following table shows, the most common pathway into institutional care is after a spell in hospital [269–271]:

Source of admission	Proportion %
Private household	29
Sheltered housing	6
Residential or nursing home	13
Hospital	51

Source: Bebbington, Darton [272]

Many older people are admitted to hospital for some health condition or accident and never return home.

Even where the pathway is not from hospital there is little sense of calm unhurried reflection and considered decision making. A detailed study [273] of older people's experiences of long-term care showed that things can happen very quickly when options for support are being discussed and points of no return (homes being sold, for example) are reached from which there is no way back. A move into care is often precipitated by a breakdown in support arrangements at home, compounded by a real as well as perceived lack of alternatives. Without information and impartial advice, people quickly become convinced that the 'last resort' (moving into care) has been reached.

The unplanned for nature of entry into institutional care adds to much of the trauma surrounding it. It is often surrounded with an atmosphere of crisis with little time to prepare [274]. However, in the minority of cases where the admission is planned and where residents are involved in the decision making process, there is evidence [275] to suggest that the adjustment to the transition is easier. Although there are indications that once the decision making process is set in motion, events are generally 'expert driven' which leads to a real or sensed loss of control and lack of involvement in decision making for the carer and the older person themselves [273, 276].

It is important to note that, tragically, there is evidence that a proportion of 'inappropriate admissions' can occur. One study [277] suggested that 14% of admissions to nursing homes should have been to residential homes, and that 17% of people should have continued to be supported in the community.

Some question whether the transition into institutional care is driven by widespread ageism in society. Research conducted for the Joseph Rowntree Foundation [273] concluded that if any of the precipitating factors outlined here had occurred at a younger age, the push into care would not have happened. Outside the world of services for older people, alternative and creative support has moved on immensely. Yet person-centred approaches and support that promote choice and control remain hard to find for older people with high support needs.

IMPACT

In terms of the Dilts framework [21] the move into institutional care can have a profound effect on a number of areas of life:

- **Sense of Purpose** – there is likely to be a significant impact from the loss of the person's independence. They are no longer solely in charge of their lives and this can undermine how people view their lives and what is important in them.

- **Identity** – there can be a major change in identity from the change from being an independent person in their own home to someone who has lost their independence and lives in a communal setting.

- **Capability** – the move to institutional care is usually associated with a deterioration in health which brings with it feelings of loss of capability and often a loss of dignity.

- **Behaviour** – tends to be significantly impacted as the person is no longer responsible for managing their own life so tasks such as shopping and cleaning fade away.

- **Environment** – there is an obvious major change of environment – from own home to new communal setting.

The magnitude of these changes is why this transition is so feared [278]. It also explains why entry into institutional care presents as a high risk for developing depression and suicidal tendencies [279–281]. Indeed in one research study [281]several participants commented that a "*quick death at home*" would be preferable to a move into care. Another commented that they feared that days within a care home would merely be spent "*in a semi-comatose state (with the help of zombie drugs) sitting in front of a flickering television in the corner of the day room.*" [281]

Leaving aside the trauma associated with loss of independence etc. unnecessary distress can be caused through the lack of information to make an informed choice [269]. Research [282]shows that older people and their relatives are largely unprepared for the reality of care home life. A survey [283] of residents and relatives found that the majority (71%) did not remember seeing any booklets or leaflets giving information about care homes.

Relatives

The move to a care home represents a transition not only for the older person, but also for their carer / partner, who may experience feelings of guilt, sorrow, loss, grief and anger [284]. The partners of 7–10% of care home residents continue to live in their own homes in the community [284]. Whilst these people don't fit the standard definition of 'carer', their caring responsibilities may still exact a huge physical, emotional and financial toll [285]. In making the transition, it is suggested [282] that there are three phases from the relative's perspective:

- Making the best of it

- Making the move

- Making it better.

These phases are sequential. They span the time from leading up to the move in the care home, the period immediately prior to and subsequent to the move and lastly relatives' efforts to engage staff in the homes and contribute to the life of the new resident on an ongoing basis.

Davies and Nolan [282, 286] developed a useful framework of five continuous dimensions which they found appeared to shape relatives' experiences during each of the phases of care home placement (see **Fig. 3.8.1** below). These dimensions have a bearing regardless of where in the transitional process a carer/ relative and older person might be.

FIG. 3.8.1

No pressure Being encouraged to take time to make decisions, be yourself, say what you want to happen	**Under pressure** Feeling the need to make decisions quickly, to conform, to conceal your own needs
Being in the know Having access to all relevant information to play a full and active role in the life and care of the older person	**Working in the dark** Lacking the relevant information to continue to play a full and active role in the life of the older person
Working together Being able to work with health and social care staff to ensure best care for the older person	**Working apart** Barriers to working toether with health and social care staff or with family members
Being in control Being able to maintain ownership of decisions about your and your relatives' future	**Losing control** Feeling that decisions have been taken out of your hands; you no longer influence events
Feeling supported Feeling that others are aware of the consequences of the move for you and for your relative, and are there for you	**Feeling unsupported** Feeling that your own experiences and/or those of your relative are of little consequence to others

Source: Davies and Nolan 2003

Although the impact of the transition on relatives is acknowledged, studies show that there can nevertheless be a lack of support and awareness of their needs on the part of professionals and staff [270]. Guidelines have been developed to counter this [275]. They suggest that staff in care homes should:

- establish an understanding of the meaning and personal significance of the situation to the resident

- help residents to confront reality and respond to the requirements of the situation

- assist residents to sustain relationships with family and friends, as well as other individuals who may be helpful in resolving the crisis and its aftermath

- help to maintain a reasonable emotional balance by managing upsetting feelings aroused by the situation

- preserve a satisfactory self-image; maintain a sense of competence and mastery.

PREVALENCE

There are an estimated 414,000 people over 65 living in some form of institutional setting [287], about 4% of the population of older people. So although it is one of the most feared transitions, it is also a minority experience. The risk of being in a care home increases with age. It is less than 1% for those aged 65-74, less than 4% for 75-84, and just under 16% for people aged 85+[230].

INFLUENCING FACTORS

People admitted to a care home are typically [272]:

- aged in their 80s

- female

- living alone or, where living with others, living in their home

- living in a house rented from the local authority or housing association

- receiving Income Support and Housing Benefit

- receiving Attendance Allowance

- living in poorer neighbourhoods

- multiply disabled

- experiencing a limiting longstanding illness.

There is a clear class dimension to the risk of entering a care home (i.e. living in rented social housing, receiving benefits and living in a poorer neighbourhood). The risk of entry into a care home is therefore not solely to do with disability or health conditions.

The main reasons cited for admission to a care home are:

Reasons for admission	Proportion %
Physical health problems	69
Mental health problems	43
Functional disablement	42
Stress on carers	38
Lack of motivation	22
Present home physically unsuitable	15
Family breakdown (including loss of carer)	8
Need for rehabilitation	6
Fear of being the victim of crime	4
Abuse	2
Loneliness or isolation	2
Homelessness	1

Source: Bebbington, Darton [272]

The proportion of residents admitted for non-clinical reasons increases with age and the proportion admitted for clinical reasons declines [288]. For residents age 95 and over, the majority (53.7%) of admittances are for frailty, housing or family reasons rather than specific health conditions. The reliability of the 'frailty' assessment for over 95s has been questioned and may be a manifestation of medical ageism with multiple co morbidities being lumped together in a single term. Nearly three quarters (73%) of residents are receiving nursing care but, in apparent corroboration of the thesis [288] that the oldest old are less likely to be admitted into care homes as a result of specific medical conditions, the proportion of residents who are admitted for residential rather than nursing care increases with the age of the residents.

Gay and lesbian

Entering residential care is greatly feared by lesbian, gay and bisexual people (LGBT) with 89% of them reporting that they dislike the prospect of moving into a home [37]. For those with partners a common concern is whether they would be able to remain together if they could no longer look after each other without assistance. While they share many concerns about care homes with their heterosexual peers, they do have an increased level of anxiety. 70% of LGBT people do not feel that they would be able to be themselves if living in a care home and 65% feel that they would have to hide things about themselves from others. This compares to 61% and 52% respectively for these concerns by heterosexual people. More than half (52%) of LGBT people do not feel that they would be able to be affectionate with their partners [37].

Ethnic minorities

There are particular challenges for older people from BME communities making the transition into institutional care. BME older people have concerns about the cultural appropriateness of care home environments as well as the language issues. There is very little specific care home provision for people from BME communities, and much of what there is solely designated as such on the basis of language provision, which is vulnerable to staff turnover [289]. There is little evidence of provision which systematically addresses ethnic diversity in terms of religious beliefs and practices, language and communication [290]. There is very little research data on the needs and provision of care homes which meet the needs of older people from BME communities. Until future research is conducted there will be a lack of knowledge about the needs of minority ethnic older people in care homes and the strategies to address access, transition, service provision and quality issues [290].

SUCCESSFUL TRANSITION

The transition into a care home can be said to have been completed well if the person eventually feels settled and reports being happy to live in their new situation.

Whilst for some people life in a care home can represent a good quality of life this is not the case for the majority. A recent study [273] found that many people interviewed in care homes did not want to be living there and this feeling can increase following a move (for example, as a result of the power imbalance referred to earlier). Not being in control of small daily events and bigger decisions about where you live is bewildering and increases feelings of vulnerability. In another recent survey [269], only 41% of family members of a person with dementia in a care home thought that the quality of life in the institution was good, with over a quarter (28%) saying it was poor.

On the other hand, the literature [273] also points out that a move into a care home can be seen as a conscious change of living arrangements, which can enhance personal feelings of 'independence' and minimise 'dependency'. The positive effects of moving to a care home described in the literature included being looked after and having cooking, cleaning and washing done by others. The picture about standards of care in care homes is not all negative. In a recent survey [269], 74% of respondents said they would recommend the care home that their relative was in to others, and 68% thought that quality of care received by the person with dementia was good.

Loneliness can be very prevalent in institutional settings, with one recent study [291] finding that 55% of those in institutional settings reporting that they experienced loneliness 'often' or 'sometimes'.

Although the initial transition into a care home can be seen as complete once the person feels settled in the home, in reality further transitions then begin [284] – i.e. maintaining a sense of identity, adjusting to a different type of community, sharing decisions, maintaining health and functioning.

INTERVENTIONS TO SUPPORT THE TRANSITION

There are ways of easing the transition into institutional care. Good practice guidance as set out in My Home Life [284], states that the transition for residents and their relatives can be eased if pressure on them is minimised:

- if they have access to all relevant information to help them play a full and active role in the life of the home and, for relatives, in the care of the older person.

- if they are able to work with staff.

- if they are able to maintain ownership of decisions about the future.

- if they feel that others are aware of the consequences of the move for them and their loved ones.

- if information is available on how to choose a home and how to ease the transition of moving.

Research [292] also demonstrates how staff can make a difference to how this major transition is experienced. In particular they need to develop improved communication strategies (based on concepts of transition) that will support residents and their relatives during the admission phase.

An example of how this might be put into practice is as follows:

Ensuring a positive transition into a care home

Brunel Care understands that the transition into a care home can be a traumatic experience, whether it is from the person's own home, another home or from hospital. In response to recognising this situation, key staff are allocated to residents pre-admission, from the initial point of contact. Each subsequent visit is followed up by the named member(s) of staff. This key worker engages in the assessment. Establishing a relationship is considered key to seeing the individual for who they are. This enables the relationship to evolve and not be rushed or forced. The person moving into the home begins to trust and develop a

rapport with the key worker, which then eases the transition, reduces anxiety and actively involves the person at each step, enabling them to make informed choices. Once in the care home, the key workers are on duty in the initial few weeks to continue this transitional work.

Source: Social Care Institute for Excellence website

ISSUES

There are only two interventions which are deployed to address the transition into institutional care. The first is embodied in the guidance and 'good practice' referred to above. Whilst this is all welcome it is unlikely that it will do more than slightly soften some of the minor aspects of the transition. More sensitive communication with care home staff for example is not going to have much impact on ameliorating the trauma associated with losing one's independence, one's home and one's partner and friends to be thrust into a communal living situation with strangers.

The other intervention to address this transition is to reduce its prevalence. Despite Government policy for years to favour supporting people in their own homes, the number of people (the vast majority of whom are older people) living in care homes rose yet again in 2011/12 [293]. There are two likely reasons for this continuing growth in institutionalisation:

- **Cost**: supporting people with high support needs in their own homes is more expensive than institutional care. There has been a long tradition of paying for much more expensive packages of care for younger people than for older people. That is very unlikely to change in the current financial situation.

- **Ageism**: there are still prevalent attitudes about what older people can expect in later life. Care home admission, whilst not generally seen as desirable, is often seen as necessary – as 'the only option'. Complicated and intensive packages of care that are normal for younger people are deemed to not be appropriate for older people.

Quality of life
Having the opportunity to 'be oneself' in a home is identified [273] as the key to a good quality of life. People's ability to feel 'at home' in a care home is described as the extent to which 'residents' are able to be themselves by making choices including how they dress, items they choose to bring into the home and control over personal space.

Through their discussions with older people Bowers et al [273] were able to codify what constitutes 'a good life' when someone needs a lot of support. The most commonly mentioned areas by older people include:

- people knowing and caring about you

- the importance of belonging – and relationships and links to local communities within this

- being able to contribute (to family, social and community life, and communal life too) and being valued for what you do

- being treated as an equal, as an adult

- respect for your routines and commitments

- being able to choose how to spend your time – pursuing interests, dreams and goals – and who you spend your time with

- having and retaining your sense of self, your personal identity – including being able to express views and feelings (self-expression)

- your surroundings – those that are shared and those that are private

- getting out and about.

Many would argue that institutional forms of care are very far from achieving this sort of vision, regardless of whether the 'transition' is handled well.

In the context of widespread ageist attitudes in society it is difficult to be clear about when and whether a transition into institutional care has been concluded successfully. As Bowers et al [273] state in their in-depth review of the subject, the picture that is presented is one of contrasting, or conflicting, perspectives, with the views and experiences of older people (in relation to a move into a home) contrasting with those of professionals, families and society as a whole. In other words, even if older people report being 'happy' after their transition into a care home, should this be taken at face value? Is institutional care an acceptable means of providing support to people with high support needs?

Control
With the sort of loss of independence which is inherent in the transition into institutional care there is also the loss of control. This most commonly appears as 'over-helping' – the sort of care or support which '*does for*' the person rather than '*doing with*' them. This apparent kindness can actually increase feelings of helplessness and incompetence for an older person, causing them to do poorly at a task that they had previously been able to do. Some researchers have talked about a "dependence support script" which defines many social interactions, whereby dependent behaviour is reinforced through helping, whilst more independent behaviours are ignored [294].

The importance of countering such dependency inducing behaviour by staff was dramatically demonstrated in some interesting experiments carried out by Langer [295]. In one experiment [295] nursing home residents were divided into two groups. The first group was given more control and were encouraged to find ways to make more decisions for themselves. For example, they were allowed to choose where to receive visitors, if and when to watch films that were shown at the home; each was given the choice of a houseplant to care for, where to place it in their room, as well as when and how much to water it. The second group were given no choice or control to make their own decisions. They were given houseplants and were told that the staff would decide where they would be positioned and would do all the watering and caring for them. And unlike the first group they were given no choice about when and whether to watch films, meet visitors etc.

The results were dramatic. Eighteen months later – members of the first group were more cheerful, active and alert, and were also all much healthier than the second group. Most surprisingly, less than half as many of the group with choice and control had died than those in the control group. These results echo those of Schultz [296] who found that increasing user choice and control by providing institutionalised older people with the opportunity to decide when they would be visited resulted in improvement on a number of psychological and physical health measures.

Many care and support settings, originating from the best of intentions, perpetuate feelings of dependence and loss of control. When intervening with older people it is important to keep in mind that unneeded or unwanted help can diminish mental health and/or accelerate physical disability. Unwanted help can also lead older people to feel that none of their own actions make any difference in their situation. These feelings can lead to a state of learned helplessness where they feels as though nothing they do influences their lives positively and when negative events occur, they feel it is because they are old, decrepit and no longer capable human beings. Unfortunately this is all too often the way in which institutional settings operate.

3.9
PREPARING FOR
END OF LIFE

"It's not that I'm afraid to die. I just don't want to be there when it happens."

–Woody Allen

This is the final transition in everyone's lives. End of life is the fundamental existential condition in later life – everyone dies, but no one knows when. Death comes to us all, but few of us spend any time or effort preparing for the end of our lives.

DEFINITION

This transition is concerned with the preparation for death rather than its actual occurrence – i.e. the extent to which people actively and consciously prepare for their own death.

Preparation is important for quality of death. If one has time to prepare for death then one has more control over whether one's death is good or bad [297]. Whilst this is important for us all, it is particularly an issue for those people who are given a terminal diagnosis (e.g. for cancer), but who have some time left before the illness takes its final course. Technically people are defined [298] as approaching end of life when they have advanced, progressive, incurable conditions and they are likely to die within the next 12 months.

NATURE OF THE TRANSITION

Preparing for end of life is a transition which is by definition tied up with health and illness and obviously takes precedence over any other kind of transition that might be around at the time. That having been said, preparing for death does not necessarily have to be initiated at a time of illness or impending death. There are many aspects of preparing for end of life which can be undertaken well in advance – e.g. writing a will, instituting an advance directive, planning the sort of funeral that one wants etc. So it is also a transition which one can have some control over and plan for.

How to prepare for end of life
Although everyone's death is different there are a number of common actions that people are advised to think about in their preparations for their own death. NHS Choices for example sets out the following set of actions:

Consider the steps listed here, which may also help you to plan ahead:

- starting the conversation with your partner, family, carers and health professionals

- exploring your options, such as where you can choose to be cared for (this will probably involve talking with health professionals and other experts, especially if you have any particular questions or worries)

- thinking about what your wishes and preferences are

- refusing specific treatment, if you want to, using a legal document called an advance decision

- legally appointing someone, using a lasting power of attorney, to make decisions for you in case you are not able to do so yourself in the future

- letting people know your wishes, through talking or writing them down, or both. When you write down your wishes and preferences, this is called a care plan or advance care plan.

As well as thinking about your future care, there are emotional and practical issues you might want to consider, such as:

- any questions or worries you have about illness and dying that you would like to discuss

- how you would like your funeral to be

- making memory boxes or videos for your family and friends

- legal and financial matters, such as making a will or planning for the care of anyone who relies on you, such as your children.

Advance care planning
Planning for end of life can be both rewarding and difficult [299]. Each person will have unique needs and will cope in different ways. The time is easier when patients, families and medical staff talk openly about end of life plans. For many people this can be a time of personal growth [300]. These events often give people the chance to find out more about themselves and appreciate what is most important to them. Amongst other things, making end of life plans can lower the stress for both the patient and the family. Knowing the patient's wishes can help make it easier for family members to make major decisions for the patient during a very emotional time. It is most helpful if end of life planning and decision making begins soon after diagnosis and continues during the course of the illness.

COMPASSION IN DYING

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing information and support around their rights and choices. They are the leading provider of free Advance Decisions in the UK and they also conduct and review research into rights and choices in end-of-life care. They seek to achieve a world in which everyone has access to the care and support that is right for them at the end of life. This means:

● access to expert information about end-of-life options

● support to make informed choices

● care that meets people's needs.

'Advance care planning' is a fundamentally important aspect of taking some control in the end of life transition. It is a way of framing some of the necessary discussions with health professionals. Advance care planning is [301] a voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record the choices about their care and treatment. This includes advance decision to refuse treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide as their illness progresses. Organisations such as Compassion in Dying provide free Advance Decision templates.

An Advance Decision enables an individual to think about what they would like to happen to them in the event that they lose the capacity to make or communicate decisions about their care. Examples of such decisions include [302]:

● The use of intravenous fluids and parenteral nutrition.

● The use of cardiopulmonary resuscitation.

● The use of life-saving treatment (whether existing or yet to be developed) in specific illnesses where capacity or consent may be impaired – for example, brain damage, perhaps from stroke, head injury or dementia.

● Specific procedures such as blood transfusion for a Jehovah's Witness.

Only five per cent of all ages report having a living will or advance care plan, from 1% of 18–34-year-olds to 12% of people 75+ [303].

Dementia

There are particular issues regarding older people with dementia approaching end of life. Ideally the person with dementia would have put in place some advance directives to specify their wishes. Without such directives, or if certain issues have not been addressed, families must make decisions based on what they believe the person would want. End of life decisions should respect the person's values and wishes while maintaining comfort and dignity.

Families

It is not only the person who is dying who is affected by this transition to end of life. Families have the dual task of attending to the patient's need for preparation and attending to their own preparation for the patient's death and their own future.

As Age UK notes [302], family, especially spouses, have to cope with many issues which grow and intensify over time including 'pre-death grief', increasingly physical aspects of care, and increasing levels of decision-making which may be compounded by lack of knowledge and experience, and poor communication with professionals. They often fear discussing end of life issues 'prematurely', leading to a tendency for 'active' interventions such as hospital admission, antibiotics and other treatments which have little use or may be against the older person's wishes. Changes in the nature of the relationship between the caregiver and the person nearing the end of life can cause high levels of anxiety and stress over a long period of time.

PREVALENCE

In 2010, 83% of deaths in England and Wales occurred in people aged 65 and over [185]. Two thirds (66.9 per cent) of people who died were aged 75 or over and more than one third (36.8 per cent) were aged 85 and over. (**Fig. 3.9.1**)

FIG. 3.9.1

	65–59	70–74	75–79	80–84	85–89	90–94	95+
% of all ages	7%	9%	13%	17%	19%	12%	6%
% of 65+	8%	11%	16%	21%	23%	14%	7%

Source: ONS, Mortality Statistics: Deaths Registered in 2010 (Series DR) Table 5, 2013

It is impossible to know what proportion of older people undertake some form of preparation for their end of life. However some insight can be gained from the number of people who undertake the most basic preparatory task — that of writing a will. Research by the financial advice website 'unbiased.co.uk' found that nearly a third (32%) of people over 55 do not have a will in place. Given that this is the most fundamental task associated with preparing for death, then the numbers of people involved in any more comprehensive preparation are likely to be much less than this. Unfortunately it is not common for people nearing the end of their lives to have discussions about dying or planning for death with clinicians, family or carers[304] . Other data [305] supports this, showing that over half a million people die each year, yet 70% have not discussed their own end of life wishes with their partner, family, friends or health or social care professionals. Only 4% of people had written down wishes about end of life care [305]. This means that people often do not get the care they want, or where they want it.

The reasons for this lack of preparation are complex. An analysis of the British Social Attitudes survey [303] found that 70 per cent of respondents say they feel comfortable talking about death, while only 13 per cent say they feel uncomfortable doing so. However, only 31% actually had spoken to someone about their wishes at the end of life, and only 12 per cent of respondents have ever discussed with anyone their end of life wishes relating to their preferred place to die.   As Age UK note [302],the main reason respondents provided for not discussing any of these issues was feeling that death is a long way off. Even among those aged 75+, the proportion of those who have not discussed any aspects of their deaths and gave this reason is 23 per cent. The main reason people in this age group gave was *people don't want to talk to me about my death*' (28%).

IMPACT

Death itself obviously affects all aspects of life. Preparing for death (not its actual occurrence) on the other hand mainly impacts on a number of aspects of the Dilts framework [21]. It is a real challenge to people's **Sense of Purpose** in life, and can occasion deep reflection and contemplation about the meaning of one's life. There is a strong relationship between questions regarding our sense of purpose in life and our **Identity** — what sort of person have we been? If this preparation is taken well in advance of death it can be a very powerful engine for personal development and change. Preparing for end of life can also be a time which filled with concerns for family and friends — how will they feel; have all the practical aspects of a death been sorted out?

Dying well

There is no single way of dying, yet there are some general principles that can guide the provision of support at end of life. People tend to die in character [306], so an important goal in working with dying patients is to allow or assist a person in the integration of dying into their lifestyle. An 'appropriate death' could be described as one that allows the person to live out their dying in a manner consistent with their values and coping mechanisms [307, 308]. The End of Life Care Strategy [304] suggests that a good death is likely to include:

- being treated as an individual, with dignity and respect

- being free from pain and other symptoms

- being in familiar surroundings

- being in the company of close family and/or friends.

With appropriate support, patients can use the awareness of their dying to integrate their values by responding to relationships and revising goals in the time that is left to them. Without such support, patients may experience a disintegration at the psychological and social levels in the chronic "*living-dying phase*" before death. This process is illustrated below (**Fig. 3.9.2**).

FIG. 3.9.2
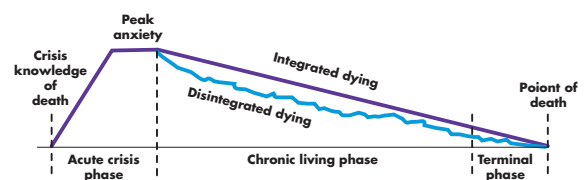
From: McCormick and Conley [306]

Research [309] by the charity Compassion in Dying, found that almost half of those who have lost someone close to them through a short or long illness, feel their loved one died badly (45%). However in cases where the dying person had recorded their end of life wishes, relatives and friends are more likely to report that they had a good death (58%).

Alongside recording end of life wishes (19%), better communication between the doctor and their loved one (39%), co-ordination of care (33%) and being able to die in a place of their choice (31%) were also identified as key aspects which could have improved the situation for the person who died in a bad way.

There are those who believe that as a society we have forgotten how to prepare for death. This is in part because of the advanced lifesaving technologies that have blurred the line between saving a life and prolonging a

dying. It is also because, although we say we want good deaths, in reality we act as if we will not die at all. Above all we have forgotten that preparing for a good death is not something to be left for the panicked ambulance ride to the hospital; rather, it is to do with numerous decisions that we make long before we die that determine our final pathway. One of the most critical decisions relates to the amount of medical intervention we are prepared to allow. It is possible to keep people alive, but with a very poor quality of life. Some people make a decision to have a better death but shorter life by eschewing some of the technological interventions at end of life. This is encapsulated in the following quote – "*She died well because she was willing to die too soon rather than too late.*" [310]

There is a view that with the advent of the huge advances in medical interventions in the late twentieth century, dying moved from the home to the hospital, and in the process obliterated Western death rituals. This has transformed the way that people behave at the deathbed, "*transforming it from a spiritual ordeal to a technological flail.*"[310] The guides that used to instruct people on how to conduct themselves at this time and the prayers etc to recite are now very seldom in evidence. The secularlisation of society has left a bit of a vacuum around the whole process of dying.

The challenge of addressing our end of life in a conscious way is well articulated in the following quote:

"Is death such an undesirable part of our existence that we are better off acting as if it were not real? Is death such an absolute end of all our thoughts and actions that we simply cannot face it? Or is it possible to befriend our dying gradually and live open to it, trusting that we have nothing to fear? Is it possible to prepare for our death with the same attentiveness that our parents had in preparing for our birth?" [311]

INFLUENCING FACTORS

One is much more likely to achieve a good death with some preparation. Too frequently in medicine, a crisis arrives and, if there is no advance planning, the patients' wishes may not be known, family members may be confused about choices, and clinicians may find themselves engaged in interventions which are futile and/or unwanted.

Research [297] has shown that patients, family members and health professionals overwhelmingly agree with the general importance of being prepared for end of life and there appears to be significant consensus about the key components of that preparation:

- Naming someone to make decisions

- Knowing what to expect about one's physical condition

- Having financial affairs in order

- Having treatment preferences in writing

- Knowing that one's doctor is comfortable talking about death and dying.

If there is sufficient time, research [297] indicates that people would want to engage in a process of achieving a sense of completion or closure, with consensus that the following issues are priorities:

- Saying good bye to important people

- Sharing time with close friends

- Resolving unfinished business

- Remembering personal accomplishments.

Triggers

For most people, most of the time, the awareness of mortality is hidden away. When a doctor discloses the diagnosis of a life threatening illness, the door of awareness is suddenly jarred open. The usual habit of allowing thoughts of death to remain in the background is now impossible – death can no longer be denied. This awareness usually precipitates a crisis for most people, who are suddenly faced with addressing and most likely rearranging their priorities in the time they now anticipate is left. The stages of grief outlined earlier in this report can come into play for those facing their own death.

However, in the absence of a terminal diagnosis there are two powerful forces which prevent this from happening:

- an overwhelming taboo against talking about dying

- an internal reticence to engage with the subject, until it is unavoidable.

This explains why so few people, except those facing a terminal illness, undertake any preparation for their end of life at all.

Feelings around end of life

End of life is associated with a multitude of strong emotions. On the one hand there are the common fears at the end of life phase, including:

- the onset of pain that cannot be managed

- the loss of bodily control

- the loss of function

- growing dependence on others

- the unknown

- loss of family and friends

- ultimately, the loss of self.

One might have thought that having an opportunity to discuss their fears about dying would be high on the list of priorities for people approaching end of life. Research [297] suggests that this is not the case. This is probably due to the fact that discussing personal fears is the hardest part of the process. Feeling personal fears suggests that death is more imminent and evokes some of the fundamental questions of being human. It causes people to explore sometimes painful emotions and often opens the door to the unknown: what has my life meant and what is next? It challenges hope and many people believe that hope cures. Patients, families and doctors may each be afraid to begin that exploration; they may also desire to protect others from feeling pain.

Other emotions are common too. As patients approach the terminal phase, research [306] suggests that they mostly want to know when death is imminent. Most have particular tasks to achieve in bringing closure to life as death draws near. Some describe the spiritual richness they experience in their last days, savouring the moments of living with the intensity of knowing that their time is limited. This was articulated so well by the playwright Dennis Potter in his last interview with Melvyn Bragg just weeks before his death:

We're the one animal that knows that we're going to die, and yet we carry on paying our mortgages, doing our jobs, moving about, behaving as though there's eternity in a sense. And we forget that life can only be defined in the present tense; it is, and it is now only. I mean, as much as we would like to call back yesterday, and ache to sometimes to do so, we can't. However predictable tomorrow is, and unfortunately for most people, most of the time, it's too predictable, even so, no matter how predictable it is, there's the element of the unpredictable. The only thing you know for sure is the present tense, and that nowness becomes so vivid that, almost in a perverse sort of way, I'm almost serene. You know, I can celebrate life.

Below my window in Ross on Wye, when I'm working, the blossom is out in full now. It's a plum tree, it looks like apple blossom – but it's white, and looking at it, instead of saying "Oh that's nice blossom" … last week looking at it through the window when I'm writing, I see it is the whitest, frothiest, blossomest blossom that there ever could be. Things are both more trivial than they ever were, and more important than they ever were, and the difference between the trivial and the important doesn't seem to matter. But the nowness of everything is absolutely wondrous, and if people could see that, you know. There's

no way of telling you; you have to experience it, but the glory of it, if you like, the comfort of it. The fact is, if you see the present tense, boy do you see it! And boy can you celebrate it.

INTERVENTIONS

End of life care is defined [298] as care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

The main organisations addressing end of life policy and provision include:

- **The National Council for Palliative Care** – an umbrella charity for all those involved in providing, commissioning and using palliative care and hospice services.

- **Dying Matters** – a broad based and inclusive national coalition set up by the National Council for Palliative Care and supported by the Dept of Health.

- **National End of Life Care Intelligence Network** – aims to improve the collection and analysis of information about end of life services provided by health and social care and the third sector.

- **Macmillan Cancer Support** – voluntary organisation providing community based palliative care.

Policy

Current policy and practice guidance espouses advanced planning, good communication and choice around place of care and death, appropriate symptom control and referral to specialist palliative services. However, as Age UK notes [302], older people experience a lack of advance planning, more repeated hospital admissions, and lower access to specialist palliative care than their younger counterparts [312].

Government policy (as outlined in the 2008 End of Life Care Strategy) is to support people to be cared for and to die in their preferred place of care, which is usually their home. This means that there should be 24/7 provision of community support, including care co-ordination, nursing and symptom control. And interventions are expected to encompass many things other than medical and pain control issues. Guidance [313] states that *"assessment about a person's physical, psychological, social , spiritual and financial support needs should be undertaken at key points (such as diagnosis; at the start, during, and at the end of treatment; at relapse; and when death is approaching)."*

The Government intention to support people to die in their preferred place does not appear to be being achieved. As noted already there is a significant mismatch between where people want to die and where they actually die. 70% want do die at home and 60% end up dying in hospital. The National Audit Office found that 40% of end of life care patients had no medical need to be in hospital.

KEY INTERVENTIONS

The key interventions to support people through their end of life transition are:

- information
- mainstream health services
- specialist palliative care.

Each of these is addressed below.

Information

There are a number of very helpful and comprehensive on line resources for people wishing guidance at end of life:

Compassion in Dying
http://www.compassionindying.org.uk/factsheets – templates on Advance Decisions

Marie Curie Cancer Care
http://www.mariecurie.org.uk/Documents/PATIENTS-CARERS-FAMILIES/publications-and-guides/end-of-life-guide.pdf – comprehensive end of life guide

NHS Choices
http://www.nhs.uk/Planners/end-of-life-care/Pages/End-of-life-care.aspx – comprehensive web-based guide

McMillan Cancer Support
http://www.macmillan.org.uk/Cancerinformation/Endo flife/Endoflife.aspx

Good End of Life
http://www.goodendoflife.com/worksheets/index.htm – a simple resource with worksheets on five key tasks: make a plan, recruit advocates, be hospital ready, chose a place and caregivers, and discuss last words

Dying Matters
http://dyingmatters.org/page/planning-ahead

Dignity in Dying
http://www.dignityindying.org.uk/ – guidance on assisted dying.

Befriending

Befriending people through preparing for end of life is not well developed but could be enormously helpful. The following is one of the strongest examples in existence:

OXFORDSHIRE BEFRIENDING AT END OF LIFE (OXBEL)

Run by Age UK Oxfordshire, OxBEL has a good number of volunteers who have undergone comprehensive training and receive ongoing supervision and support from paid volunteer coordinators. The volunteers provide one-to-one befriending to adults of all ages, who either have a life-threatening condition or are at end of life. Befriending can last for a matter of weeks, months or many years. This free service is currently focussing mainly on those on the End of Life Register, who are referred either by health and social care professionals or by themselves.

Mainstream health services

Given that most people are in contact with health services during the period up to their death, the behaviour of health professionals can have a huge impact on one's ability to prepare for end of life. The care of the patient must go beyond the management of physical symptoms to include how they communicate with the patient at this sensitive time [306]. This can be a difficult time for clinicians. Many of them can feel uncomfortable when a patient is dying and nothing curative can be offered. Feelings of discomfort can result in clinicians creating a safe emotional distance from their patients which in turn can result in the dying patient feeling depersonalised and inhibited in openly talking about their most important concerns in the final phase of their life [306]. Most patients find great relief in being able to talk openly about the process of dying. Effective communication around the dying process can therefore be so crucial in reducing the patient's suffering by recognising their personal needs, feelings and expectations.

Supporting end of life care is not solely a responsibility of specialist palliative care services. In fact, palliative care services are only accessed by a minority of people. Most people die having only had contact with mainstream hospital or primary care services. Primary care is a particularly important resource. Research shows that 31% of the public want information about end of life care from their GP [305]. This contrasts with research [314] which found only 33% of GPs feel confident about starting a conversation about end of life issues. The campaign group 'Dying Matters' has undertaken pilot work to bolster GPs competencies in this field. In one pilot study for example, after training and support from

Dying Matters, the percentage of GPs who were confident or very confident about starting a conversation about end of life issues rose to 91%. This study also gives some insight into the sort of actions that GPs take after a conversation about end of life issues.

Specialist palliative care

Palliative care services give care to people who are near the end of life and have stopped treatment to cure or control their illness. Services are usually for people who are not expected to live for longer than six months. Palliative care focuses on quality rather than length of life. The goal of palliative care is to help patients live each day to the fullest by making them comfortable and relieving their symptoms. Palliative care services are designed to support people to die at home but support is also provided in hospice centres where appropriate.

Assisted dying

Assisted dying is an important aspect of preparing for end of life for some people. The term 'assisted dying' commonly refers to situations in which people with incurable and terminal illnesses request the help of others in ending their lives. There is a lot of confusion about various terms used. The following clarifies the situation:

- **Assisted dying** only applies to terminally ill, mentally competent adults and requires the dying patient, after meeting strict legal safeguards, to self administer life-ending medication. Assisted dying is legalised and regulated in the US States of Oregon and Washington.

- **Assisted suicide** allows assistance to die to chronically ill and disabled people who are not dying. Assisted suicide is permitted in Switzerland.

- **Voluntary euthanasia** allows a doctor to administer life ending medication directly to the patient. Voluntary euthanasia is permitted in the Netherlands and Belgium.

- **Euthanasia** is a term often used to describe life ending medication being administered by a third party, perhaps without the consent of the patient.

Assisted dying is a very controversial subject. It is not legal in the UK, but those wishing to pursue it commonly travel to Switzerland to use the services of Dignitas. About 180 UK citizens have used Dignitas over the last ten years.

The Suicide Act 1961 still makes anyone who aids and abets the suicide of another person liable to imprisonment for a maximum of 14 years, although in 2010 the Director of Public Prosecutions issued new guidelines to clarify who could face prosecution for assisting in another person's suicide. A range of factors are now to be taken into account including the motivations of the person assisting and the victim's ability to reach a clear and informed decision about their suicide.

The law would appear to be out of step with public opinion. A YouGov [315] poll found that 75% of the British public agreed with the idea of a law which would mean people with terminal illnesses being provided with life-ending medication to take themselves if two doctors thought they met all of the safeguards.

The views of the medical profession are less positive. An extensive survey [316] of medical physicians showed that the proportion against a change in the law was 66% against euthanasia and 65% against assisted dying. Opposition to euthanasia and physician assisted suicide was highest amongst Palliative Care and Care of the Elderly specialists, with more than 90% of palliative care specialists reporting that they are against a change in the law.

Some of the main arguments against assisted dying include:

- **Slippery slope**: the fear that once assisted dying is introduced for the terminally ill it may be extended to other vulnerable groups.

- **Consent**: the fear that some people may be influenced to accede to assisted dying without having given genuine consent.

- **Discrimination against disabled people**: the concern that it may be used to end the life of severely disabled people based on little more than prejudicial attitudes.

- **Conflict of interest**: that assisted dying is in direct conflict with commitments given under the Hippocratic Oath.

DIGNITY IN DYING

Dignity in Dying is a campaigning organisation which is committed to achieving a change in the law for terminally ill, mentally competent adults.

They propose legislation similar to that in place in the US states of Oregon and Washington and they continue to work to design and refine legislation that makes use of all that has been learned from overseas experience whilst being compatible with UK law, healthcare and culture.

Some have argued that improved palliative care services would be an alternative to assisted dying provisions. However, as was concluded by the House of Lords Select Committee Report on the Assisted Dying for the Terminally Ill Bill, there are a number of patients whose desire for medically assisted dying will not be addressed by more or better palliative care. The National Council for Palliative Care, the British Medical Association and Macmillan Cancer Relief have all acknowledged this fact. In England and Wales, where approximately 500,000 people die annually, it can be expected that around 1,000 terminally ill adults would use assisted dying provision each year.

The NHS encourages people to use other methods to retain control over the process of dying [302], such as:
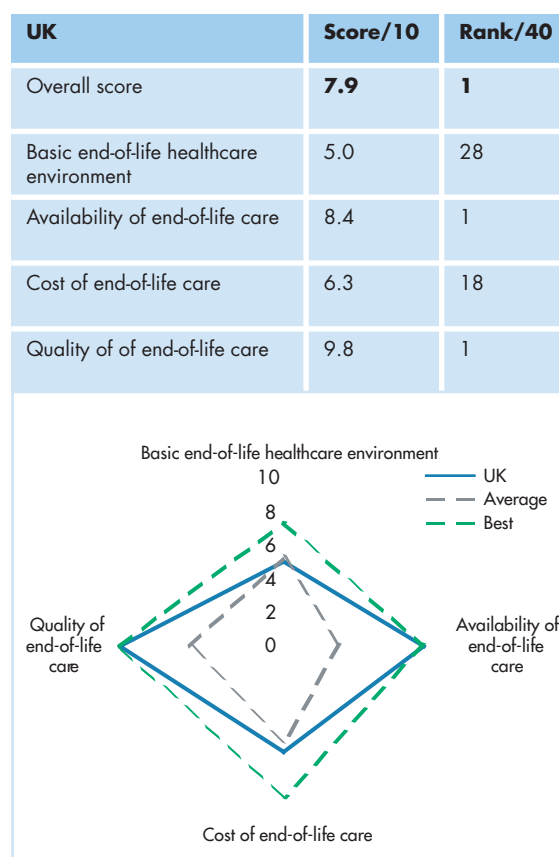
● Refusing treatment (such as chemotherapy)

● Do not resuscitate orders (for CPR)

● Withdrawing life-sustaining treatments, such as nutrition, hydration and/or ventilation

● Palliative sedation (administering medication in high enough doses that the person is unconscious and unaware of pain).

ISSUES

"The reasonable expectation that an older person and their family may have a dignified, pain free end of life care, in clean surroundings in hospital is not being fulfilled." [317]

In many respects Britain has excellent palliative care, an outstanding hospice movement and excellent examples of care within the NHS and independent sectors. Indeed, the UK was ranked first in the world in overall quality of death according to recent research [318]. That having been said, there is nevertheless room for improvement [305]. Too many people are still unable to access end of life care where and when they need it. For example, 83% of all deaths are of people aged 65 and over; only around 65% of them access specialist palliative care services [319]. There are also reported to be significant geographical variations in services, and there are insufficient community based services to enable people to remain in their preferred setting [319]. Campaigners [319] claim that no other service depends so heavily on the voluntary sector, which currently provides about 80% of specialist palliative care beds, as well as many community based services.

FIG. 3.9.3

UK	Score/10	Rank/40
Overall score	**7.9**	**1**
Basic end-of-life healthcare environment	5.0	28
Availability of end-of-life care	8.4	1
Cost of end-of-life care	6.3	18
Quality of of end-of-life care	9.8	1

Source: Economist Intelligence Unit

Place of death

The place of death remains significantly out of line with people's wishes. For example in 2006, 503,000 people died in England and Wales, in the following places:

● 290,000 in hospital

● 95,000 at home

● 80,000 in some form of care home

● 24,000 in hospices.

Evidence suggests [320, 321]that the level of care, dignity, the environment, and peacefulness of the setting could all be improved in care homes and hospitals to make end of life care a better experience for people dying in these settings and their families.

As noted already there is a significant mismatch between where people want to die and where they actually die. The National Audit Office also found that 40% of end of life care patients had no medical need to be in hospital. Most people are unlikely to die in their preferred place of death, regardless of where they live in England [321]. The majority of people die in hospital. However, this

FIG. 3.9.4. Most preferred place of death by age group

KEY
- own home
- hospice
- hospital
- care home
- home of a relative or friend
- elsewhere

Age		
16–24	73%	6%
25–34	75%	14%
35–44	72%	20%
45–54	58%	37%
55–64	67%	628%
65–74	56%	37%
75+	45%	41%
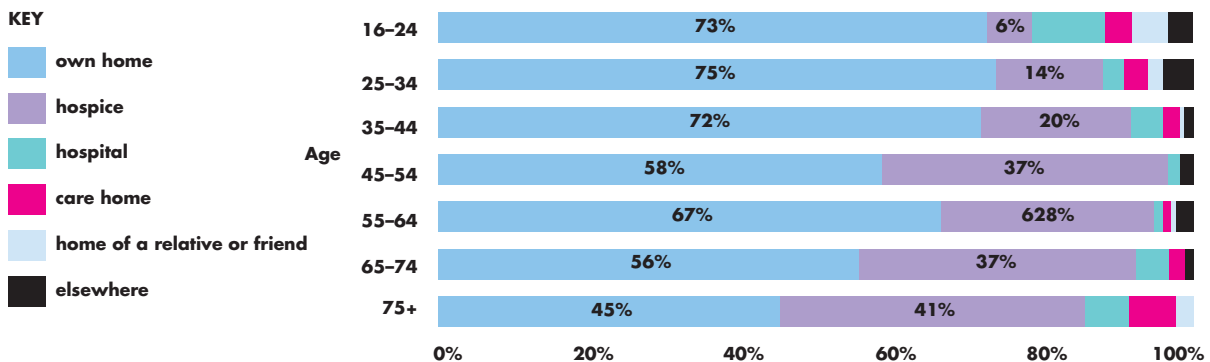
Source: Age UK [302]
Age differences were statistically significant (Kruskal-Wallis test=43.287; p-value<0.001)

becomes more common with age, as does dying in a care home (the second least-preferred place to die). Not only do home deaths decrease for people aged 65+, but so do deaths in hospices.

However there is a need for a nuanced approach to this question. Further research [322] has shown that as age increases, a preference to die at home *decreases.* Preferences for home death decreased from 75% (for those aged 25–34) to 45% (for those aged 75+) [322]. And when the notion of a lack of sufficient support from family, friends and doctors is factored in, 60% of those who initially expressed a preference to die at home report that they would change this view [303].

There are a number of reasons for this shift in preference for place of death: most women outlive their partners and live alone; if people do have spouse carers, these spouses are usually also old and have health problems; there is great concern about being a burden on family and being dependent on others, especially for 'intimate' needs such as toileting and bathing [312, 320].

Access to palliative care
Older people often have special needs and issues at end of life. Most older people die from chronic health problems and would benefit from palliative care during a slow decline [302]. However, access to palliative care has traditionally been for younger people with cancer [323]. For example, cancer is the underlying cause on only 25% of all deaths, yet 95% of those who [324] access specialist palliative care services are people with cancer. And age appears to be a factor. Only 5% of older people die in a hospice, falling from 9% of 65–74-year-olds to 2% of

people over 85 [325]. The main problems with older people accessing palliative care are the lack of places, and huge variability and uncertainty about when death from chronic health problems will occur [302].

The quality of end of life care in many acute hospitals needs to be improved. Apart from anything else, 54% of the most serious complaints in acute hospitals relate to care of the dying and bereavement [319].

MARIE CURIE NURSING SERVICE

The Marie Curie Nursing Service (MCNS), part of Marie Curie Cancer Care, provides end of life nursing at home to around 28,000 people annually in the UK. It aims to allow people who so choose to be able to spend their last few days at home. The MCNS is staffed by registered nurses and senior healthcare assistants who provide home-based care to around 28,000 people at the end of life annually in the UK.

Although it initially focused on caring for people with cancer, it has increasingly provided care to people with other conditions. The MCNS offers a number of different models of care:

- Planned – eight- or nine-hour shifts of usually overnight nursing care, booked in advance.
- Reactive – similar to planned care, but available at short notice.
- Multi-visit – shorter episodes of care, usually with multiple visits per nursing shift.
- Rapid response – urgent support in response to crises occurring 'out of hours'.

Evaluating the effectiveness of palliative care services is fraught with methodological problems [324, 326], nevertheless the Nuffield Trust has undertaken an interesting study of the effectiveness of the Marie Curie Nursing Service in supporting people to die at home.

The results of the Nuffield Trust study [327] showed that people who received MCNS care were significantly more likely to die at home than those who received 'standard' care. People who received MCNS care were also much less likely to use all forms of hospital care than those in the control group, and hospital care costs were significantly lower for MCNS patients compared with the matched controls:

- 76.7% of those who received MCNS care died at home, while only 7.7% died in hospital. In contrast, 35.0% of the controls died at home, while 41.6% died in hospital.

- People who received MCNS care were less likely to use all forms of hospital care than controls. 11.7% of MCNS patients had an emergency admission at the end of life, compared to 35% of controls; while 7.9% of MCNS patients had an A&E attendance, compared to 28.7% of controls. Across most types of care, MCNS patients used between a third and half of the level of hospital care of controls.

Variation

Dying in a person's preferred place varies depending on where they live [321]. Research [328] has built up a picture of how the care system dealt with over 73,000 patients during the last 12 months of their lives. The study revealed considerable variation between local areas in the care people received at the end of life. In addition, a recent review of palliative care funding in England [329] identified huge variation in the amount primary care trusts (PCTs) spend on palliative care services. The review estimated that around 75% of those who die each year could benefit from palliative care, and that there are likely to be around 90,000 people annually who would benefit from palliative care but do not receive it. It also calculated that the introduction of a properly funded palliative care system would lead to 60,000 fewer in-hospital deaths and a reduction in hospital costs of £180 million annually by 2021.

Hospital care

Research [330] has suggested that around a third of people who die in hospital might have been able to die at home . A recent survey of families of people who died [331] found that 54% of respondents whose relative died at home rated the quality of care in the last three months of life as outstanding or excellent; compared to a third of those whose relative died in hospital. The survey results also showed that relatives of those who died at home rated coordination of hospital, GP and community services more highly than relatives of those who died in hospital did. They were also much more likely to say that the deceased person was treated with dignity and respect in the last few days of life. These findings are consistent with the conclusions of studies that have suggested that quality of life and satisfaction with care are higher among people who receive palliative care services [332, 333].

Care homes

Care homes are the second least-preferred place to die [321]. Care home deaths increase with age, from 7% of people aged 65–74 to 34% of people 85+ [325] 12% of those who die in hospital will have been admitted from a care home [302]. Age UK notes [302] that with increasing numbers of people living alone towards the end of life and with a complex condition and comorbidities, more may need to be cared for in care homes. It is therefore important to understand why people do not wish to die in these places and what improvements people would like to see made to these settings to provide them with appropriate end of life care. An example might be the development of home and hospice-like environments within care homes.

Ethnicity

As Age UK notes [302], people from minority ethnic and/or religious groups potentially have additional challenges when dealing with end of life issues. For example, different values and expectations (such as the best place to die, gender and care, and the role of family in care and decisions), attitudes to death, responsibility, and medical treatment, not to mention complications arising from language barriers. There is also quite a lot of variation in where people die when ethnicity is factored in. For example, Pakistani and Bangladeshi elders are far more likely than white Britons to die in hospital, and far less likely to die in a care home or hospice.

Policy response

Campaigners [319] would wish to see:

- that the End of Life Care Strategy is fully implemented

- the establishment of a Cabinet Committee for End of Life Care

- ensure 24/7 access to specialist palliative care services

- ensure that end of life care is a core component of training for health and social care staff

- equip people to be more confident in discussing their wishes and priorities for end of life care.

Further recommended [298] priorities for development include:

- Ensuring that each GP practice has a mechanism to identify people approaching end of life and has a register of them

END OF LIFE CARE SERVICE

NHS Northamptonshire and Nene Commissioning commissioned Primecare, a private healthcare provider, in partnership with Age UK Northamptonshire to deliver a three-year End of Life Care Service in the county with the aim to:

- Increase the proportion of all deaths that occur at home by 9.34%

- Reduce the rate of hospital deaths in the county by 9.7% by 2013

- Improve patient choice at end of life

Older people and their carers, in the last days or weeks of life, are provided with a range of high quality home care services to enable them to die with dignity in their own home. The service allows people to remain in their communities and prevents unnecessary admission to hospital or institutional care.

On average each month they receive around 58 new referrals, of these they are able to accept 35 and approximately 18 people die in their own home.

This is an Enhanced Community Service to meet the needs of both individual patients at the end of their lives and their carers.

- Age UK Northamptonshire's part of the service is 24 hours, 365 days a year.

- Accessible by any health care professional (GP, District Nurse, hospice, acute hospital, community beds) via the Co-ordination Centre for End of Life care.

- Provides day and night sitters (and other care packages as required) to provide low level support for patients and carers,

which may be pre-booked but may also be unplanned and therefore require an urgent response.

- A Rapid Response service manages any unexpected deterioration in the patient or carer situation, which would otherwise lead to admission into hospital at the end of life. Age UK Northamptonshire aims to keep older people in their own homes.

Supporting people at End of Life also involves accompanying patients or carers to GP and hospital appointments, ensuring that food, medication and other essentials are available. Carers must be supported by helping to re-establish the infrastructure of their lives, including social networks and mechanisms to cope with their dependents' condition and circumstances.

- All people on the end of life register should receive a holistic assessment of their care and support needs

- All people on end of life register should have access to an identified care-coordinator.

Age UK [302] identifies a number of key policy issues including:

- Viewing older people's care needs as only social or only health rather than taking a personalised, holistic care approach

- Lack of health professional training in end of life issues and older people's health and care issues

- Poor understanding of the trajectory of older people's health i.e. transition from living well / with multiple conditions / frailty / to end of life phase.

In summary, Age UK [302], argues that all health and care staff need training in the treatment and care of older people at the end of life; communication among organisations/professionals and between professionals and patients and carers is paramount; care needs to be coordinated across all organisational boundaries (including into the patient's home); and advanced planning for end of life should be encouraged more widely.

Wider issue

End of life is something that everyone should consider preparing for; not just those with a terminal illness. The campaign group "Dying Matters Coalition" is engaged in trying to raise the profile of the need to prepare for end of life. One approach they take is to encourage communities to break the taboo of talking about death and dying. Amongst other things they advocate [334] a community development approach to engage the wider public. Proposed activities include:

- awareness raising using local media

- holding 'Dying Matters' conferences

- undertaking dying awareness events in the local community

- develop, in partnership with local agencies, a dying matters resource pack

- promote the development of 'Dying Matters Champions'

- awareness raising in schools

- work with local faith communities.

"Everyone deserves to live well and die well and this is more likely if as a society we feel more confident talking about it and thinking about the realities of dying – and planning our end of life care" [305].

4
RESILIENCE

"That which does not kill us
makes us stronger."

—Neitzsche

Reslience is difficult to define and to measure, and there is little agreement about what constitutes it and how to foster it! One researcher [335] has gone so far as to state: *"…so daunting is the number of issues that have been raised with regard to the concept that some researchers and clinicians despair of ever being able to resolve these various issues."* In essence, it is about the ability of some people to 'bounce back' from difficult life events or situations.

Some of the questions at issue here include [336]:

● Can a person be resilient in one context and not another, at one time and not another, for one kind of stressor and not another?

● Is a concept of resilience necessary or is this just a positive way of renaming the same underlying phenomena of vulnerability and risk?

● Does resilience research 'blame the victim' – i.e. when some older people do not overcome adversity?

● What are the processes behind the protective factors associated with resilience?

This section is not going to be able to address this level of complexity and uncertainty, however it is going to highlight some of the most relevant research and understanding of the subject.

Although there are many and various definitions of resilience, Windle [337] captures the essence of most of them – "*the successful adaptation to life tasks in the face of social disadvantage or highly adverse conditions*". Or further – "*Resilience is the process of negotiating, managing and adapting to significant sources of stress or trauma. Assets and resources within the individual, their life and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity. Across the life course, the experience of resilience will vary.*"

One of the problems with studying resilience is the lack of agreement about how to measure it. Windle [338] in a review of nineteen measurement scales concluded that there was no 'gold standard' amongst them and all required further validation work. This is an important

issue as the different approaches to measuring resilience have led to huge inconsistencies about its prevalence with some research [339] noting that the proportions of people found to be resilient varied from 25% to 84%. This raises the question as to whether resilience researchers are measuring the same thing.

How one develops resilience has been debated over the last couple of decades. Originally, resilience was believed to be a personality trait, but now resilience tends to be identified as being more dynamic and influenced by multiple factors. There is widespread consensus [340, 341] that three major categories of protective factors exist:

● Individual capabilities and attributes

● Interpersonal relationships

● Environmental (i.e. services) and community support.

4.1
PERSONAL CAPABILITIES

There are a number of research studies which throw light on the personal capabilities associated with resilience, although as with most aspects of resilience, there is a lack of consensus.

There have been a number of different 'waves' of enquiry into resilience [342]. The first wave attempted to identify the internal and external qualities or protective factors that help people to cope with or bounce back from adverse life situations. A few researchers [343] compared the data sets from various studies and compiled a composite list of defining attributes for resilience, which included:

● High self esteem

● High self efficacy

● Having high expectancy in life (a sense of purpose and achievement)

● Having self determination

● Optimism and effective coping styles

- Having a good support system
- Having positive relationships with others
- Having a sense of humour about life and oneself
- Being flexible.

Interestingly, these attributes do not appear to be moderated by socioeconomic circumstances [344]. In other words, social circumstances do not appear to affect how resilient people are.

One of the most controversial, but empirically based, researchers from more recent enquiry is George Bonanno [192, 197] whose key claims about resilience include the following:

- That resilience is the most common, natural reaction to loss or trauma.
- Because it is 'natural', that resilience cannot be taught through specialist programmes
- Policy and treatment for the past century has relied on the false idea that humans are not resilient.

RESILIENCE IN LATER LIFE

A significant large scale review [345] of the English Longitudinal Study on Ageing, involving more than 7,000 older people, revealed a number of interesting findings about resilience in later life. It looked at a number of situations that might require resilience to overcome them, including financial adversity, loss of mobility and widowhood. The results showed:

- With regard to financial adversity
  - 72% appeared to be resilient (i.e. suffering no depressive symptoms).
  - Being married and the availability of wider social support was related to greater resilience.
  - Satisfaction with life was strongly correlated with resilience.
- With regard to widowhood
  - Around 57% appeared to be resilient (i.e. not suffering from depression), and there were no differences by gender or age.
- With regard to loss of mobility
  - Around 60% appeared to be resilient to this major functional decline.
  - There was no connection between resilience and socioeconomic factors.
  - There was no connection with social support.

- Overall
  - Over half of older people appear to be able to live better than expected lives despite adversity and trauma. They were able to not only avoid depressive symptoms but also enjoy their lives and remain optimistic for the future. "*It is a major indication that resilience exists in later life and that a fair number of older people can potentially resist adversity.*" [345]
  - Resilience is strongly related to self reported satisfaction with life and an optimistic outlook on life.
  - Resilience was not related to age. It is not the property of any particular age groups.
  - Resilient people were able to minimise the losses to their quality of life from various adversities but they were not able to make a complete recovery. They never bounce back quite fully.
  - There was little evidence of gender, socioeconomic factors or social support exerting much influence.

PERSONALITY LINKS

There is a debate over whether resilience is a personality trait or whether it can be learned. Much research has therefore been conducted comparing resilience assessment instruments with personality assessments. A study [346] undertook to see if resilience correlates with the "big five" dimensions of personality, which includes neuroticism, extraversion, openness, agreeableness, and conscientiousness. The comparison found that resilience had a strong negative relationship with neuroticism, which suggests that individuals with low neuroticism scores are better able to cope with and adjust to stress and adversity and have higher resilience than individuals with high neuroticism scores. Resilience was positively related to extraversion and conscientiousness, suggesting that individuals who have more social interactions and interpersonal closeness and who are able to apply task-oriented coping to stressful or adverse situations are more resilient. Although the results show that resilience is correlated with low neuroticism, high extraversion, and high conscientiousness, it is still unclear whether resilience is a result of an individual's personality traits or if it is a learned result associated with an individual's personality.

FIG. 4.1.1

		Number of positive events			
		0–1	2–3	4+	
Number of negative events	0–2	30 (15.8%)	25 (13.2%)	13 (6.8%)	68 (35.9%)
	3–5	34 (17.9%)	27 (14.2%)	17 (8.9%)	78 (41.2%)
	6+	17 (8.9%)	15 (7.9%)	11 (5.8%)	43 (22.7%)
		81 (42.8%)	67 (35.4%)	41 (21.6%)	

Source: Ryff, Singer [347]

Focussing solely on a number of personality traits is a rather static and one dimensional approach to understanding resilience. By way of contrast, Ryff et al [347] set resilience within a life course context and emphasise a number of dynamic processes which might be at play:

- On the one hand there is the idea of '**cumulation of adversity**', which suggests that the experience of numerous negative life events and life transitions over time will tend to compromise health and resilience.

- On the other hand there is the idea of '**cumulation of advantage**', which suggests that there may be a series of positive life events and life transitions (good family life, good job, happy marriage etc), which may have ameliorative or protective benefits which bolster resilience.
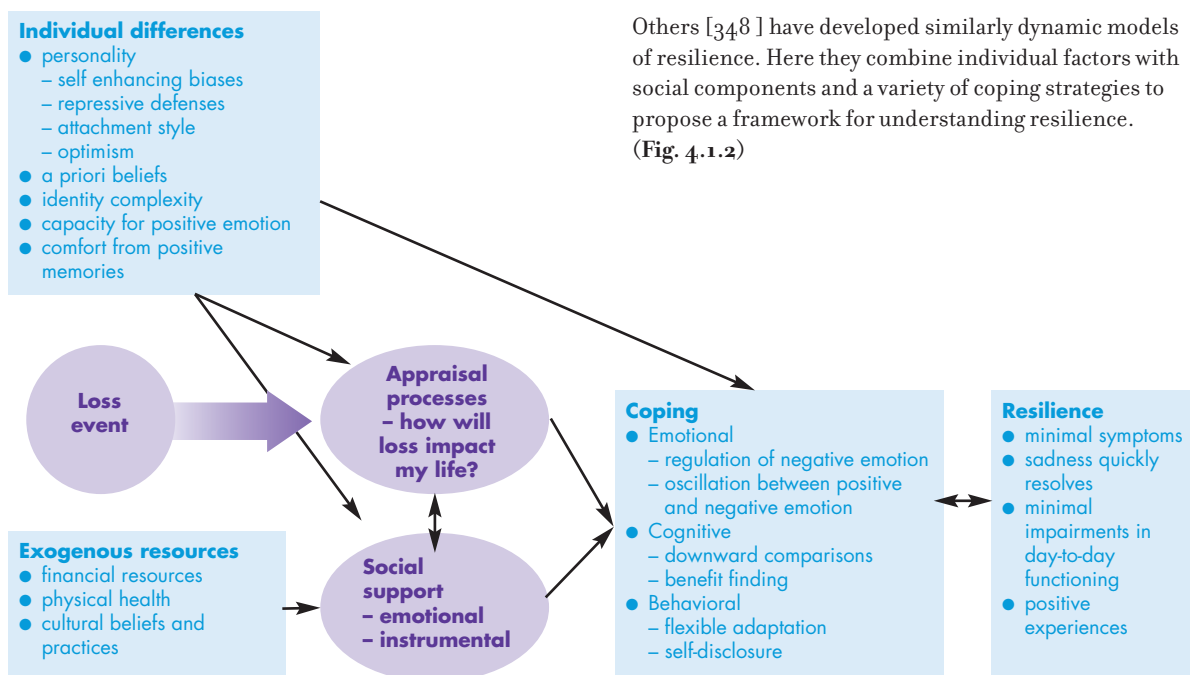
Ryff et al use this to develop the idea of 'cumulative challenge' which is arrived at by mapping the various positive and negative events over time. There are similarities here with the mapping of the life course which we saw in the introductory sections on the life course approach. (**Fig. 4.1.1**)

They draw a number of conclusions from their work:

- That there are a large number of life events in later life. In other words it is a time when life challenges accumulate.

- The variability in these events goes some way to explaining different resilience pathways (see below).

- That life is replete with both positive and negative transitions and life events, and that the positive ones may go some way towards offsetting the impact of the negative events.

Ryff et al assert that it is possible, through mapping individual life histories, to combine these in such a way that different 'pathways' or trajectories emerge. They found that high resilience pathways were associated with good starting resources (i.e. early childhood etc), quality social relationships, advancement in work hierarchies and positive social comparisons.

Others [348] have developed similarly dynamic models of resilience. Here they combine individual factors with social components and a variety of coping strategies to propose a framework for understanding resilience. (**Fig. 4.1.2**)

FIG. 4.1.2

Individual differences
- personality
  – self enhancing biases
  – repressive defenses
  – attachment style
  – optimism
- a priori beliefs
- identity complexity
- capacity for positive emotion
- comfort from positive memories

Loss event

Appraisal processes – how will loss impact my life?

Exogenous resources
- financial resources
- physical health
- cultural beliefs and practices

Social support – emotional – instrumental

Coping
- Emotional
  – regulation of negative emotion
  – oscillation between positive and negative emotion
- Cognitive
  – downward comparisons
  – benefit finding
- Behavioral
  – flexible adaptation
  – self-disclosure

Resilience
- minimal symptoms
- sadness quickly resolves
- minimal impairments in day-to-day functioning
- positive experiences

Source: Mancini and Bonanno [348]

SUBJECTIVE WELLBEING

The research evidence that happier people live healthier and longer lives is overwhelming. It is therefore a very important potential contributor to resilience. A meta review [349] of more than 160 studies found "clear and compelling evidence" that, all else being equal, happy people tend to live longer and experience better health than their unhappy peers. The general conclusion from each type of study is that feeling positive about life, and not experiencing significant levels of stress, or not being depressed, contributes to both longevity and better health.

OPTIMISM

Research on the effects of a 'glass half full' mental attitude (optimism) have demonstrated a number of health and wellbeing benefits:

- Increased life span

- Lower rates of depression

- Lower levels of distress

- Greater resistance to the common cold

- Better psychological and physical wellbeing

- Reduced risk of death from cardiovascular disease

- Better coping skills during hardships and times of stress.

A number of pieces of research are worth looking at to highlight the general evidence about the benefits of an optimistic outlook:

- The incidence of depression and anxiety predicted heart disease, and predict disease progression in those with cardiovascular disease [350].

- Positive moods such as joy, happiness and energy, as well as characteristics such as life satisfaction, hopefulness, optimism and sense of humour were associated with reduced risk of mortality in healthy populations and predicted longevity [351].

- 4,989 students who filled out an optimism scale at entry into university in 1964–66 were followed for 40 years. Pessimistic individuals had lower rates of longevity compared with optimistic individuals [352].

Optimism has been shown to explain between 5–10% of the variation in the likelihood of developing some health conditions, including cardiovascular disease [353–355], stroke [356], depression [357] and cancer [358]. A meta analysis [359] has confirmed the assumption that optimism is related to psychological wellbeing: "Put

simply, optimists emerge from difficult circumstances with less distress than do pessimists." Furthermore, the correlation appears to be attributable to coping style: "That is, optimists seem intent on facing problems head-on, taking active and constructive steps to solve their problems; pessimists are more likely to abandon their effort to attain their goals." [359]

There is a question as to whether the effects of subjective wellbeing are of sufficient size to be of practical policy significance. The evidence suggests strongly that they are:

"*The effect sizes for subjective wellbeing (SWB) on health are not trivial; they are large when considered in a society-wide perspective. If high SWB adds 4 to 10 years to life compared to low SWB, this is an outcome worthy of national attention. When one considers that the years lived of a happy person are more enjoyable and experienced with better health, the importance of the SWB and health findings is even more compelling. It is perhaps time to add interventions to improve subjective well-being to the list of public health measures, and alert policy makers to the relevance of SWB for health and longevity*" [349]

High levels of subjective wellbeing and optimism are therefore critical to resilience and to ageing positively.

What is optimism? Optimism is an 'explanatory style' [360]. In other words, it is a habitual way that we interpret what happens to us in life. Martin Seligman who has written and researched extensively on this subject [360] has shown that optimists and pessimists react to difficult situations in life in very different ways:

- **optimistic** people tend to interpret their troubles as transient, controllable, and specific to one situation

- **pessimistic** people tend to believe that their trouble last forever, undermine everything they do and are uncontrollable.

There are therefore three dimensions to both explanatory styles:

- **Permanance** – is the situation going to last for ever or pass quite quickly

- **Pervasiveness** - does it affect many areas of life or is it just restricted to the one in question

- **Personalisation** – to what extend do I have control over the situation.

So for example when some difficulty besets a pessimist, they tend to think that it affects many other parts of their lives (like a pack of cards tumbling), that it is likely to always be this way or happen over and over again and that there is little or nothing they can do to make it better.

One of the most important dimensions of Seligman's work is his assertion that optimism can be learned. Seligman proposes practical steps can be taken to increase or bolster optimism – what he calls the "ABCDE strategy" [360]. In essence it involves recognising and then disputing pessimistic thoughts.

GRATITUDE

Gratitude has been found to be a very powerful emotional state for promoting strength and resilience. Insufficient appreciation and savouring of the good events in one's past and an overemphasis on the bad ones have been shown to undermine contentment and satisfaction [361].

By way of contrast, gratitude amplifies the savouring and appreciation of the good events gone by, an approach which is particularly relevant given the number of later life transitions which involve loss. As with optimism, gratitude is a fundamental positive orientation toward the positive in the world. It has been described as *'the quintessential positive psychological trait'* [362].

In the last few years gratitude has been shown to be a robust predictor of wellbeing. On the basis of this, gratitude interventions have been developed and shown to substantially decrease depression and increase social functioning. Such successes have led to calls for gratitude interventions to be used more in clinical settings [362]. This is directly relevant to the question of resilience. For example, if gratitude naturally protects people from stress and depression, then this would suggest that increasing gratitude therapeutically may build up a level of psychological capital which is beneficial during the difficult periods in peoples' lives and makes them more resilient. Research has added weight to this hypothesis. Research [362] about the ability to undertake a significant life transition showed that gratitude lead to the development of social support and reduced levels of stress and depression.

The researchers assert that the research findings support the importance of gratitude interventions and the calls for them to be used in clinical and coaching practice. Potentially, giving people the skills to increase their gratitude may be as beneficial as such cognitive behavioural life skills as challenging negative beliefs. Some go so far as to say that gratitude is uniquely important to wellbeing and social life [363].

RESILIENCE EDUCATION

It is argued by some that 'resilience education' could help individuals identify and nurture their internal resilient qualities to bolster their ability to cope with loss [347, 364–368]. For example, Edith Grotberg [369] identifies three sources of resilience,' *What we have, what we are and what we can do.*' According to her, resilience is not something that people either have or do not have: rather, resilience can be learned and as we learn we increase the range of strategies available to us when things get difficult. There is some research evidence to substantiate these claims [368, 370]. There are very few educational interventions to promote resilience [371], however a few examples are explored below.

Reslience training programme

Richardson and Waite [364] describe a structured resilience training programme that consists of five day-long sessions spread out over a five week period to allow for introspection. The first session presents participants with the multidisciplinary understanding of resiliency. People are then instructed to explore their moral framework. The second session helps provide an understanding of how the mind and body function in relation to one another. The third session helps build personal resilience and how to explore the innate qualities an individual possesses. The fourth day focuses on building constructive relationships at home and work and recognising that distrust can be unlearned. The fifth session focuses on resilient relationships, which are a step above constructive relationships and allow for individuals to be altruistic and make an impact in the world. An evaluation of this resilience education programme [364] showed that it provided significant improvements in resilience, self-esteem, interpersonal relationships, and purpose in life. There was also a significant shift toward a more internal locus of control, which is desirable for resilience. These changes were also noted at the six-week follow-up. This study suggests that resilience education can help individuals to cope with adverse life events and crises in more positive and constructive ways, though it is important to note that this intervention was carried out with working age adults in a work setting.

Full of Life

Full of Life is a peer-to-peer community based project to promote emotional resilience skills for older people. The project, supported by the Young Foundation, has developed and piloted a service to improve the wellbeing and resilience of people aged 65 and over who were experiencing isolation, mild anxiety or depression. The project is a collaboration between the Young Foundation, Age UK and Dr Chris Williams, Consultant Psychiatrist at the University of Glasgow. Local volunteers, recruited through existing Age UK networks and wider local

outreach, have been trained to run local peer discussion groups around a set of supporting materials. The course has been developed specifically for older people, based on Cognitive Behavioural Therapy (CBT) and Positive Psychology methods of 'helping people to help themselves'. Components of the course include identifying and challenging negative emotions, developing coping strategies, social problem solving skills, negotiation and relaxation techniques.

Mayo Clinic offer

The Mayo Clinic in the States says on its website it offers the following resilience education programme, which appears to incorporate a large element of mindfulness training:

"Resilience is your ability to adapt well and recover quickly after stress, adversity, trauma or tragedy. If you have a resilient disposition, you are better able to maintain poise and a healthy level of physical and psychological wellness in the face of life's challenges. If you're less resilient, you're more likely to dwell on problems, feel overwhelmed, use unhealthy coping tactics to handle stress, and develop anxiety and depression.

You can develop resilience by training your attention so that you're more aware of the present moment. You use purposeful, trained attention to decrease the negative thoughts in your mind and bring greater focus on the present moment. Forming a resilient disposition includes:

— *Fostering acceptance*

— *Finding meaning in life*

— *Developing gratitude*

— *Addressing spirituality*

— *Retraining your attention*

Programs incorporating these approaches can improve your resiliency, enhance your quality of life and decrease your stress and anxiety."

Road to resilience

An online booklet has been developed by the American Psychological Association: http://www.apa.org/helpcenter/road-resilience.aspx.

This advocates the following ways to build resilience:

● **Make connections**. Good relationships with close family members, friends or others are important. Accepting help and support from those who care about you and will listen to you strengthens resilience. Some people find that being active in civic groups, faith-based organisations, or other local groups provides social support and can help with reclaiming hope. Assisting others in their time of need also can benefit the helper.

● **Avoid seeing crises as insurmountable problems**. You can't change the fact that highly stressful events happen, but you can change how you interpret and respond to these events. Try looking beyond the present to how future circumstances may be a little better. Note any subtle ways in which you might already feel somewhat better as you deal with difficult situations.

● **Accept that change is a part of living**. Certain goals may no longer be attainable as a result of adverse situations. Accepting circumstances that cannot be changed can help you focus on circumstances that you can alter.

● **Move toward your goals**. Develop some realistic goals. Do something regularly — even if it seems like a small accomplishment — that enables you to move toward your goals. Instead of focusing on tasks that seem unachievable, ask yourself, "What's one thing I know I can accomplish today that helps me move in the direction I want to go?"

● **Take decisive actions**. Act on adverse situations as much as you can. Take decisive actions, rather than detaching completely from problems and stresses and wishing they would just go away.

● **Look for opportunities for self-discovery**. People often learn something about themselves and may find that they have grown in some respect as a result of their struggle with loss. Many people who have experienced tragedies and hardship have reported better relationships, greater sense of strength even while feeling vulnerable, increased sense of self-worth, a more developed spirituality and heightened appreciation for life.

● **Nurture a positive view of yourself**. Developing confidence in your ability to solve problems and trusting your instincts helps build resilience.

● **Keep things in perspective**. Even when facing very painful events, try to consider the stressful situation in a broader context and keep a long-term perspective. Avoid blowing the event out of proportion.

● **Maintain a hopeful outlook**. An optimistic outlook enables you to expect that good things will happen in your life. Try visualising what you want, rather than worrying about what you fear. Take care of yourself. Pay attention to your own needs and feelings. Engage in activities that you enjoy and find relaxing. Exercise regularly. Taking care of yourself helps to keep your mind and body primed to deal with situations that require resilience.

● **Additional ways of strengthening resilience may be helpful.** For example, some people write about their deepest thoughts and feelings related to trauma or other stressful events in their life. Meditation and spiritual practices help some people build connections and restore hope.

SUCCESSFUL AGEING

The more one investigates resilience in later life, the more one 'bumps up against' the factors that enable people to age successfully. In other words, studies which have looked at what factors appear to influence some people's ability to live long, healthy and happy lives, can easily begin to be cited as the sort of things which enable these people to be resilient to the vicissitudes of ageing.

A lot of academic thinking and research has gone into what factors are associated with ageing successfully. One of the classic academic definitions [52] of successful ageing defines three components:

● Absence or avoidance of disease

● Maintenance of physical and mental functioning

● Active and independent engagement with life.

This is helpful, but can be seen as missing a number of important facets. In her detailed study of the literature around 'successful ageing', Professor Ann Bowling [372] distils (see box below) the elements from three main viewpoints – biomedical; psychosocial and lay perspectives (noting that there was some overlap).

Leaving aside the obvious requirements of good physical and cognitive functioning, Ryff and Keyes [373] propose a theoretical model of psychological adult wellbeing that encompasses six distinct dimensions of wellness or successful aging:

● **Self Acceptance**: positive evaluations of oneself and one's past life

● **Personal Growth**: a sense of continued growth and development as a person

● **Purpose in Life**: belief that one's life is purposeful and meaningful

● **Positive Relations with Others**: the possession of quality relations with others

● **Environmental Mastery**: the capacity to manage effectively one's life and surrounding world

● **Autonomy**: a sense of self-determination.

Although this search for the key components of successful ageing can all seem rather academic, it is important. The dominant medical model tends to concentrate solely on the biological components of physical (and to a small extent, mental) health. However when older people themselves are asked [372] for their definition of successful ageing, whilst physical health is their most important domain, the next most important ones are psychosocial. These include:

● A positive outlook and self worth

● Self efficacy, or sense of control over life

● Autonomy and independence

● Effective coping and adaptive strategies in the face of changing circumstances

● Social role and activities.

MAIN CONSTITUENTS OF SUCCESSFUL AGEING

Theoretical definitions

● Life expectancy

● Life satisfaction and wellbeing (includes happiness and contentment)

● Mental and psychological health, cognitive function

● Personal growth, learning new things

● Physical health and functioning, independent functioning

● Psychological characteristics and resources, including perceived autonomy, control, independence, adaptability, coping, self esteem, positive outlook, goals, sense of self

● Social, community, leisure activities, integration and participation

● Social networks, support, participation, activity

Additional lay definitions

● Accomplishments

● Enjoyment of diet

● Financial security

● Neighbourhood

● Physical appearance

● Productivity and contribution to life

● Sense of humour

● Sense of purpose

● Spirituality

Source: Bowling A, (2005)

FIG. 4.1.3

Source: Robertson [374]

A pragmatic distillation of the various academic modeling of the components for successful ageing could look more like this – see **Fig. 4.1.3**.

It is useful to look at each of these in turn:

- **Physical health**: the issues and requirements here are fairly well known and there is a huge wealth of material available. In very simple terms leaving aside certain genetic factors, physical health can be significantly enhanced and maintained through a good diet and regular exercise.

- **Mental health**: there is much truth in the old saying that there is "*A sound mind in a healthy body.*" Mental health can be significantly influenced by physical health and vice versa. When it comes to ageing many people are very worried about losing their thinking skills. The research is much more positive than the general public's ideas on ageing. General knowledge and things like vocabulary and learned skills, including some number skills, often stay pretty well intact even into very old age [375]. And there are things that people can do to retain their memory and cognitive abilities. Although the scientific studies are not conclusive about whether 'brain training' works, it is nevertheless clear that people who engage in mental activities have a richer mental life. Examples include offerings from Tony Buzan [376].

- **Emotional wellbeing**: both physical and mental health will have an impact on emotional wellbeing and vice versa. Research shows that happiness, optimism and a positive attitude towards ageing is associated with better health, wellbeing and living longer [51, 377-381] It is also known that emotional wellbeing and happiness generally increase with age [382, 383]. This in itself is a very important finding in relation to

resilience – what mechanism accounts for older people's increasing happiness? Understanding this may provide some insights into how to increase resilience. Laura Carstensen has researched this area and developed a theoretical framework for understanding the results – 'socioemotional selectivity theory' [383]. This proposes that people's goals and cognitive functioning are tied to their awareness of where they stand in the life span. Younger people explore new experiences with the belief that they've got plenty of time to spare and long, nebulous futures to prepare for. They are often willing to tackle any cognitive task just for the challenge. But for an older person, the timeline shrinks with the awareness of impending mortality. Greater attention is paid to seeking emotional rewards through meaningful activities. In one series of studies, Carstensen, along with others [384] presented younger and older participants with a series of positive, negative or neutral images. The results showed that while younger adults remembered both positive and negative images, older people recalled more positive images than negative images. In another test, when presented with photos of people either smiling or scowling, older people remembered the smiling faces more quickly. That selective attention to the positive might explain why older people report the least amount of distress in day-to-day life, are less likely to be depressed and experience lower rates of phobia than younger people do.

- **Personal growth**: it is just as important in later life as it was in earlier phases to develop oneself through engaging fully in life's rich array of experiences and opportunities for learning. There is no end to learning, but it needs a belief that it is just as important in later life to sustain it.

- **Independence**: one of the biggest fears that people have about ageing is the potential loss of autonomy and control over their lives and living situations. This is usually associated with illness and disability, but contrary to the general public's perception, illness and disability do not necessarily need to compromise them. There are many examples of people with severe impairments leading very active and independent lives. Control is important in other ways. Research has shown how a sense of control is also associated with longevity [385, 386].

- **Interdependence**: independence is important, but so is *inter*dependence. Human beings are generally social animals and relationships with others and engagement in local communities is fundamental to their wellbeing. Indeed loneliness has now been recognised as being as harmful to wellbeing as smoking 15 cigarettes a day [387]. Keeping the level of engagement with others which is satisfying is crucial. Not everyone needs the same level of interaction – but we all need to achieve the level that keeps us from feeling lonely.

- **Financial security**: is self evident.

- **Appealing environment**: as we get older our homes and neighbourhoods tend to become more important to us. We are likely to spend more time in them than perhaps we did when we worked full time for example. Ensuring one's living situation is fit for later life is a crucial part of positive ageing.

- **Spiritual or philosophical guidelines and/or practice**: impending death makes a difference to how one views the world and one's life. That is not to say that everyone becomes "spiritual", but it does mean that making sense of life and the world can become more important. There are a variety of ways of achieving this, including through philosophical understandings or resolutions of old 'existential questions'.

- **Sense of purpose**: although linked to 'making sense of life', finding a sense of purpose in life has more to do with meaning and motivation. This requires a lot of thinking about in later life as previous drivers may become obsolete as one becomes less economically active or becomes free from parental responsibilities.

Successful ageing courses

Courses to support people to achieve 'successful ageing' have begun to appear in the UK [388]. Personal development approaches to 'successful ageing', drawing on social gerontology and humanistic psychology have also been constructed. An example [374] includes the following 10 step approach:

10 STEPS TO AGEING POSITIVELY

Step 1 Set your intention to age positively

Step 2 Find out what you believe about your own ageing

Step 3 Replace negative or unhelpful beliefs with positive ones

Step 4 Create a positive mental image of yourself as an older person

Step 5 Maximise your optimistic outlook

Step 6 Increase your sense of gratitude

Step 7 Be mindful – practice mindfulness meditation

Step 8 Undertake a life review

Step 9 Establish what is most important to you

Step 10 Develop a life plan for your later years

Source: positiveageing.org.uk

Whilst not specifically badged as promoting resilience, as has been noted above, there is a very strong connection between 'successful ageing' and 'resilience in later life'.

FIVE WAYS TO WELLBEING

There is an evidence base around the components of good mental health which is potentially relevant to the cultivation of resilience. The Five Ways to Well-being were developed by nef from evidence gathered in the UK government's Foresight Project on Mental Capital and Wellbeing [389]. The Project, published in 2008, drew on state-of-the-art research about mental capital and mental wellbeing through life.

The concept of wellbeing comprises two main elements: feeling good and functioning well. Feelings of happiness, contentment, enjoyment, curiosity and engagement are characteristic of someone who has a positive experience of their life. Equally important for wellbeing is our functioning in the world. Experiencing positive relationships, having some control over one's life and having a sense of purpose are all important attributes of wellbeing.

Their review [389] of the most up-to-date evidence led nef to suggest that building the following five actions into day-to-day lives is important for wellbeing (and potentially for resilience as well):

The Five Ways to Wellbeing

Connect...
With the people around you. With family, friends, colleagues and neighbours. At home, work, school or in your local community. Think of these as the cornerstones of your life and invest time in developing them. Building these connections will support and enrich you every day.

Be active...
Go for a walk or run. Step outside. Cycle. Play a game. Garden. Dance. Exercising makes you feel good. Most importantly, discover a physical activity you enjoy and that suits your level of mobility and fitness.

Take notice...
Be curious. Catch sight of the beautiful. Remark on the unusual. Notice the changing seasons. Savour the moment, whether you are walking to work, eating lunch or talking to friends. Be aware of the world around you and what you are feeling. Reflecting on your experiences will help you appreciate what matters to you.

Keep learning...
Try something new. Rediscover an old interest. Sign up for that course. Take on a different responsibility at work. Fix a bike. Learn to play an instrument or how to cook your favourite food. Set a challenge you enjoy achieving. Learning new things will make you more confident as well as being fun.

Give...
Do something nice for a friend, or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out, as well as in. Seeing yourself, and your happiness, as linked to the wider community can be incredibly rewarding and creates connections with the people around you.

4.2
COMMUNITY CONTEXT

As noted previously, there is a growing consensus [340, 341] that community support is an important dimension of resilience.

The term community support is used in a number of ways, but for the context of this report it is best thought of as the process of building networks within communities that result in individuals, families and the wider community experiencing a sense of wellbeing and greater quality of life. It is argued that community networks can enhance people's ability to cope with difficulties and disasters. It can be defined as:

> "*a quality or state that produces good outcomes for individuals and communities in spite of serious threats to their adaptation or development; these threats may arise both from shocks or emergencies and ongoing daily conditions of life*". [390]

Disadvantaged communities can and do evolve networks and systems that help people and families build the resilience and support needed to deal with everyday challenges and risks. Where there are strong community relationships and connections and where a neighbourhood is alive with activity and cross cut with networks of relationships providing informal support and mutual aid, it is argued that people will be much better able to cope with pressures and will have a better quality of life.

Proponents of this approach claim that "*Such an understanding challenges the view that disadvantaged families are passive recipients of health and social services, supported by paternalistic ways of working that encourage dependency and reliance. Rather, through involvement in community affairs, families will gain new insights into their own health improvement and that of the wider community. Opportunities will be created to unlock existing knowledge, build confidence, resilience, contacts, ideas, enthusiasm and energy.*" [390]

Research [391] demonstrates that in disadvantaged but settled communities there is a strong relationship between social networks and people's level of wellbeing. A wide ranging review [392] of the literature on the relationship between community development and health and wellbeing concluded that – "*There is strong evidence that strong social networks protect people against the impact of stressors, mental or physical. That is, strong social networks confer resilience. This appears to span a range of conditions, stressors and populations.*"

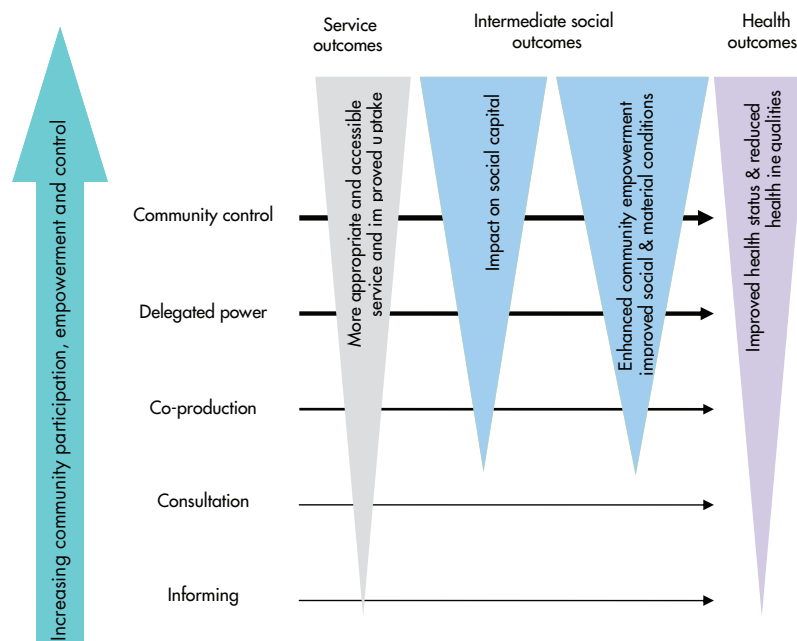The report goes on to cite some very specific research evidence:

- Low levels of social integration and loneliness, significantly increase mortality.

- Older people with stronger networks are healthier and happier [393, 394].

- Social networks are consistently and positively associated with reduced morbidity and mortality:

  - Protective against dementia [395]

  - Protective against cognitive decline [396]

  - Protective against mortality [397, 398]

  - Protective against cardiovascular disease [399–401].

- Strong communities with good networks of social relationships also appear to have helped areas cope in the face of adversity [402]. "*It is social relationships that are most effective in maintaining resilience in the face of adversity*."

Other data supports these messages:

- A person's social networks can have a significant impact on their health. One large scale international study showed that over seven years, those with adequate social relationships had a 50 per cent greater survival rate compared with individuals with poor social relationships [403]. Social networks have been shown to be as powerful predictors of mortality as common lifestyle and clinical risks such as moderate smoking, excessive alcohol consumption, obesity and high cholesterol and blood pressure [404].

- Social support is particularly important in increasing resilience and promoting recovery from illness [405]. Strong social capital can also improve the chances of avoiding lifestyle risks such as smoking [406, 407]. However, in the most deprived communities, almost half of people report severe lack of support [408], making people who are at greater risk less resilient to the health effects of social and economic disadvantage.
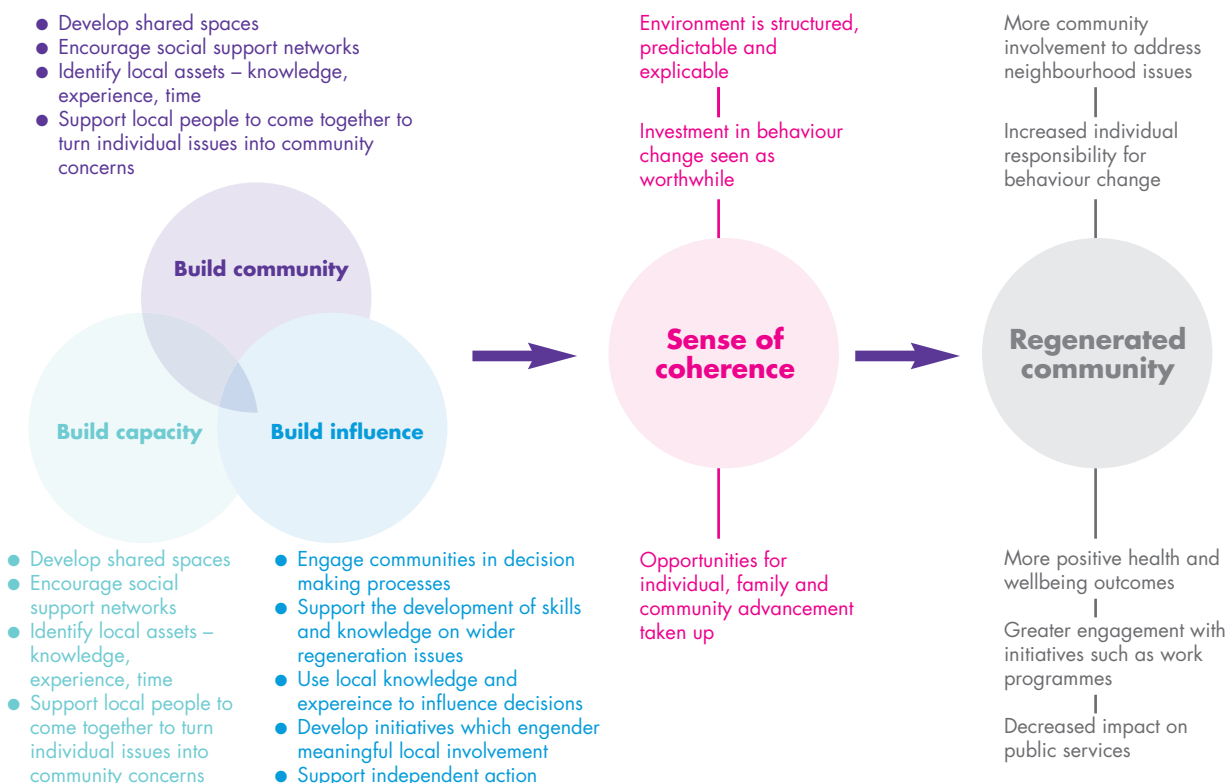
Guidance from the National Institute for Clinical Excellence [409] sets out a helpful framework for understanding the link between community empowerment and health outcomes: (**Fig. 4.2.1**)

FIG. 4.2.1. Pathways from community participation, empowerment and control to health improvement

From National Institute for Health and Clinical Exellence [409]

FIG. 4.2.2

- Develop shared spaces
- Encourage social support networks
- Identify local assets – knowledge, experience, time
- Support local people to come together to turn individual issues into community concerns

Environment is structured, predictable and explicable

Investment in behaviour change seen as worthwhile

More community involvement to address neighbourhood issues

Increased individual responsibility for behaviour change

Build community

Build capacity

Build influence

Sense of coherence

Regenerated community

- Develop shared spaces
- Encourage social support networks
- Identify local assets – knowledge, experience, time
- Support local people to come together to turn individual issues into community concerns

- Engage communities in decision making processes
- Support the development of skills and knowledge on wider regeneration issues
- Use local knowledge and expereince to influence decisions
- Develop initiatives which engender meaningful local involvement
- Support independent action

Opportunities for individual, family and community advancement taken up

More positive health and wellbeing outcomes

Greater engagement with initiatives such as work programmes

Decreased impact on public services

The logic model diagram (**Fig. 4.2.2**) sets out another framework. It locates community resilience (in the circles labelled 'build community' and 'build capacity') and co production (in the circle labelled 'build influence) as core components contributing to a regenerated community with improved outcomes in most areas of life.

INTERESTING PRACTICE

The following sets out a number of models which employ community capacity to bolster the resilience of individuals within communities:

Health Empowerment Leverage Project [410]
HELP's mission is to maximise health through brokering dynamic cooperation and problem-solving between communities, health agencies and other partners. People everywhere have the potential to improve their own health, wellbeing and local conditions by working together. But to do this they need support and engagement from the health agencies and their partners. Health and local conditions are improved by a combination of service change, behaviour change and new hope. This approach is both needs and asset based.

The HELP approach to any area where they are invited to work is first to look at the local situation from both perspectives – public services and local residents. They start especially from the concerns of people who are willing to be active in their communities. These concerns may not just be about health, but all sorts of health improvements come about through collaborative working on other issues too. They then help to form or strengthen neighbourhood partnerships between residents and public services, both health and other services and stakeholders. The next step is development of action plans which advance both the concerns of the residents and the priorities of the public agencies. Finding the issues which link people in the neighbourhood motivates them to seek change and, by doing so, change their own lives. They then help both sides to follow through on the improvements they seek, and they show how they can measure and describe the changes they bring about.

HELP employs the "*Connecting Communities Seven Steps Towards Sustainable Community Health Improvement in Disadvantaged Neighbourhoods*" approach:

STEP 7 Range of sustainable vibrant Health Improvement initiatives as result of 'fully engaged scenario' leading to ongoing TRANSFORMATIONAL CHANGE.

STEP 6 Monthly partnership meetings providing continuous positive feedback loop following visible 'early wins' for community via project outcomes.

STEP 5 Community self organisation evidenced by creation of constituted community led, multi-agency local operational partnerships, residents associations and emergent projects with dispersed leadership.

STEP 4 Creation of new neighbourhood community of practice providing receptive context for dialogue and co-learning between community and agencies – C2 part 3 'The Visceral Experience' (exchange visits).

STEP 3 Deliver C2 part 2 'Creating an Enabling Neighbourhood Environment' as foundation for successful implementation of HNA findings and desired change.

STEP 2 Undertake CNA, process which consults 'frontliners', actively listens to communities on issues impacting on their health and reviews Public Health data, leading to agreed priorities and resource allocation for improvements.

STEP 1 Establish committed group of 'frontline' community service providers to engage in Connecting Communities (C2) programme part 1 - 'How to do effective Community Needs Assessment' (CNA) in a targeted neighbourhood.

Local Area Coordination

Local Area Coordination is a model which has been in existence in Australia for a number of years[411]. The Local Area Coordinator supports 50 to 65 individuals and their families who live in a defined local area. They provide a local, accessible and single point of contact for people of all ages who may be vulnerable due to age, disability or mental illness. They are the "front end" of the service system. They work by helping people to identify their own vision for a good life and ways to achieve it.

Local Area Coordination (LAC) is an approach that recognises and supports the value of individual gifts, skills and assets, the powerful and positive role of families and relationships and the contribution that local communities can make as alternatives to professional health and social care services. It provides a foundation for helping people to stay strong and to be valued members of their local community.

LAC turns the existing system on its head and drives positive cultural change across the whole system by putting a greater emphasis on:

- Recognising the gifts, assets and contributions of local people
- Building stronger and more inclusive communities
- Promoting citizen and family leadership
- Working with communities to support inclusion and mutual contribution
- Planning for the future, staying resilient and well-connected
- Supporting people to achieve their fundamental aspirations.

This is a fundamental change in both organisation and values. It is based on carefully developed models and practices. It is not achieved by simply renaming existing systems or by organisational restructuring. It is an approach which:

- **Starts at the start** – a Local Area Coordinator, from within their own local community, provides information, advice and support to help people solve their own problems.
- **Asks the right questions** – instead of focusing on deficits the Local Area Coordinator helps people focus on their own vision for a good life, building on their own assets and relationships.
- **Acts as a bridge to community** – the Local Area Coordinator builds real relationships with people, the local community and its multiple resources, spotting and creating new opportunities.
- **Transforms local systems** – the Local Area Coordinator helps people make good use of necessary services and helps to transform the impact of services on local communities.

Local Area Coordination is built on 7 powerful principles:

1. **Citizenship** – with all its responsibilities and opportunities
2. **Relationships** – the importance of personal networks and families
3. **Information** – supporting decision-making

4. **Gifts** – all that individuals, families and communities bring

5. **Expertise** – the knowledge held by people and their families

6. **Leadership** – the right to plan, choose and control your own life and support

7. **Services** – as a back up to natural support.

Building on a real relationship and a real presence within the local community the Local Area Coordinator will:

- help people identify their strengths and capacities to solve their own problems

- provide practical assistance to ensure crises are overcome or avoided

- help ensure people achieve their legitimate entitlements

- support people to maximise their contribution as citizens.

FIG. 4.2.3

| Capacity | Prevention & Practical Support | Entitlement (where needed) | Citizenship | |
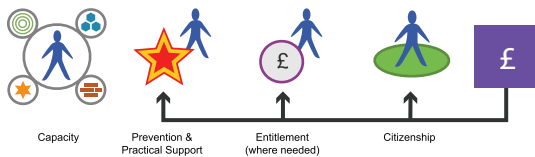
From Broad et al [411]

Combining Personalisation and Community Empowerment (CPCE)

This is a new model currently being piloted in Leeds, Belfast and Sandwell. As the title suggests it is an approach which combines the standard personalised approach to the provision of support from social care, with the capacity and resilience within local communities. This has included establishing 'DERIC', a Social Investment Financial Intermediary (SIFI), to obtain a cornerstone loan of £1.05m from Big Society Capital to fund the initial seven CPCE programmes. In Leeds the aim of CPCE is to further develop and extend existing Neighbourhood Networks, enabling them to become skilled brokers, commissioning services from and for the local community to achieve earlier, less costly interventions supported by an increase in community capacity and social capital (hence CPCE). By working more effectively it is argued that it is possible to release resources in the form of a 'community dividend' that can be shared by the local authority, local communities and local people. Since 2012, a Community Social Worker and a few Neighbourhood Networks have been working to identify potential customers with Fair Access to Care Services (FACS) eligible needs. If they agree, review is conducted to reconfigure their care package and develop a 'life plan' which is delivered combining commissioned professional care together with volunteers ("Community Supporters"), within the local community. The process is indicated in **Fig. 4.2.4**.

An example of how the process works in practice is as follows – Elaine, who is 70 years old, suffers mobility problems and was recently bereaved. She now receives a range of voluntary support, including social activities, regular visits and help with her shopping. As a result of the support from the community she has reduced her home care support package and stopped taking anti-depressants.

FIG. 4.2.4. Local Links, Leeds – Combining Personalisation with Community Empowerment
High Level process, v1
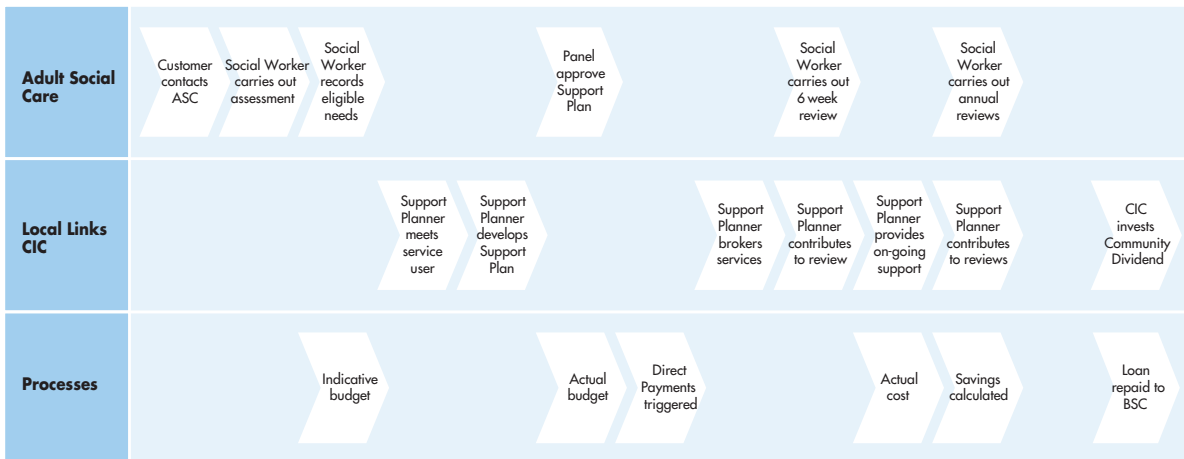
5
SUMMARY AND RECOMMENDATIONS

5.1
OVERVIEW OF COMMON THEMES

This review of transitions in later life has highlighted a number of broad themes which are common across some or all of the individual transitions:

TRANSITIONS

The review of transitions in later life provides a much more dynamic and realistic approach to understanding the lives of older people than traditional approaches which focus on 'age'. A life course approach reflects the way older people experience life. And the conceptualising of life events as 'transitions' encourages people to begin to see these events as emotional processes that they undergo and can emerge from. The processes themselves can be understood in a variety of ways which again can foster an awareness of the different stages that people normally address in their journey (see more below).

NEW NARRATIVE

The huge increases in longevity have made it imperative that a new narrative for later life is developed. The prevalent negativity and short sightedness about this 20 to 30 year span of life needs to be changed significantly. This is particularly true of the issue of 'retirement' (see below). But it goes wider than this. More of all these transitions in later life are likely to be experienced by more people than ever before. And it is doubtful whether the general public are prepared for this. We need a new understanding about the potential for individual growth and happiness and the possible contribution to society that could be achieved. It is particularly important to counter the overwhelmingly negative and fatalistic perceptions about ill health, which as research [412]

shows are not substantiated in real life (i.e. 80% of over 85s, all of whom had one or more long-term health condition, reported that their health was 'good', 'very good', or 'excellent'.)

CHANGING REACTIONS

The impact of many of the transitions cited here is largely determined by how people think about them. And thoughts (especially negative ones) can produce significant harm and distress. There is a need to operationalise the research emanating from the field of psychology that 'thoughts are not facts', and that human beings can change the way they think. There needs to be much more use made of the effective technologies for addressing this i.e. Cognitive Behavioural Therapy and Mindfulness Meditation. As the research cited throughout this review, in most cases it is not what happens to people that matters; it is how they react to life events which is key. Greater attention to psychological reactions across the wider population of older people could ease the impact of most of the transitions reviewed. And this relates very directly to the idea of 'teaching resilience' which the review indicates is a real possibility.

"One of the most significant findings in psychology in the last 20 years is that individuals can choose the way they think"

Martin Seligman, *Authentic Happiness*, 2002

COMPLEXITY

Transitions are seldom experienced in a neat sequential pattern. Later life is messy and transitions will often occur at the same time and/or influence or even trigger each other. This fact ties in very significantly with the point made above about the need for a new narrative about later life. And it needs to draw on the conceptual framework of 'transitions' as that can help people to see their later years as encompassing a number of 'journeys' to be tackled and which most people can survive very well.

EQUALITIES

There is very little data on the experience of various minority groups in relation to the life transitions in later life. There is a growing diversity amongst the current and incoming cohorts of older people that has yet to be reflected in the research. Different cultural contexts are likely to generate different experiences of some or all of the transitions and there is therefore a need for more attention to be paid to these factors.

LONELINESS

It is clear from all the research cited in this review that human beings are primarily social animals. We need other people to achieve and maintain our resilience to the range of life events and transitions. Nearly all the life transitions reviewed here can be a trigger into loneliness. At the same time, many of these risks can be mitigated by strong vibrant communities and through personal resilience. Again, the technologies for modifying and controlling how we think are relevant here (i.e. CBT and Mindfulness).

VARIABILITY

In all the transitions reviewed the evidence indicates that there is significant variation in the adequacy of interventions to support people through a particular transition. Whilst 'localism' may be advocated by Government, few would consider that people should experience significant differences in access to support, based solely on where they live.

PERSONAL GROWTH

Transitions in later life tend to be viewed in a negative light. In other words they are usually associated with loss. This is clearly the case with many of them (e.g. bereavement, acquiring a health condition, etc.), but

even with these examples it is possible to acknowledge the opportunity for personal growth. Many people emerge from their grief wiser and stronger. Many people with long-term conditions also develop personal strengths and insights which would not otherwise have arisen. As with most things in life there are choices to be made about how life events are viewed. It would be possible to frame many if not all the life transitions in later life as opportunities for personal growth. This would require (as part of a new narrative of ageing) a recognition that later life is a journey with many challenges. Dealing with these challenges and reflecting on one's experience has the potential to bring with it much wisdom and satisfaction. As Mary Catherine Bateson [53] notes – "*Experience doesn't make people wise. It is reflection on experience that makes us wise.*"

5.2
KEY GAPS AND OPPORTUNITIES FOR ACTION REGARDING SPECIFIC TRANSITIONS

RETIREMENT

- With ever increasing longevity there is a need for a new narrative about whole concept of 'retirement'. This can not just be ignored, nor can debates on retirement continue to only focus on the negative idea of 'working longer'.

- Negative attitudes towards retirement need to be addressed.

- The transition from 'cliff edge' to 'fluid retirement' is disproportionately available for white collar staff. There needs to be a push to enable this kind of approach to take hold in other parts of the labour market.

- There is a need to address the fact that within the general population there is little awareness of the need, nor understanding of how to, address the emotional dimensions of retirement. Pre-retirement course offers therefore need to become more comprehensive in terms of their content and take up.

- Volunteering and civic engagement support needs to start earlier to enable more people to participate in volunteering prior to leaving the labour market.

MOVING HOME

- There is scope to increase provision of dedicated retirement communities and more attractive general housing for older people.

- The market needs to more closely reflect the pattern of current tenure by older people.

- Care should be taken when considering actions to promote 'downsizing' by older people. Older people should not be expected to solve the wider housing crisis by being expected to move out of their family homes. There are practical and policy reasons for being careful and judicious about this.

- There is a need for more comprehensive housing advice on the full range of options for older people when considering a move. Housing providers have a big potential role to play here and the provision of information and advice should be specifically tailored and targeted at older people.

BECOMING A GRANDPARENT

- The contribution that older people make through their caring for grandchildren needs to be more widely recognised.

- More policy attention is required on the risks to the 'sandwich generation', and within that grandmothers, as older people are encouraged to remain in the labour market for longer.

RELATIONSHIP BREAKDOWN

- There is a need for more public debate about the issue of relationship breakdown in later life.

- There is a need for organisations supporting people through relationship challenges to make specific provision for couples in later life.

- There is a need for more awareness of the potential for relationship challenges arising from early and traditional retirement. Inclusion of relationship issues in "pre-retirement provision" could be one way of addressing this.

- Relationship breakdown needs to be recognised as one of the risk factors for loneliness and needs to be treated as such by those seeking to address loneliness.

BECOMING A CARER

All the issues here refer to the issue of the transition to *becoming* a carer rather than their ongoing support.

- There needs to be much greater recognition of the emotional and psychological impact of becoming a carer. There is very little provision to address this dimension. The focus of public policy has been on the provision of practical support (particularly breaks) for ongoing support.

- Cognitive Behavioural Therapy (CBT) and mindfulness meditation need to be made much more widely available to support people through this transition. How people view and construct their situation makes a huge difference to how they experience it, and the point of transition is a potent window for change.

- Carer education and self care are similarly important early on in the transition.

BEREAVEMENT

- There is a cogent argument for the raising of public awareness about bereavement, how normal the feelings are and what people can expect to feel through the process. There are a number of 'key messages' that could help people experience their grief more positively. A campaign along that of "the five ways to wellbeing" might be justified.

- More needs to be done to counter the risks of loneliness arising from bereavement.

- More needs to be done to effectively assess those people who are likely to require specialist support because of 'complicated grief' reactions.

- There appears to be a need for better coordination between services and to address the variation of provision across the country.

- Many of the multicultural issues surrounding bereavement are not fully understood or acted upon.

- Bereavement support in care homes needs attention

- Good quality bereavement support should be as available to those who do not access specialist palliative care services as to those who do. The class and cultural dimensions of this need to be addressed.

- Any tendency towards medicalising the grief process should be resisted.

- Peer support groups play an important role in this transition and should be supported.

- CBT should be available for all those who experience complicated grief and could benefit from it.

ACQUIRING A HEALTH CONDITION

- Self management strategies should be supported and encouraged to include attention to the emotional and psychological dimensions of acquiring a health condition. Addressing the emotional aspects should not solely be for those people referred to specialist psychology services. This is an area requiring radical change to policy and practice. CBT and mindfulness meditation need to be offered to a much wider group of people acquiring a long-term condition than is currently the case.

- The targeting of support needs to reflect the socioeconomic bias of the prevalence of people acquiring long-term conditions.

- Greater efforts need to be made to ensure that self management truly becomes mainstream practice.

ENTERING INSTITUTIONAL CARE

- Entering a care home is one of the most feared events in later life and should be avoided at all cost. Financial and other policy considerations which result in far larger numbers of older people than younger adults entering institutional care could be challenged, though the financial austerity facing social care will make this exceedingly difficult.

- Alternative models of support should continue to be sought and encouraged.

- Good practice guidelines on facilitating the transition into institutional care require constant and universal application.

- The loneliness that older people can often experience as a result of the transition into institutional care warrants much more attention.

END OF LIFE

- There is a need for much wider consideration by the general public of preparing for their own death if more people are to experience 'a good death'. The development and widespread distribution of guidance on the issues involved is required.

- Concerted action is required to reverse the huge mismatch between where people want to die and where they actually do.

- The issues regarding the legality of "assisted dying" is in urgent need of resolving.

- There is a need for an accompanying public debate about what it means to 'have a good death' in the context of sophisticated medical interventions which can arguably keep people alive longer than is best for them.

- Continual pressure needs to be applied to raise the quality of how mainstream health services address and support people and families during the end of life transition.

- Specialist palliative care services need to be more equitably accessible by people other than those with cancer.

5.3
PRIORITISATION

Given the large number of possible life transitions in later life it is important to find a way of understanding which are more important and in need of policy attention than others.

CRITERIA

In order to do this it is important to be clear about what criteria are used to make this assessment.

From the analysis above it is clear that there are a number of criteria which need to be considered in order to assess importance:

- **Prevalence**
  The number of people who are likely to experience the transition in later life.

- **Breadth of Impact**
  The extent to which the transition will impact on others, including non-older people.

- **Significance of Impact**
  The level of emotional distress likely to be experienced (see Dilts framework – above).

- **Amenability to Intervention**
  The extent to which current or potential interventions could ameliorate the negative outcomes.

- **Controllability**
  The extent to which the transition can be controlled through anticipation and preventative strategies at a personal or community level.

POSSIBLE TRANSITIONS

The most likely transitions in later life include the following:

- Retirement

- Moving home

- Becoming a grandparent

- Relationship breakdown

- Becoming a carer

- Bereavement

- Acquiring a long-term health condition

- Entering a care environment – e.g care home, nursing home, extra care scheme

- Dying and end of life care.

PRIORITISATION

The following matrix presents a way of scoring possible transitions in later life:

High priority	Scores **3**
Medium priority	Scores **2**
Low priority	Scores **1**

	Prevalence (% of 65+)	Breadth	Significance	Amenability	Controllability	TOTAL Score
Retirement	High impact affects nearly 100% of people in later life	Mostly impacts just the person themselves, and their spouse	Big impact on Sense of Purpose, Identity, Behaviour etc	Potential to develop new pre-retirement offer and change the 'narrative'	Very amenable to planning and control	**13**
Moving house	Only impacts on a small number – about 3% of older people	Mostly impacts on the person themselves and their spouse	The main impact is on Environment and a little on Identity	Plenty of scope for improved advice and new market offer	Is mostly in control of individual, though illness can take over	**8**
Grandparent	Affects nearly all >90% of older people	Impacts on individual and spouse and significant impact on children and their families	Main impacts are on Sense of Purpose and Identity and Capabilities	Scope for some policy recognition	Situation is completely out of individual's control and can only be planned for near the point of transition	**8**
Relationship breakdown	Only impacts on a small number – around 2% of older people	Impacts on self and partner. Some possible impact on adult children	Big impact on Identity, Behaviour and Environment	Scope for better provision of support	People have a high degree of control over their relationships – though partners can be unreasonable	**9**
Becoming a carer	Impacts on a reasonable number – about 11.5% of older people	Impacts directly and very importantly on the spouse or parent being cared for	Big impact on nearly all domains	Significant scope for better offer of emotional and psychological support	There is nothing that the person can control or plan for	**12**
Bereavement	Impacts on a significant number – 25% of older people	Impact is largely on the individual	Biggest impact is on Identity, with some impact on Sense of Purpose and Capabilities and Behaviour	There is a significant policy and practice agenda	There is nothing that the person can control or plan for	**10**
Health condition	Affects a very significant number -58% of older people	Can impact on family and friends, particularly if there are caring needs	Big impact on Capabilities and Behaviour	There is significant scope to address the emotional and psychological aspects	Lifestyle and emotional wellbeing can impact on risk of acquiring a health condition – but some illnesses just happen	**13**
Entering Care	Affects a very small number of older people – around 4%	Impact is almost exclusively on the individual	Big impact on Sense of Purpose, Identity, Behaviour and Capabilities	Scope for change is limited by financial austerity and ageist attitudes	Little scope for control, especially where serious illness is a factor. Note class dimension though	**7**
End of life	Potential for 100% of older people to undertake some preparation for end of life. Current picture beyond those with terminal illness is very different	Impact can be very significant for families and friends – through resolving issues and modeling a 'good death'	Big impact on Sense of Purpose and Identity	There is significant scope for policy and practice development	It is possible for everyone to prepare for their own death	**13**

CONCLUSIONS

The above table does not pretend to be a 'scientific' selection process. It does however provide a bit of structure to the consideration of what are the priority transitions where action could make a difference.

From this analysis the key transitions in later life which warrant priority attention for policy and practice development are:

- **Retirement**

- **Becoming a carer**

- **Acquiring a health condition**

- **Preparing for end of life**

- Other transitions worthy of some attention include **relationship breakdown** and **bereavement**.

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The Calouste Gulbenkian Foundation is an international charitable foundation with cultural, educational, social and scientific interests. Based in Lisbon with branches in London and Paris, the Foundation is in a privileged position to support national and transnational work tackling contemporary issues. The purpose of the UK Branch, based in London, is to bring about long-term improvements in wellbeing particularly for the most vulnerable, by creating connections across boundaries (national borders, communities, disciplines and sectors) which deliver social, cultural and environmental value.