



## **Improving later life.**

Vulnerability and resilience in older people.

# We are Age UK

**Age UK works to improve later life** for the **14 million older people in the UK.**

We do this by addressing health inequality, reducing loneliness and isolation, improving retirement incomes and tackling poverty and discrimination against those in later life in all its forms. **We also speak for the long-term interests of every one of us, so that experiences of ageing grow better for each passing generation.**

# **Improving later life.**

## Vulnerability and resilience in older people.

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## Welcome

On behalf of Age UK it's a great pleasure for me to welcome you to this fourth book in our 'Improving Later Life' series. These publications aim to present the latest research findings written by the experts themselves, in an accessible style, to help inform those of us who are older, or who work with or on behalf of older people.

The theme of this book is 'Vulnerability and Resilience'. It is based on the premise that some factors and experiences make us more susceptible to the risk of adverse outcomes in later life, while others help to buoy us up and protect us. Really, you could argue that the overriding aim of all the services that work with older people ought to be to minimise the former and accentuate the latter – this against a context in which it is recognised that older people are an incredibly diverse population.

This kind of thinking is very well embedded in work with children and young people, where there has been a lot of policy and research work done around prevention and early intervention in recent years, and it has a great deal to offer older people too.

There is a lot of interest at present among policymakers in understanding how to help older people to stay as fit, well and independent as possible for as long as possible, and older people say this matters a great deal to them too. An important part of this is working out what helps and hinders in this respect, and this is where thinking about vulnerability and resilience needs to come in.

For example, thanks to research, we know now in a way we didn't a few years ago that experiencing loneliness in older age has serious potential health impacts. Conversely, there is also now good evidence to show that having good social networks as you age can serve to protect you against various health risks. The implication is clear: an effective health promotion strategy for older people ought to include some focus on helping them to sustain and refresh their friendships. This is an important message for Age UK and it underpins the 'No one should have no one' campaign that we have recently launched. It is also helping to motivate our growing interest in services that are effective in supporting older people to make new friends and enjoy shared activities, like choirs, dance classes or volunteering.

Some people are luckier in life than others, with more of the characteristics and experiences that help protect against adversity and fewer of those that make it more likely. However, it is also true that we can all go through periods when we are especially vulnerable; for example, following bereavement. At times like this we need some extra care and support, so the thinking in this book really isn't about 'them' it is about all of 'us' too.

## Key findings

### What are the key aspects of vulnerability in later life?

Even if we disregard the role of chance and accident, there is still a wide variation in the extent to which we may become vulnerable and the age at which this process can start, depending on many factors, including:

- The attitudes held by the individual and by society in general
- An individual's contact with family and friends
- The range and availability of support from others
- The financial resources of the individual
- The suitability of the home and environment
- The extent of neighbourhood and local deprivation
- The individual's education and working history
- The health behaviour of the individual over the life-course

### What can be done to help build resilience in later life?

The authors have many suggestions, including specific ones for different issues, but in general we can all:

- Adopt a holistic view of all kinds of vulnerability in later life as the main focus rather concentrating on parts of the problem or parts of the body
- Make better use of the research evidence to identify problems earlier and to target resources
- Concentrate more on combating the effects of neighbourhood deprivation
- Work towards providing an age-friendly environment
- Facilitate home adaptations, aids and a better range of housing options
- Root out ageism among professionals and society in general



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# Foreword

Dr Eileen Burns

Too often our elders are depicted as either the hero – the old soldier, proudly wearing his medals, the land girls with their old photos – or the victim, the old lady swindled out of her savings, the old man mugged in the street.

In my work and in everyday situations, the report I most often hear from older people about ‘how they feel’ is that they feel the same person now as they did when they were 21 – intrinsically they are that same individual.

The ongoing scientific developments in our understanding of frailty are essential to help health and social care systems understand this reality and to grow the evidence for effective interventions; the recent work of the British Geriatrics Society in conjunction with Age UK and the Royal College of General Practitioners (‘Fit for Frailty’) is an excellent example of this work.

Vulnerability is, however, a much broader issue, encompassing not just those who have physical disability or memory problems (although clearly these can contribute enormously). It includes those factors which we may all recognise as contributing to a time in our own lives when perhaps we may have felt vulnerable: a bereavement, an occasion on which we were without financial resources, a situation when we were alone and knew no-one. Older people may face these challenges more frequently and the impact of a lifetime of exposure to poorer life chances means those older people from less affluent backgrounds are at greatest risk.

If we don't recognise and offer support to older people who are vulnerable, we risk their moving into a situation where their quality of life deteriorates and they and their families experience worse outcomes with consequential costs for the state. Hence this publication, which provides an excellent summary of the available evidence regarding the maintenance of resilience and the avoidance of vulnerability, is both authoritative and timely.

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# Social engagement

## Overview

### Key issues

One of the key issues which faces those working in the field of gerontology as researchers, practitioners and policy makers is how or when do we define an older person as vulnerable and when should we intervene. This is a thorny issue. From the outset, as a researcher, I take my lead from the older people I interview, and from the older people I know in my everyday life – my friends and family and the people I meet in my community.

They are people who are ageing normally, not necessarily successfully, but not poorly either. The majority of the older people I know are not vulnerable. And yet there is an assumption made by governments and by research governance committees, for example, that because someone is over 65 they need special treatment. And that, in turn, implies that, once you're past a certain age, you suddenly lose capabilities and are no longer able to make decisions for yourself or look after your own self-interest. This is not the case; the issues are far more complex, as the chapters in this section clearly show.

Starting first with my own research with widowed people, there is a sense that they are irritated by professionals and policy makers who think they know what is best for older widowed people, for example that all widowed people need help with financial matters, with their emotional experiences of grief, with loneliness. However, widowed older people, as with married and divorced older people, can make decisions about when they need help with their grief and when they do not. They make decisions about whether to go out and make friends or join clubs and they know when the time is right. They avail themselves of the opportunities for social participation and community engagement outlined by Catherine Hennessy and Michael Murray and Katie Wright-Bevans. Older people understand the differences between loneliness and social isolation, as suggested by Christina Victor, and widowed men and women articulate the distinction.





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They utilise the social support, social ties and opportunities for participation and action that are around them; these are discussed in more detail by all of the contributors. The majority of the older people I study (and who I know from my own life) go about their everyday lives in a competent and efficient manner and don't need interventions.

Of course there are older people, as there are younger people, who do need help and who do ask for help in one aspect or another of their lives. There are those too, perhaps a small minority, who would benefit from support or intervention of some kind. They may not know what is available, or how to access the support. There are those people who do not realise that their lives could be improved, their quality of life enhanced, if someone helped them. So the question is, how do we know when to intervene and when to leave well alone?

An important but subtle distinction is also to be made between providing support services (in the broadest sense), or access to those services, and intervening in the lives of older people. As with any life stage, there are times when older people need services or support – access to GPs and health services, financial or legal services, or housing advice, for example. Those services need to be available and easily accessible to everyone. But intervention suggests a more externally directed approach – a professional going in and doing something to the person or for the person, in general with consent, but initiated by the professional. I would argue that, in most cases, although not all, it is the former which is most needed; intervention, on the other hand, may be reserved for the minority.

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**There are those people who do not realise that their lives could be improved.**

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## Vulnerability

Who, then, is vulnerable? My starting point is to ask older people themselves. I would be unlikely to ask older people whether they see themselves as vulnerable because this is a loaded term – nobody likes to think of themselves as vulnerable – but if someone described themselves as vulnerable, one should sit up and take note. It is important to ask people what they need, or indeed what would help people in the same position as themselves. In my own research with widows, and with spousal carers of people with dementia, I always, as a matter of course, ask participants questions about what would have helped them, what advice they would give to others in the same boat and what support local or central government could give them. My experience suggests that, in general, my appraisal of how well they are coping matches their own. In 2009, I found that there were gender differences in the amount of informal and formal support offered to older widowed people: men were offered significantly more support than women. The explanations for this may be three-fold. Older widowers may require more support than women, professionals (and volunteers) believe men need more support than women, because of traditional gender roles, or older women are offered support but do not take it up, again perhaps because of traditional gender roles. It is difficult to know whether one explanation is sufficient but I suspect that it is a combination of the three. Occasionally, there is a mismatch between the perceptions of the researcher or professional person and the older person, and I will return to this shortly. However, most older people, as younger people, know when they need help.

## When to intervene

A key aspect of understanding when to offer support and when to intervene is knowing when to offer help, and when to refrain. It is important to recognise that the time has to be right. An example comes from research on resilience in older widowed men. Most of the men studied were coping well, and almost 40 per cent met criteria for resilience at the point of interview. But it was clear in these retrospective interviews that it had not always been so. The widowers became resilient gradually, or, importantly in this context, following a turning point: the time had to be right for them to become resilient. Help and support offered too early would be ignored, and help offered too late might be too late. The challenge was getting the timing right, but it is important to take the lead from the older people themselves. In the majority of cases the availability of support – social, community, family, professional – was important. Thus, we should be led by older people.

Only in a few cases in the study was intervention necessary. In the most striking case, a widower became resilient after a friend intervened and arranged for him to move house, so saving his life. In this example, the widower knew that he was living his life in a dangerous way. But what happens when older people think they are doing better than others think, or when others think an older person is doing better than the older person thinks? How can we manage the gap between older people's perceptions and those of the professionals, and of family and friends? Who is right, and who is wrong? It is unlikely to be clear-cut.

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**It is important to ask people what they need, or indeed what would help people in the same position as themselves.**

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## Older widowed women find comfort and support from women in the same boat.

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Older widows often spoke of being unhappy about support services brought to them by people who were not widowed. As Michael Murray and Katie Wright-Bevans suggest, community-based interventions that are local and inter-generational are valuable. They do not require older people to go out of their way to get involved, and they do not corral older people together, although older people may choose to be with other older people. Older widowed women find comfort and support from women in the same boat. The social participation suggested by Catherine Hennessy is also important, and interventions and opportunities need to be culturally appropriate, as suggested by Christina Victor.

In our recent research on spousal carers of people with dementia, my colleagues and I found a mismatch between the services and opportunities available to older people and take-up of those services by older people. This raises some questions. First, are the services and opportunities the ones that are needed by spousal carers; that is, do older people not take advantage of them because they don't meet their needs? Second, if the services are useful, how do we work with older people to encourage them to utilise them? Once more, the time needs to be right. There may be times when the burden of spousal care becomes too much, when the carer does not have the time or the energy or the skills to seek help for themselves and their spouse. In these circumstances, professionals and service providers need to be able to intervene, to step in and to act to support the carer and the person with dementia. In these cases, it is important that service providers know that the older people need help, and what help is the most appropriate and acceptable.

## Suite of services, supports and signposting

One of the striking aspects of the community of people in later life is their heterogeneity: older people represent the variations in our society and are shaped by the varieties of their experiences over the life course. So it should come as no surprise that there are great individual differences in the needs, strengths and desires of older people for their later years. An interesting finding from our spousal care study was that spousal carers relied more on, and valued the support of, friends over and above family members. This illustrates that there may be a mismatch between what service providers believe – older people need strong families – and what older people actually need – strong friendships. There is not a one-size-fits-all package of support around social interactions for older people. Instead, there should be a suite of opportunities for older people to access that meets their needs and suits their

personal preferences. As all contributors to this section suggest, there is a need for local, community-based, culturally relevant services and opportunities that are available if and when an older person needs them. Personalisation in support services is becoming more common, especially in the areas of e-health and social and welfare services, and there is no reason why this cannot be extended to the social sphere. It is important that these services and opportunities are clearly signposted, easily accessible and free or inexpensive.

Older people, and their friends and relatives, need to be able to find the services that are suitable for them without having to spend time looking for them when they could be doing other more necessary, worthwhile or enjoyable activities. The final issue is how to know when the time is right to intervene or to offer support; we should be led by older people and those who know them best.

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**As with any life stage**, there are times when older **people need services or support** – access to GPs and health services, financial or legal services, or housing advice, for example.



# Social engagement

## Isolation and loneliness



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### Key messages

- Loneliness and isolation are not a normal part of ageing. They need to be tackled because they have serious negative consequences for physical and mental health in older people. A lack of social ties confers vulnerability.
- It's crucial to recognise that 'isolation' and 'loneliness' are two distinct concepts so that research, policy and practice result in appropriate interventions for each.
- The development of effective interventions also depends on understanding that a complex interplay of factors contributes to isolation and loneliness and that the experience and needs of different groups of older people will vary markedly.

### Introduction

Key to a good quality of life in old age, and other stages of life, are our social relationships and social ties. There is an extensive body of research work, from a range of disciplines, that links good social relationships in later life with a range of positive quality of life measures and health outcomes. Conversely, poor social embeddedness is associated with poor quality of life and a plethora of health outcomes including mortality, physical and mental wellbeing, health behaviours and, potentially, use of health and social care services. When considering the evidence about social ties and health and wellbeing, there is a range of different types of social relationships that are linked with wellbeing and where a lack of these social links confers vulnerability upon the older person. We can broadly differentiate between group-based social links as illustrated by participation in social activities,

and family and friendship networks and inter-personal relationships with specific individuals such as a spouse, children or grandchildren. Vulnerability in later life is experienced by those who lack these social resources in terms of either group-based relationship networks (the socially isolated) or strong inter-personal relationships (the lonely). In this chapter, we focus upon the challenges experienced by these two groups of vulnerable older people.

### **Isolation and loneliness in later life**

One of the key and most enduring stereotypes of old age and later life is that of the lonely and isolated older person. There is almost an expectation that loneliness and isolation are part of 'normal' ageing and are to be expected as we grow older. A number of important consequences flow from our failure to challenge the pervasive nature of this expectation of old age, the most important of which is that we often neglect to situate the experience of loneliness and isolation within a lifecourse perspective. This means that, when we are looking at those who are isolated or lonely in later life, we often do not look to see if these vulnerabilities are recent or lifelong phenomena. It is important to differentiate these two groups as it is likely that the causes, consequences and potential solutions vary between them.

It is common to see the terms isolation and loneliness used interchangeably. However, these are two distinct, but related, concepts that define deficits in group-based social ties and interpersonal relationships respectively. This differentiation is important. A failure to draw these distinctions in research, policy and practice may result in the development of inappropriate and ineffective interventions to combat these vulnerabilities. Social isolation describes the situation whereby an individual lacks engagement with the social world in terms of social participation and/or family/group-based networks, the quality of these social ties is deficient and the individual has only a minimal number of social contacts. Thus, the focus is concerned with the size of older people's social networks and the numbers of contacts an older

person has. Interventions for isolation would therefore focus upon enhancing the number of contacts a person has and the number of links in their social network. Loneliness is focused upon both the quality and/or quantity of the interpersonal social relationships that an older person has. It describes the situation where the aspiration or desire of the older person for social relations in terms of quantity, quality or mode of the interaction (on-line, telephone or in-person), or some combination of these, is not met. Hence, interventions to combat the vulnerability conferred by loneliness would focus upon enhancing the quality of relationships but not necessarily the quantity.

### **How common are isolation and loneliness?**

The essential features that differentiate isolation from loneliness are the lack of engagement with the wider social world and a minimal number of social contacts. These are not, however, mutually exclusive states. It is perfectly possible to be isolated but not lonely and vice versa.

How many older people are lonely and/or isolated? To some degree this depends upon the measures used to collect the data. In terms of loneliness, surveys using self-reported loneliness consistently report that 10 per cent of those aged 65 and over experience significant loneliness. In terms of isolation, there is more variability as many measures include living alone as a measure of isolation. If we exclude this, then approximately 25 per cent of those aged 65 and older may be defined as isolated. Overall, 70 per cent of those aged 65+ are neither lonely nor isolated; six per cent are lonely, 22 per cent are isolated and three per cent experience both.

We have demonstrated that isolation and loneliness in later life are not the norm. However, there are some groups who are more likely to be vulnerable to these states and for whom levels of isolation/loneliness are much higher. For example, we know that widows are more vulnerable to experiencing isolation than the still married or never married. Less well recognised are the links with material resources – the least

wealthy or those from less skilled occupations are more 'at risk' of experiencing isolation than their more privileged peers.

One group that is largely absent from our evidence base about loneliness and isolation are older people from minority communities. We do know that levels of loneliness are double that of the general population for those from African Caribbean, Pakistani and Bangladeshi communities. However, for those from Indian communities, levels of loneliness match the general population. This example serves both to raise the importance of recognising the significance of the ageing of our minority communities and to demonstrate that these populations are not homogeneous.

Thus, whilst our evidence base can broadly define those groups most vulnerable to isolation, we need to remember that the 'risk factors' are not homogeneous.

Furthermore, statistical tools may be able to identify vulnerable groups but they cannot identify specific vulnerable individuals within them. Nor can they tell us why, for example, some widows become lonely and others do not, and our evidence base is much less robust in this area.

## Conclusion

Isolation and loneliness compromise the quality of life of older people. As such, developing interventions and programmes to mitigate them is both humane and central to the current policy agenda that emphasises the importance of wellbeing. However, to date, interventions to combat loneliness and isolation have been largely ineffective. We do know that group-based social interventions seem to work best, and that we need to consider the broader environment, such as making places and activities accessible to all older people with transport. The solutions to loneliness are not just about social provision.

To develop effective services, we need to ensure three key things: first, that we define the objectives of the service (e.g. is it focussed on loneliness or isolation); second, that we develop a deeper understanding of the complex interplay of factors that render older people vulnerable to these states and locate these within a life course perspective; and, third, that our evidence base takes into account the dynamic nature of the older population by including 'new' ageing populations such as those from minority groups.

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Campaign to End Loneliness: [www.campaigntoendloneliness.org/](http://www.campaigntoendloneliness.org/)



There is almost an expectation that **loneliness and isolation are part of 'normal' ageing** and are to be expected as we grow older.



# Social engagement

## Social participation

### Key messages

- Detachment from social participation in older age can have negative impacts on health and wellbeing, including depression, physical and cognitive decline, and increased mortality.
- Many things can cause social detachment, including personal factors – such as loss of a loved one, leaving a job and chronic illness – or environmental constraints.
- Promoting the resilience of older people at risk of social exclusion requires efforts at a variety of levels, including communities, service providers and policy makers, to enable self-help.



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### Introduction

Social participation is recognised as a key component of active ageing, which is characterised by optimal health and wellbeing. Epidemiological studies point to a variety of possible health benefits associated with maintaining social activities in later life. Among these are decreased rates of mortality, reductions in functional decline, depression and risk of cognitive impairment, better self-perceived health and more healthy behaviours. Social participation builds on an individual's social networks – ties with family, friends and others – which may change or diminish with transitions from work, loss of a spouse or the onset of limiting illness. Understanding the factors that affect levels of social engagement in later life is therefore important to identifying ways of bolstering the older individual's stock of social connections and supports.

### What causes social detachment?

Findings from the English Longitudinal Study on Ageing (2002–03 to 2010–11) highlight the risk factors for social detachment – disengagement from participation in a range of societal activities – in 'older age' (defined as age 50 and over in the study). Older

individuals who were poorer, less educated, without a partner, developed a limiting chronic health condition, or lost access to transport were more vulnerable to becoming detached from multiple domains of social participation including civic, leisure and cultural activities. Although the overwhelming majority of older adults remained attached to social networks, men had a higher likelihood of experiencing detachment in later life than did women.

In addition to personal characteristics that may restrict an individual's type and level of social participation, aspects of the social and physical environment can also affect the engagement of older adults living in the community. The social environment, including prevailing cultural norms and values about ageing and age-appropriate behaviours for older people, can constrain their opportunities for participation. Stereotypic media images of older people reflect and reinforce ageist assumptions about older people's capabilities and aspirations, and internalised negative views of ageing can potentially act as a barrier to opportunities for social participation among older individuals. Policies and practices which limit older adults' ability to participate on an equal footing with other age groups in areas such as paid work, learning, and decision-making, or through other age-based eligibility exclusions from services and opportunities, likewise may reduce their possibilities for social engagement.

With ageing, the 'person-environment fit' – or the demands of the environment on an individual's functional capacity – becomes increasingly important for social participation. For example, barriers to access in the built environment such as stairs and the lack of lifts can be powerful deterrents to participation for individuals with mobility problems. The 'walkability' of neighbourhoods, including pavements with even surfaces, perceived safety from crime and accessibility of services and amenities, have also been found to be associated with the level of older people's social participation. Other aspects of the built environment, such as inadequate signage, can pose additional barriers to individuals with special way-finding needs due, for example, to vision problems or dementia.

Other challenges for navigating and participating in daily life in the community include the growing need to interact with technology and machines; this can pose obstacles for those with limitations in sensory, motor or cognitive abilities. The availability and accessibility of public transport, and the existence of community venues and hubs where older people can meet and interact, are also key aspects of infrastructure that facilitate social participation.

## Supporting participation

A range of innovative frameworks and approaches highlight how older people's social participation can be maintained and fostered at the individual, neighbourhood and community levels. Key among these is the World Health Organisation's concept of 'age-friendly' environments and communities that aim to be 'accessible, equitable, inclusive, safe and secure, and supportive' to promote the health, wellbeing and participation of older citizens. Twelve major cities in the United Kingdom (UK) are now members of the UK age-friendly network of cities. Through Age Friendly Leeds, for example, the city has involved key agencies and sectors in working together to improve outcomes for older people through better services, access and infrastructure as well as changing attitudes towards ageing to emphasise its positive aspects and the contributions that older people make to society. Chris Phillipson's chapter in the Resources section discusses this further.

Older citizens are both the beneficiaries of and contributors to the city's age-friendly movement through their role in these activities through Neighbourhood Network Schemes. Drawing on the age-friendly community model, current national policy highlights similar aims and approaches for facilitating the social participation of people with dementia and their family carers through 'dementia-friendly' communities. In all of these schemes, social mobilisation – providing ways and means to build, enable and support older people's connections to social networks in the community and to foster their mutual aid – is highlighted in the role of service providers.

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# Vulnerability to detachment from social participation in older age is a function of multiple factors that can contribute to unnecessary withdrawal from the wider life of the community.

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At the individual level, resources and support for maintaining social participation for those at risk of social detachment and isolation must be enabling, encouraging and enhance the older person's autonomy. A review of evidence on interventions to increase socialisation showed that group-based educational and social activities for specific groups of older people were particularly effective. Positive outcomes have also been found for low-level one-to-one interventions such as telephone befriending in helping users gain confidence and re-engage with community and social activities. The use of the internet for activities to promote social contact among older people is being explored, for example, by Plymouth SeniorNet, which links older residents in sheltered accommodation at risk of social isolation with same age volunteers through a computer club. The project delivers individualised learning programmes to help older people go online to access information, entertainment and specialised services, and to communicate with family and friends. Demonstrated participant benefits include a significant increase in the number of contacts with others, reduction in loneliness and improvement in mental wellbeing.

## Conclusion

Vulnerability to detachment from social participation in older age is a function of multiple factors that can contribute to unnecessary withdrawal from the wider life of the community. Promoting the resilience of older individuals and groups at risk of social exclusion requires efforts at a variety of levels, including assistance and action by communities, service providers and policy makers that enable self-help. An increasing array of good practice examples is pointing the way for how to achieve this.

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Challenges for **navigating and participating** in daily life in the community include the growing need to **interact with technology and machines.**

# Social engagement

## Community



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### Key messages

- Older people can face social isolation in their communities, especially if they feel fear of others or are resistant to change or apprehensive about taking part in new activities.
- Inclusive community projects, especially those that actively engage older people in the design, boost participation.
- Life-affirming approaches that promote ability and talents are more successful than those that focus on deficits, as are interventions that develop a sense of collective agency.
- Intergenerational projects and all-age facilities are also successful ways to promote engagement.

### Introduction

As noted in Christina Victor's chapter, it is well established that loneliness and social isolation contribute to various indicators of morbidity among older people. Contemporary families and local communities are both more diverse and transient, and, as a consequence, many older people experience social isolation from their families and local communities. Fear of others and resistance to change can perpetuate isolation and loneliness in older people.

The challenge is to develop strategies that can better enable older people to become more socially engaged. Community-based strategies have been found to be beneficial in promoting wellbeing, increasing social interaction and promoting greater civic participation. Older people have often been resident of a single neighbourhood for much of their adult lives and have limited contact outside their neighbourhood. This is particularly the case for those from more disadvantaged neighbourhoods. Often they will be apprehensive about participating in a novel local activity. It is for this reason that the character of these activities is crucial.

## What makes community engagement projects successful?

Rather than focussing on individual socially isolated older people, community projects are designed to be inclusive. They may initially attract the more socially active but are designed to draw in others who may be more anxious about participation. It is the non-threatening and life-affirming approach that is most important. Rather than focus on deficits, these projects are designed to promote often forgotten or unexplored talents. An important aspect is the extent of active involvement of the older people themselves in the design of local initiatives. This provides them with a sense of control and ownership, and increases the likelihood that they will continue participation. Another key element is the opportunity to create something of value that can be shared with others. This, again, contributes to a sense of collective agency. Examples of these forms of intervention are community arts, music and gardening activities. What unites these activities is the sense of control that the older people can exert, the fulfilment gained from creating something artistic and the satisfaction of the public display that often accompanies them.

A study of community arts found that older people were excited by the opportunity provided, although they were somewhat apprehensive about being left to run the group themselves. Of central importance is the role of the community facilitator who can work with and inspire the older people. Through participation in these activities, older people can grow in confidence, not only about their creative ability but also about their more general capacity and ability to engage in social interaction.

While older people are often reluctant to venture outside their immediate neighbourhood, evidence suggests that, where they have the opportunity of participating in similar arts projects in other venues, they can also reap benefits. These projects can vary from visiting an art gallery or museum to participating in a reading group in the local library. The work of the Reader Organisation is producing increasing evidence of the benefits of shared reading.

These benefits have been found with different groups ranging from those with dementia to those with chronic pain. These sorts of shared arts intervention have also been found to be beneficial in other settings such as care homes.

## Intergenerational engagement

The apprehension expressed by many older people about participation can be challenged by involvement of younger people in intergenerational projects that are designed to encourage younger and older people to work together on joint endeavours. These have been found to be very beneficial. Projects tend to involve older and younger people working together towards a common goal and can include community arts, story sharing, skills sharing or both groups learning new skills together. The intergenerational element of such community projects aims to increase the confidence of older people through providing opportunities to share their skills, knowledge and life experience with others. Research suggests that, where younger people are learning from older people, older people will feel valued and experience increased confidence. The success of many intergenerational projects is attributed to all participants experiencing mutual benefit. Younger people often gain new skills or learn about local history and older people are given a space to re-affirm their identity and reminisce.

Many intergenerational projects work on an inter-personal basis where one younger person is paired with one older person. Intergenerational life story work or oral history projects are one example in which pairs of participants are common. Projects need not involve large group social participation in order to increase social inclusion. The wider community is commonly involved in projects through the production of a deliverable such as a community mural, play, performance or celebration event. Older people are therefore ideally presented with an opportunity to create and maintain social ties with those beyond the immediate intergenerational relationship, or at least feel confident enough to take other opportunities for social participation.

The stratified nature of social institutions (e.g. schools, youth hostels, retirement villages) reduces the likelihood of everyday intergenerational interactions between older and younger people outside of family members. This gap can be filled by intergenerational community activities, which give older and younger people alike the opportunity to participate in a wider and more diverse social network than they otherwise would.

Logistical difficulties are often encountered in establishing and sustaining intergenerational community action so strong organisational partnerships are required for success. Once established, these links can aid the long term sustainability of intergenerational networks as each partner organisation will have continued access to a 'pool' of older and younger people.

A major challenge facing all of these community projects is access to appropriate facilities and support from community facilitators. Facilities should be accessible and appealing to all ages, rather than being aimed at specific age groups. Organisations and institutions can seek to ensure that their facilities and social environments are all-age friendly in an attempt to move away from the age stratification that hinders intergenerational interactions.

## Conclusion

As we age, the character of our social relationships changes and this may result in social isolation, in turn leading to a variety of health problems, particularly among older people living in disadvantaged communities. We are now moving on from assessment of the problems of ageing in communities to the development of interventions, with a welcome growing body of evidence on the role of community activities in overcoming isolation and supporting active ageing. Well-designed, inclusive, life-affirming activities that give older people a sense of control, fulfilment and value to others serve to reduce isolation and increase confidence. Social inclusion for older people need not, however, be limited to inclusion within older communities. Intergenerational contact can promote inclusion within the wider community but strong organisational partnerships and safe, accessible spaces are required for community projects to flourish.

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It is well established that **loneliness and social isolation** contribute to various indicators of morbidity among older people.

# Resources

## Overview and financial resources

Every individual has a range of resources. Our genetic make-up at birth is an important ‘biological resource’, and the family we are born into and the community in which we grow up will define or determine certain economic and social resources in our early years.



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As we age we acquire and lose resources. Those resources include where we live, what we own, what we have in our bank accounts, what skills we have learned, the support we get from our family and friends, our connections in the community, our access to collectively provided services such as schools and the NHS, and so on. They hugely shape who we are.

In particular, they have a major influence on what might be seen as our ‘vulnerabilities’ – our needs – and our ‘resilience’ to the challenges that life throws at us.

Many older adults find themselves with fewer resources than when they were younger. They may have lost close family members or friends, or be geographically distant from them. They may no longer have earnings from employment, and their income from a pension or state benefits may be rather modest. Their health may have deteriorated, and their ability to forge new links in the local community may be limited by deteriorating physical, sensory or cognitive abilities, or of course by an unhelpful environment. Community resources may be – or may feel – less appropriate given their needs or circumstances, or just be harder to access. These might all be seen by some observers as the inevitability of ageing, although why they should be so easily accepted as ‘inevitable’ surely needs to be questioned.

So what is the problem? And what can be done to alleviate it?

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# Making it easier for older people to continue in paid work if they wish to would help to avoid some poverty.

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## Poverty

The number of older adults living in poverty has fallen over the last two decades, but still remains high: 1.6 million older people currently live on or below the poverty line. Improvements have come about partly as a result of government efforts to improve entitlements for welfare benefits, and to work with other state and third sector bodies to improve take-up. But the fact that so many older people are resource-poor shows that neither policy has been successful. Part of the problem is that many older people do not realise that they are eligible to claim, while many do not want to claim, perhaps because they feel slightly embarrassed or stigmatised.

The underlying issue for many individuals is that their savings and pension income fall a long way short of what they were previously earning from employment, or they may never have had much in the way of income when younger. Making it easier for older people to continue in paid work if they wish to would therefore help to avoid some poverty. Encouraging and supporting people to invest in a good pension scheme earlier in their working lives would also help. But there will always be people whose economic resources in old age are very modest. Collective action through welfare benefits or other means must remain a social priority, hand-in-hand with every effort to make entitlements more widely known, de-stigmatised and claimed. A small research study in Shropshire, evaluating a local Age UK scheme, showed how benefits advice services grant-aided by the local council can be very successful in increasing benefit take-up, and at low cost to the state.

## Debt

Most adults have financial debts. Difficulties generally do not arise when those debts are secured (e.g. mortgage debts secured by property). But unsecured or otherwise problematic debts can be enormously stressful.

Problem debt of this kind may affect only a small number of older people, but the challenges they face can be disproportionate. In particular, debt problems are well known to be a strong risk factor for mental health problems at all ages. Indeed, connections run both ways: people with chronic mental health problems are more likely to run into debt in the first place, and the accumulated impact of that vicious cycle over the lifespan could be devastating.

Attitudes to debt among older people are not always helpful, with a marked reluctance to use credit to meet relatively modest expenses, and thereby head off the bigger longer-term problem. Macroeconomic recession and central government austerity policies do not make things any easier: with council-provided social care less readily available to people with so-called ‘low-level needs’, cuts to other public services and earnings from individual capital (such as savings) dwindling, problem debt could become a growing problem among older people.

Addressing these difficulties requires action on many fronts: working to keep older people out of poverty of course; making it easier for them to get reliable financial advice; and expanding the availability of debt counselling services, which can help in even the most difficult circumstances.

## Housing

Housing is a key resource for many people although it can be a mixed blessing. As Jeremy Porteus discusses later in this volume, it can be either ‘castle or prison’. A house can be a home full of memories, suiting our preferences and adapted to our needs, and often our single most valuable (economic) asset. But as our needs (and preferences) change, it can also become physically more hazardous, or isolating, and the financial resources tied up in it may be hard to release.

Adaptations such as grab rails, better lighting and other home improvements can make important differences; ‘handyperson’ services can also be a good investment. Home care for individuals with personal care needs can make a big difference, and extra care housing is increasingly being discussed as a next-step option for some people. Information and communication technology (ICT) – particularly telecare and telehealth – can support health and social care remotely, although some older people and care professionals still appear reluctant to give up standard services, not least because of the human contact they provide.

## Neighbourhood

In fact, social isolation among older people appears to be growing (as highlighted in the previous section). This is bad enough in its own right if it leads to loneliness, but isolation is also a risk factor for poor health, including depression, cardiovascular problems and cognitive decline. In his article later in this volume, Chris Phillipson discusses the roles that neighbourhoods can play in contributing to the lives of older people, including combatting the negative effects of isolation.

Chris describes the goal of ‘lifetime neighbourhoods’, but for a neighbourhood to be a valuable resource for older people, it needs to be age-friendly, safe, and changeable in the ways that the people who live there want to see. It should not stop people getting to outdoor spaces (green or otherwise). It should have a minimum of physical barriers and the right kinds of facilitator (such as longer time intervals for pedestrians to cross roads). It should have good and accessible community transport, particularly for those older people no longer able to drive or be driven. It should have safe spaces to allow full community participation. And it should support the implementation of community contributions to health and social care support, for at least some of which there is already an established economic as well as social case.

## E-exclusion

One relatively new 'resource' for much of the population is access to ICT for social, commercial, educational and other purposes. Telecare and telehealth come under this heading, but the range of technologies is of course much wider, including the internet, smart phones, tablet computers and digital television. However, as many as 4.8 million people aged 65 or over find themselves 'e-excluded': not able to use ICT. This could be because they have never learned how to do so, or because physical, sensory or cognitive decline makes it impossible given the ways that mainstream ICT devices are configured. It could be an attitudinal issue: seeing the 'new digital order' as something more suitable for 'younger generations'. But in many cases it seems to be a question of real or perceived affordability.

The problem is that ICT is slowly replacing centuries-old conventions and habits: online shopping and banking mean that you no longer need to leave the house to carry out certain core transactions; email and social media allow you to connect with friends and family without actually being in the same location; online games can entertain you as you compete against a computer rather than a human opponent. The potential for isolated older people to gain support through these ICT-based channels is tremendous, but not if you are e-excluded.

Supporting older people to gain the necessary skills to use ICT is obviously one solution, and putting more computers and better WiFi into libraries, day centres and care homes is certainly needed. But the industry also needs to do much more to make ICT devices and services more accessible to older people through age-friendly design and perhaps paying attention to pricing strategies. Given the very rapid pace of technological development and the fact that the big profits are to be made in sales to younger generations, government might need to intervene to encourage such a reorientation.

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**The potential for isolated older people to gain support through these ICT-based channels is tremendous, but not if you are e-excluded.**

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## Final thoughts

As resources ebb and flow over the life-course, so new opportunities but also new vulnerabilities will arise. Much can and needs to be done to ensure that older people are not disadvantaged in either respect: they need access to the same opportunities as anyone else; and their changing personal, social and economic needs require better collective action.

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**1.6 million** older people  
currently live **on or**  
**below the poverty line.**



# Resources

## Homes and housing



**Jeremy Porteus** is director of the Housing LIN (Learning and Improvement Network) and vice-chair of the Housing and Ageing Alliance. He was also secretary to the All Party Parliamentary Group inquiry, Living Well at Home.

### Key messages

- Housing that is not fit for purpose can contribute to vulnerability through increased risk of falls, injury and social isolation, sometimes caused by difficulties with property management and maintenance.
- These problems can be alleviated through home adaptations using assistive technology, and support in enabling social contact.
- Downsizing to more manageable accommodation, either in mainstream housing or various specialist options, offers a way to reduce the risks.
- Specialist housing communities, such as extra care housing or sheltered accommodation, can help reduce social isolation.

### Facts and figures

- Around one-third of all homes are headed by a person over current retirement age.
- By 2033, 59 per cent of households will be headed by someone aged 65 or over, and 21 per cent will be amongst those of 85 years and over.
- 90 per cent of older people live in mainstream housing and 75 per cent are home owners.



## Introduction

At any age, we look to our home as a place of security. As we get older, what we need from our home – and the type of housing that can meet those needs – changes. Housing appropriate to their needs can help older people remain independent and maintain a good quality of life. It is estimated that more than three million people over 65 receive different sources of public funding to help them live well at home. Here we consider the challenges that many older people face if they wish to continue living independently in their own home and the housing options open to them.

## Falls and accidents – prevention

Anyone can have a fall, but older people are more vulnerable to falls than other age groups. Around one in three adults over 65 who live at home will fall at least once a year. Falls may result in broken bones or other injuries and affect self-confidence, limiting independence. They can be prevented by aids such as grab rails and significant adaptations such as walk-in showers – see home improvement agencies (HIA) below. Such factors should be considered in a needs assessment, for example, by an occupational therapist (OT) or HIA case worker.

However, older people can also reduce the risk by practical measures such as good home lighting and fitting a handrail to the stairs. In some cases, an individual's OT assessment might recommend a home hazard assessment.

## Aids, adaptations and home improvement agencies

Some 1.4 million people have a medical condition or disability that requires specifically adapted living accommodation. Research has shown that investment in housing adaptations and equipment would save money by reducing accidents and increasing independence.

Home Improvement Agencies (HIAs) can advise older or disabled people on such works and how to select tradespeople. For a fee, HIAs can also manage the process and supervise the work. They can also advise on council grants and other funding sources that might be available, such as Disabled Facilities Grants or local grant-giving charities. HIAs sometimes also provide 'handyperson' services. Information on the work of HIAs and local contacts is available at: **[www.foundations.uk.com](http://www.foundations.uk.com)**

## Telecare and telehealth

Telehealth can help people with long-term health conditions to remain at home. It involves the electronic exchange of data between an individual and a health care professional.

Telecare has been designed for people with social care needs and involves the remote monitoring of an individual's condition or lifestyle. It aims to manage the risks of independent living. Examples include automatic movement sensors (including opening fridge doors), falls sensors and medication dispensers.

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## **Financial pressures have forced most councils to raise the threshold for free home care to those with the very highest level of need.**

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Perhaps the most developed form of assistive technology, community alarms (also known as personal alarms), often worn as pendants, connect to an operator at a response centre 24 hours a day. The centre contacts the individual's family member, friend or neighbour or, where appropriate, an emergency service.

Some older people can get free alarms from councils or voluntary organisations while others are supplied by commercial organisations.

### **Home care**

Home care, also known as domiciliary care, has helped many people stay in their own home while receiving help with either personal care or about the house. These services are 'preventative': they avoid unnecessary and often costly admission to residential care.

However, financial pressures have forced most councils to raise the threshold for free home care to those with the very highest level of need. Increasingly, older people are either paying a private agency directly or through a council-commissioned arrangement. It is worth checking whether free or subsidised services are available locally through the voluntary sector.

### **A castle or a prison?**

As other chapters discuss, studies show that acute loneliness and social isolation can affect the health, wellbeing and quality of life of older people. A range of interventions has been developed to support older people who feel isolated in their home, including befriending schemes and community navigators. Community Navigators are often local volunteers or voluntary organisations who help older people find their way to activities or services which they would enjoy or find useful.

Specialist housing communities, such as extra care housing or sheltered accommodation, have also been shown to reduce social isolation. In 2009, Lisa Callaghan and colleagues at the University of Kent studied nearly 600 residents of extra care housing. Some 82 per cent described their social life as 'good' or 'as good as it can be' and many had made new friends.

## Staying put or moving?

Many older people prefer to remain living in mixed-age housing and communities. However, other older people might consider downsizing as their family home becomes difficult for them to manage. Others might choose specialist housing due to problems such as mobility, loneliness and the need for care and support.

Specialist sites and phone lines provide valuable information and advice on housing options. These include [www.housingcare.org](http://www.housingcare.org) and FirstStop at [www.firststopcareadvice.org.uk](http://www.firststopcareadvice.org.uk). The latter is also a good source of advice for all issues relating to living well at home.

## Extra care housing

Extra care developments are made up of self-contained homes with design features and services that support self-care and independent living. They provide an option to people whose disabilities, frailty or health needs make ordinary housing unsuitable but who do not need or want to move to a care home. Care and support are available around the clock with packages tailored to the individual's changing needs.

Modern extra care housing is built to high standards of design aimed at meeting the increased aspirations of older people, as well as their specialist needs. People have their own front door but the schemes also have communal facilities.

More information about the design of extra care housing can be sourced on the Housing LIN's 'design hub' at:

[www.housinglin.org.uk/Topics/browse/Design\\_building/Design](http://www.housinglin.org.uk/Topics/browse/Design_building/Design)

## Sheltered housing

To some extent, traditional sheltered housing is increasingly being supplanted by extra care housing. The two forms of housing do differ – not least in the fact that many sheltered housing schemes no longer have a 24 hour staff presence in the form of an on-site warden or scheme manager. This reduction in on-site staffing, historic under-investment and the small size of many units have affected its popularity in recent decades.

A 2013 briefing by the Housing LIN points out that current sheltered housing residents value their homes. Remodelling older schemes could restore their former popularity.

## For professionals working with older people

### Advising older people about their housing choices in later life

The specialist advice service FirstStop offers this online training module for professionals and volunteers working with older people:

**[tinyurl.com/kum3qsp](http://tinyurl.com/kum3qsp)**

### Understanding demand for housing for older people

The Housing LIN (Learning and Improvement Network) has developed a free online analysis to help local councils predict the demand for specialist housing for older people and where to develop. This can be accessed at:

**[www.housinglin.org.uk/Topics/browse/HousingExtraCare/ExtraCareStrategy/SHOP/SHOPAT](http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/ExtraCareStrategy/SHOP/SHOPAT)**

### What older people want

The Housing & Ageing Alliance, a coalition of organisations (including Age UK), has published a useful manifesto which sets out key proposals to ensure all related policies aim to enable older people to live independently where they choose. This can be found at:

**[www.housinglin.org.uk/\\_library/Resources/Housing/HAA/Housing\\_\\_Ageing\\_Alliance\\_Manifesto\\_Sept\\_2014.pdf](http://www.housinglin.org.uk/_library/Resources/Housing/HAA/Housing__Ageing_Alliance_Manifesto_Sept_2014.pdf)**

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As we get older, **what we need from our home** – and the type of housing that can meet those needs – **changes.**

# Resources

## Developing age-friendly neighbourhoods



**Christopher Phillipson** is Director of the Manchester Institute for Collaborative Research on Ageing (MICRA) at the University of Manchester.

### Key messages

- Neighbourhoods have far-reaching influence on the wellbeing of older people who live in them.
- Older people can become vulnerable through a lack of transport, services, facilities, opportunities for social engagement, and fear of crime in their area.
- Neighbourhoods that are ‘old age’ friendly are friendly for all ages, and can realise benefits for communities across environmental, social and economic dimensions.

### Introduction

Age-friendly neighbourhoods are a crucial resource for improving the lives of older people. At least 80 per cent of the time of those aged 70 and over is spent in the home and the surrounding area. As noted in the chapter by Michael Murray and Katie Wright-Bevans, older people are likely to have spent a significant part of their life in their current home and neighbourhood. Supportive communities can be a major asset for improving the quality of daily life but, at the same time, they can contribute to the vulnerabilities associated with old age. The majority of older people live in cities and suburbs and these may be experienced as ‘unfriendly’ for a variety of reasons. Cities have to meet the needs of both long-term residents and those who are highly mobile (e.g. students, young professionals). The two groups may, however, have different degrees of commitment to their localities and contrasting views about how neighbourhoods should develop. The loss of resources such as banks, post offices and corner shops is a serious problem for many communities. Older residents may be particularly vulnerable to these changes – especially people with limited mobility and those who rely on facilities within easy reach. The fear of being a victim of crime may also be an issue, with people feeling unsafe about moving around their neighbourhood at particular times of the day or night.

But urban environments do bring many advantages to older people: cities have a host of resources and facilities vital for improving wellbeing (e.g. museums, libraries, art galleries); they provide access to specialist resources and facilities; and they link people to a wide range of social networks both within and beyond the neighbourhood.

### **Creating age-friendly neighbourhoods**

Recognising the neighbourhood as a valuable resource for all age groups has become a major priority. But the idea of building neighbourhoods for life comes into its own with ageing populations, especially given the need to improve support for those affected by dementia or those with physical disabilities. What kinds of changes are needed to ensure that supportive communities are a reality for older people? A central feature must of course be that residents (of whatever age group) can influence change in the areas in which they live and can participate in decision-making about services and facilities. Planning for 'lifetime neighbourhoods' is now an important goal in social policy, but the key issue will be ensuring that older people have direct influence over those making decisions about the services and facilities that influence the quality of daily life. What issues are likely to be important here? Services relating to health and social care will of course be crucial – and neighbourhoods can play a vital role in the implementation of community-based care. But neighbourhoods play a central role influencing many other aspects of wellbeing in old age.

First, there are clear physical and mental health advantages linked to mobility outside the home and being in outdoor spaces in particular. Neighbourhoods that are designed to make it easy and enjoyable to go outdoors will help people attain recommended levels of physical activity through walking. Access to natural environments and green, open spaces is important in promoting health and wellbeing.

Second, removing barriers to mobility within neighbourhoods is a central issue for those faced with physical or cognitive disabilities. Key to achieving this are: minimizing obstructions that might slow down pedestrian traffic or present a safety hazard; providing road crossings at a greater number of wide or busy junctions; phasing traffic light signals at road crossings to allow pedestrians a longer time to cross; and ensuring that surfaces are non-slip and non-reflective.

Third, transport plays a vital role in maintaining independence and wellbeing, as well as ensuring that communities are connected and services and amenities can be reached. Older people can become very isolated if, for example, the person who acted as their driver has died; or if they are unable to renew their driver's licence; or if they have a disability which prevents them from driving. Neighbourhoods flourish where they are integrated with a transportation network offering a variety of options, including community transport and free dial-a-ride schemes. Other interventions are also important, for example, improving the physical accessibility of buses (low-floor buses and minimum door widths); positioning bus stops at key locations with user-friendly seating; and clear, legible and standardized signage at transport intersections.

Fourth, extending the range of housing options within communities is an important part of an age-friendly approach. To date, progress has been slow in increasing housing choice, beyond specialist provision such as retirement villages and extra-care housing. The reality, however, is that older people will continue to prefer to live in communities with a mix of ages. Interest in a greater variety of housing options (such as co-housing and house-sharing) is likely to grow given the growth of single-person households. Meeting this demand will require a creative partnership between older people, housing associations, building companies and other relevant groups. In many cases, groups of older people will themselves want to take control in developing new types of housing more directly tailored to the needs and aspirations they bring to daily life.

Fifth, creating safe spaces within neighbourhoods is an important part of an age-friendly approach. In some cases, this will draw on existing resources such as libraries, community centres, colleges and sheltered housing schemes. Work is needed to ensure that groups of older people in areas of high economic deprivation have access to spaces that allow full participation within the community. Outreach activities to those in residential homes, befriending schemes for those who are housebound and extending access to educational programmes are crucial areas for expansion within communities.

## Conclusion

Developing social and physical environments that reflect and respond to the needs and aspirations of older people is now a key focus for social and public policy. Policies and programs directed at achieving 'age-friendly' communities have come of age and current best evidence suggests that they require a wide range of interventions. Building on the above recommendations, the following principles for developing age-friendly neighbourhoods might be identified:

- They should provide a mechanism for empowering older people and ensuring social participation in the broadest sense.
- They should seek to preserve social diversity within communities, encouraging a mix of generational groups wherever possible.
- They should promote integration between the physical and social dimensions of the environment.
- They should promote collaboration across a broad range of stakeholders, not least older people themselves.

These principles, hand-in-hand with involving older people and those approaching later life, in setting the agenda, will enable us to realise the benefits that the age-friendly developments have to offer, not only for older people but for wider society across its environmental, social and economic dimensions.

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Urban environments do **bring many advantages to older people**: cities have a host of **resources and facilities** vital for improving wellbeing.



# Health and disability

## Overview

Terms like vulnerability, frailty, physical disability and impairment are frequently associated with a deterioration in health and wellbeing in later life. As the chapters in this section illustrate, this can be associated with a decline in a person's ability to undertake those 'instrumental' activities of daily life (IADL) that revolve around household activities such as cleaning, cooking, shopping and so on, to the ability to undertake those more personal tasks such as washing, bathing and dressing (known as Activities of Daily Living, or ADL) that are so important to maintaining a sense of self, dignity and independence as we grow older.

It can also be related to the greater likelihood of experiencing multiple health problems (co-morbidity), particularly in older old age, each of which can require different methods of treatment and medication (polypharmacy). As the chapter by Alessandro Ble and David Melzer nicely illustrates, this can bring a whole range of different challenges for health professionals, practitioners, service providers and families in

relation to how we diagnose, effectively treat and support vulnerable and disabled older people to achieve the best outcomes and maintain or improve their quality of life.

Of course, just like any other age cohort, health and physical dis/ability will vary hugely across our older populations with some people remaining fit, active and healthy well into their older old age whilst others may experience physically disabling conditions and frailty at a much earlier point in their later lives. Equally, we need to recognise that improvements in health and medicine mean that many people who have lived with disabling conditions throughout their life course are now surviving into old age. One outcome of this is that, while life expectancy is increasing in the UK at the rate of around two years every decade, it often involves people living for many more years with long term conditions and disability as survivors of what were previously life-threatening diseases.

Our ageing population is therefore raising debate about whether increased longevity means living longer but with an increase in chronic health conditions, or whether we will remain healthier in younger old age and experience a compression of morbidity in later old age (i.e. those aged 85+). As James Nazroo's chapter reveals, this is likely to be a particular issue for the least affluent of our older populations. So understanding who is most likely to experience poor and disabling physical health in later life, and why, is important. In part this can be linked to people's lifestyle choices and behaviours. However, this is an overly simplistic view and there is a significant body of evidence that demonstrates how structural influences that affect where people live, their socio-economic circumstances and changes in these



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circumstances over the lifecourse play a significant role in contributing to differential health outcomes between the richest and the poorest older people across the UK. This is particularly true in relation to functional impairment that affects an older person's ability to undertake IADL.

Of course, all of these influences can be seen as inter-related – poor nutrition, obesity, smoking and substance abuse are well proven to be greater amongst the poorest in our society. Combined with lower pensionable income, these factors play an important part in contributing to increased health inequalities in later life, resulting in a greater likelihood that chronic and disabling health conditions will be experienced amongst the poorest of our older populations.

### **Debate around frailty and disability in later life**

What we mean by frailty and disability in relation to health care in later life is also an important question. Increasingly, frailty is being used less as an all-encompassing term for health deterioration and disability arising as a consequence of ageing processes and more as a precise definition for those deemed to be at risk of adverse outcomes due to advancing age. As James Nazroo's chapter notes, there are a number of well-cited studies that have attempted to identify measurable components of frailty that can aid health professionals in their assessment of an individual. The chapter by Peter Gore, Andrew Kingston, and Carol Jagger illustrates how similar scales of measurement have also been developed to measure ADL and IADL amongst older people. These sorts of tools are clearly important in helping health professionals to assess what support or assistance an older person might require.

However, it is worth noting that this type of approach to frailty has also been subject to criticism, in that, by defining it as some sort of disorder or condition that can be measured and observed within particular older people, frailty becomes an 'illness' that requires medical treatment or healthcare support to manage. It is clearly important that older people are supported to manage their daily lives and remain as independent as possible for as long as possible. However, critics have argued that, by placing frailty within a health/medical agenda, we run the risk of overlooking important questions about how those older people who are viewed as 'frail' experience their sense of personal and physical vulnerability. In other words, frailty and vulnerability are not just states that are related to the physical decline of our bodies as we age, but are linked to how the environment around and about us is designed in ways that support or hinder older people.

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# Frailty and vulnerability are not just states that are related to the physical decline of our bodies as we age, but are linked to how the environment around and about us is designed in ways that support or hinder older people.

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They are also related to ageist attitudes that can make older people feel vulnerable in a society that is largely designed around a younger, fitter population and to how aware, supportive and inclusive communities are of their older populations. It has also been suggested that separating frail from non-frail older people can be divisive in that this separation not only becomes a tool for controlling access to resources, but it can act to conceal connections between different groups of older people who may have more in common than they realise.

## Solutions?

The National Institute for Health and Care Excellence (NICE) has made a number of recommendations regarding mid-life changes that can help to reduce the risk of frailty and disabling conditions in later life. These recommendations, aimed at policy-makers, commissioners and practitioners, focus on promoting change in various behaviours and lifestyle patterns such as drinking, smoking, exercise, nutrition and so forth. Early identification of risk and the implementation of preventative solutions are clearly an important strand of any strategy to reduce vulnerability in later life and promote independence. Appropriate interventions may range from the relatively simple (such as health promotion campaigns, the provision of exercise or smoking cessation programmes, housing adaptations or aids to support mobility) to the highly complex,

requiring input from multiple agencies addressing multiple, often cross-cutting needs. Importantly, this requires holistic solutions that require public, private and voluntary sector organisations to work together, and different clinical disciplines to work across traditional boundaries in order to address the often multiple physical and cognitive health problems experienced in later life.

**However, as noted above, any focus on individual behavioural change cannot be taken in isolation from the wider structural issues that need to be addressed and are known to contribute to health inequalities across the lifecourse and in later life.** As

a recent (2014) United Nations report noted, there is a significant mismatch between increasing life expectancy and the development of opportunities to empower older people. Addressing these structural mismatches is an urgent priority for all governments.

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There is a significant mismatch between **increasing life expectancy and the development of opportunities** to empower older people.



# Health and disability

## Frailty

### Key messages

- Frailty is a broad concept reflecting generalised decline in multiple body systems leading to muscle loss, weakness, and loss of mobility and function and that relate to greatly increased vulnerability to adverse events.
- Although we are seeing ongoing improvements in life expectancy, there are suggestions that levels of frailty are not reducing and, for the socioeconomically poorest groups, who have the highest risk of frailty, they may well be increasing.
- There are many approaches to assessing levels of frailty, with increasing focus on developing screening measures that can be used to identify those who are vulnerable and putting in place appropriate interventions.

### What is frailty?

The word frailty brings to mind terms such as delicate, fragile, weak, infirm and even feeble. In both clinical practice and population research, frailty is a key concept that draws on these terms and is used in attempts to understand vulnerability in later life and to identify those who are vulnerable. As the term implies, its use is intended to reflect a more holistic assessment of an individual than a particular diagnostic entity. It is said to relate to a non-specific state that reflects declines in multiple body systems that result in impairments in physical, cognitive and psychological function, with consequent reductions in the ability to complete activities of daily living (ADL). Importantly, this state also relates to future risk of a range of adverse outcomes, such as falls, fractures, hospitalisation, institutionalisation and mortality.



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## How do we identify frailty?

Because frailty is a syndrome, rather than a specific illness or disease, it is not straightforward to diagnose. There is no discrete cluster of symptoms, or biological changes, that define it. In practice, it has often been argued that clinicians know frailty when they see it – they can identify whether someone has moved to a state of not only dependency but also acute vulnerability to adverse events (such as a fall, or infection), and to experiencing consequences from those events that are more severe than would otherwise be expected.

In research settings there are a number of ways of assessing, or identifying, frailty. These fall into two broad approaches. The first are those that assess key components that are theoretically relevant to frailty in order to produce a measure that clearly distinguishes between those who are frail and those who are not. The classic example of this approach was developed by Fried and colleagues, and involves the assessment of muscle loss, weakness, reduced physical performance and tiredness. The second approach simply counts up the number of things wrong with the person (the number of ‘deficits’ they have), covering items such as mobility, ADL, sensory impairments, illnesses/diseases and symptoms. This approach has been developed by Rockwood and colleagues, who argue that the specific deficits counted do not matter, rather what is important is to count a reasonably large number (thirty or more) so that people can be placed reliably on a continuum of frailty. The merits of these two broad approaches can be (and are) hotly debated, but, in research terms, the choice really depends on the nature of the research question.

## How are levels of frailty changing?

One important question is whether we are seeing reductions in levels of frailty alongside the well-documented improvements in life expectancy – the so-called ‘compression of morbidity.’ Recent evidence suggests that this is not the case: at best, at a given age in later life, more recent cohorts have the same levels of frailty as older cohorts. Even more negatively, there is evidence that, for the poorer segments of the population, levels of frailty are increasing. That is, they are higher at a given age for more recent cohorts than for older cohorts. This suggests an expansion, rather than compression, of morbidity for those who are poorer. The implication is that reductions in levels of frailty are not occurring alongside improvements in life expectancy and, for those in lower socioeconomic positions, we might be seeing a contradictory increase in levels of frailty alongside improvements in life expectancy. This is a very worrying phenomenon, and the reasons behind these changes are not clear. They could be a consequence of widening social inequalities, or a reflection of the success of medicine, with those in ill-health living longer than they used to, or they could be a consequence of higher levels of illness as a result of higher levels of risk factors such as obesity.

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**Because frailty is a syndrome, rather than a specific illness or disease, it is not straightforward to diagnose.**

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## How can we respond to frailty?

If frailty can be considered as vulnerability, or loss of resilience, it is worth considering how resilience might be maintained or built. At a biological level, it seems appropriate to focus on maintaining and building physical reserves through exercise and diet, tailored to the individual's abilities and needs. At a clinical level, addressing core illnesses or diseases may have value, although heroic interventions need to be considered on the basis of the individual's capacity to withstand them. At a social level, it is appropriate to put in place resources that allow the frail individual to maintain social connections, networks and rewarding and valued roles, all of which have been shown to contribute to health and wellbeing. However, as these three levels suggest, what is most important is to take a holistic view of the individual's abilities, conditions and context, and put in place supports and interventions that address her or his needs.

Finally, at a population level, we need more careful consideration of both socioeconomic inequalities in the risk of frailty and the possible increases in levels of frailty in more recent cohorts. What are the underlying reasons for these and how might we develop public health policy to respond?

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What is most important is to **take a holistic view** of the individual's abilities, conditions and context, and **put in place supports and interventions** that address her or his needs.



# Health and disability

## Vulnerability in daily activities

### Key messages

- Having difficulty with the daily activities we perform to take care of ourselves (ADL), such as being able to dress and feed ourselves and get to the toilet, are useful markers of vulnerability.
- Earlier markers of potential vulnerability are having difficulty with household activities (IADL), such as shopping, doing the laundry or housework.
- Older people meet difficulty in IADL and ADL in a particular order and this order can help older people and professionals to prepare earlier for vulnerability and weigh up options for interventions.

### Identifying vulnerability

Many older people fear the point when they are restricted in daily activities and can no longer look after themselves. Over fifty years ago, in 1963, Sidney Katz developed an index of ageing containing items that have become known as basic activities of daily living (BADL), or simply ADL. His five activities: feeding, dressing/undressing, bathing or showering, using toilets and transferring from bed to chair, were those which, when not performed, indicated a high dependence on others. Originally another item, continence, was also included but very soon this was seen to fit earlier in the disablement process. Although the Katz index was useful, it could not detect milder, yet still important, levels of disability. So in 1969, Powell Lawton and Elaine Brody developed an additional scale, Instrumental ADL (IADL), focused on the ability to perform household care activities and functioning in the wider society. This IADL index consisted of eight items: cooking, shopping, laundry, housework, using public transport, using the telephone, taking medications and managing money, though subsequent research has found that the two latter items have a cognitive component, tapping a different construct to the other IADL items.

When combined together to measure disability, ADL and IADL are good predictors of outcomes indicating older people's vulnerability, including health service use, admission to residential care and mortality. The majority of research studies of ageing include IADL and ADL, and they are used by professionals assessing older people's long term care needs. In the latter context, an interesting, though underused, scale was developed by combining ADL, IADL, cognitive

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## The average time between having difficulty bathing and difficulty with mobility around the home was three years.

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function and incontinence to produce a measure of need for health and social care, the 'Interval of Need' scale. The lowest level of need (long interval need) would require intervention once per day or less, with help required to go out of doors alone, shop and do light housework or laundry, whilst the highest level (critical) would require 24 hour care due to severe cognitive impairment or the need for help going to the toilet.

### Using and interpreting IADL and ADL information

The wealth of research on ADL and IADL has given us a much clearer idea about how the items operate. Specifically, we know how to ask them to get a true assessment of restriction. More crucially, we know that older people meet difficulty with items in a particular order.

As IADL/ADL items are usually self-reported (rather than through observation), the choice is between asking about performance (do you), ability (can you), or capacity (could you).

Although this seems rather pedantic, studies have clearly shown a gap between what older people think they can do and what they actually do. For disability or vulnerability, we need information on performance (do you...) rather than self-reported ability (can you...), but there may be an argument for collecting both performance and capacity data as discrepancies in these may represent compensations (incapacity yet performance) or reflect gender-specific tasks such as cooking.

The original index had response categories: without aids or help (independent), with aids, only with the help of another person. Later, an extra category of independent with difficulty was added. Difficulty is more a characteristic of the person and less affected by social support and therefore more appropriately indicates disability. Moreover, household structure has, and continues to, change – which means differing availabilities of help.

When Katz first developed his index, he noted that ADL items were lost in a particular order so individuals need help first with bathing, then dressing and finally feeding, and that the order of loss was opposite to the order in which functions are gained in childhood. Many studies have confirmed this ordering but evidence has also accrued for a gradient of severity for IADL and a combined ordering for IADL and ADL items together (IADL generally preceding ADL). Examination of the largest set of IADL and ADL to date



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found that difficulty with activities were met in the following order (from the most to the least difficult): cutting toenails, shopping, using steps, walking 400 yards, heavy housework, bathing, cooking a hot meal, moving around the house, transfer from chair, light housework, toileting, dressing, transfer from bed, washing hands and face, and feeding. The only difference between men and women was that women reported difficulty with heavy housework earlier than men. The first activities lost require manual dexterity and balance (cutting toenails, heavy housework), then long distance mobility and balance (shopping, steps and walking), upper limb control and balance (bathing through to bed) and finally upper limb control (washing hands and face and feeding). Balance is therefore an important component for many of the activities.

It is worth noting that not all older people have high dependency. In the Newcastle 85+ Study, a fifth of people aged 85 could perform all 15 ADL and IADL items without difficulty. Moving through the hierarchy of dependency may also take considerable time. In a population of over 75s in Melton Mowbray, Leicestershire, the average time between having difficulty bathing and difficulty with mobility around the home was three years, followed by, on average, six years before having difficulty with toileting. However, once this point was reached, activities were lost much quicker.

### **Why is the order of loss of activities important?**

Knowing the order in which activities are lost can inform a number of audiences. Older people may be better able to plan for impending dependency or better understand the need to exercise to maintain abilities. Health professionals might use rapidity of loss to trigger fuller medical assessments. The order of IADL/ADL decline provides a new and unique insight into the most appropriate conceptual interventions to deploy at a particular stage and the ideal urgency of response. For instance, someone who has extended the time between early difficulties through various means may now

have reduced amounts of time with higher levels of vulnerability, which in turn makes the decline more rapid in the later stages. When designing and deploying interventions to arrest decline or restore ability (re-able), or compensate for functional loss (equipment/adaptations), the order also provides a framework by which to measure the impact (when benchmarked against average rates of decline). Understanding the order of accumulated decline also helps with the design of interventions that could be suitable for an individual for longer periods by putting a particular IADL/ADL difficulty in context. As we accumulate more evidence on the stakeholder impact (costs/time etc) at different stages, it becomes possible to assess the most effective (and cost effective) interventions, and benchmark these against existing practices.

### **Conclusion**

Mapping interventions onto the order of IADL/ADL decline in terms of re-ablement, compensatory technology and care allows individuals and their families to not just realistically face and plan for increased vulnerability, but also to weigh up the options to potentially shape the individual's journey, to make this the best within the constraints of what they are able/willing to do. This has the potential to provide an evidential framework for early intervention and prevention, and the means to evaluate approaches taken in different areas.

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In the study the only **difference** between men and women was that **women reported difficulty with heavy housework** earlier than men.



# Health and disability

## Multiple health problems and medication

### Key messages

- While many older people remain free from major or limiting multiple long-term health problems, having ‘multimorbidities’ becomes more common as we age.
- Healthy lifestyle, checking and treating abnormally high blood pressure, glucose and cholesterol levels, cancer screening and several other interventions are all likely to reduce the development of specific parts of multimorbidity.
- ‘Polypharmacy’ – being prescribed multiple medications – also increases with age, which increases the risks of drug interactions and difficulty in adhering to treatment regimes.
- People with multiple conditions need a different approach by health, social care and service professionals to the normal focus on single diseases.

### What is multimorbidity?

There is a popular view that having multiple long-term health problems – so called ‘multimorbidity’ – is characteristic of all older people. Although rates of multimorbidity do rise with advancing age, many older people remain free from major or limiting multimorbidities, while some younger people develop this condition earlier in life. Older people with greater multimorbidity burdens are more likely to develop disability, social distress, depression and poor quality of life. Whether or not multimorbidity *per se* brings about greater risk of early mortality is still a matter of debate among researchers.

Fortunately, the majority of both younger and older people can be helped to cope well with multimorbidity and can continue to enjoy a good quality of life. However, meeting the needs of older people with multimorbidity requires a very different approach from that normally offered by health services focussed on single diseases.

### Trends in chronic conditions in older people

The prevalence of multiple chronic conditions has increased over time in the UK in primary care records and this trend is more evident in people aged 85 and older – the so called ‘oldest old’. Our recent analysis of GP electronic records shows that, between 2003 and 2012, the proportion of the oldest old diagnosed with three or more selected major chronic diseases increased from a third to more than half (for those aged 65 to 84, the prevalence increased from a quarter to more than a third). When we considered some of the most prevalent geriatric conditions (i.e. dizziness, incontinence, skin ulcers, falls and fractures) we found that the percentage of the

85 plus year olds with two or more geriatric syndromes increased from 18 per cent to 25 per cent, while there was no significant trend in the 65 to 84 age group. These trends are not fully explained but are likely to be due to a combination of better recording, improved methods of diagnosis, changes in disease definitions, actual increases in incidence of specific conditions, and possibly also over-diagnosis.

Multimorbidity is more common among older people living in the most deprived areas and possibly also more common in women. Socio-economic status is associated with burden of disease, particularly when both physical and mental health disorders are considered together. Moreover, older people living in less affluent neighbourhoods may develop multiple health issues more than a decade earlier than those living in the less deprived areas.

### **The challenges of polypharmacy**

One of the most obvious and yet central implications of being affected by multiple long-term conditions is receiving multiple medications for long periods of time – a phenomenon named ‘polypharmacy’. Polypharmacy is extremely common in older people and shows increases over time similar to those found for multimorbidity, with larger increases in the oldest groups of the population. We recently showed that, in the past decade, the percentage of people aged 85 and over prescribed three or more medicines for long periods of time has increased from 45 per cent to 66 per cent, compared with a change from 38 per cent to 51 per cent in the 65 to 84 age group.

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**Multimorbidity is more common among older people living in the most deprived areas and possibly also more common in women.**

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While polypharmacy may be helpful for treating multiple morbidities, older people taking multiple medicines have higher risks of being harmed by drugs than their younger counterparts because of age-associated physiological and pathological changes. Older people are more likely to develop unintended or untoward drug reactions from single drug substances and from the combination of two or more drugs (drug-drug interactions) as well as from the combination of drugs prescribed and the specific diseases affecting them (drug-disease interactions).

Another phenomenon – known as the ‘prescribing cascade’ – is described in older people. When symptoms of adverse drug reactions are misinterpreted as symptoms of disease, this may lead to inappropriate prescriptions of further drugs, in turn leading to the onset of additional symptoms bringing about additional treatments, and so on.

Finally, the greater the number of medications prescribed, the more challenging it is for people to take all their medicines: adherence to treatment regimens is more difficult.

### **Preventing multimorbidity**

There is currently little evidence-based guidance on how to prevent multimorbidity. However, it is likely that healthy lifestyles, including healthy diets and regular physical activity, are important. The current obesity epidemic in 45 to 74 year olds is a major but avoidable threat to health and disability in later life. Secondly, modifying harmful habits is likely to help, including quitting smoking and limiting alcohol intake. Thirdly, regularly checking blood pressure, blood lipids and glucose levels, whenever appropriate, according to the directions of their GPs, can be important. Finally, participating in the national cancer screening programmes and in vaccination programmes can help. Further research on multimorbidity prevention is needed.

### **Caring for people with multimorbidity**

Multimorbidity poses challenges to the daily work of health care professionals. Clinical guidelines tend to focus on single conditions and are often not applicable in multimorbidity. Optimal treatments might even be contra-indicated because of a patient’s concomitant diseases or medications. Prescribing – a key clinical act – is a major challenge for doctors. The higher the number of medications prescribed to a single patient, the greater the risk of medication errors and inappropriate prescribing. In general, clinical decision-making in older people with multimorbidity is complex, risky and time-consuming.



In order to provide the best care to older people affected by multimorbidity, health care professionals need to move away from the traditional single-disease therapeutic approaches. The approach needed should start with a comprehensive assessment, carefully understanding and noting all the current symptoms, active conditions and treatments. The assessment should include impacts on cognitive and physical functioning as well as on activities of daily living, the patient's emotional status and social support. Problems then need to be prioritised, based on the patient's informed preferences. Current evidence suggests that setting meaningful objectives and targeting specific agreed conditions or functional limitations seems to be more effective than interventions aimed at achieving generalised results. Moreover, periodic medication reviews should be scheduled in order to optimise the patient's treatment, stopping drugs that are no longer indicated, ineffective or duplicates, depending on the patient's clinical, psychological and social condition. Potential drug-drug or drug-disease interactions should be identified. Lab tests should be scheduled to check for potential drug-related effects (e.g. testing thyroid function, anaemia, sodium, etc.). This complex process is time-consuming and longer visits should be scheduled for older people with multimorbidity.

Studies of medication adherence in polypharmacy show that people may have difficulties including several drugs into their everyday routine and may have limited understanding of how to handle the multiple medications. To increase adherence to treatment regimens, some practical tips might be helpful. For example, older people should be encouraged to discuss the purpose and characteristics of their treatments with pharmacists and doctors. Patients deserve clear information on how to use their various medications. Older people should also be encouraged to report any new signs or symptoms occurring after taking a drug, especially the recently prescribed ones.

Continuity of care by the same group of health professionals and agreement on patient-specific multidisciplinary care plans – rather than having multiple professionals treating different diseases in the same patient – can be very helpful in achieving better outcomes, consistent care and accurate clinical monitoring.

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**Older people should also be encouraged to report any new signs or symptoms occurring after taking a drug, especially the recently prescribed ones.**

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## Conclusion

Along with enjoying the benefits of longer and healthier lives, society and health services need to adjust to the challenges of multimorbidity and polypharmacy. More research is needed on multimorbidity in order to increase the evidence on preventive strategies and clinical management. A decisive change in healthcare is also needed towards people participating in setting realistic treatment goals, rather than professionals focussing on treating individual diseases. Healthcare also needs to provide sufficient time, individualised care plans and continuity to allow more effective care of patients with multimorbidity and/or polypharmacy and proper review of their progress.

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The **greater the number of medications prescribed**, the more **challenging** it is for people to take **all their medicines**: adherence to treatment regimens is more difficult.

# Cognitive and mental health

## Overview



**Ian Deary** is Professor of Differential Psychology at the University of Edinburgh, and the Director of the Medical Research Council Centre for Cognitive Ageing and Cognitive Epidemiology.

As a sometime medical doctor and as a psychology researcher studying older people, I have to balance the positive and the negative with regard to ageing. I am aware that, on average, many aspects of the body and the brain are not what they were. The cardiovascular system, and the immune, respiratory, renal and other systems do not function as well, on average, as they did in youth.

When it comes to the brain, some thinking skills also show average declines, for example memory, reasoning, and the speed of making simple decisions. Some mental skills hold up well in older age, such as vocabulary, general knowledge, and some number skills. So, we should prevent our discussion of older age being solely about decline. There are two more reasons for doing so. First, even among the bodily and brain systems that show average decline in older people, some people age faster than others, and some don't decline nearly as much. It would be good to know what characterises those who age relatively well. Second, although health and cognitive skills are important, they are not the whole story when it comes to ageing. Feelings of wellbeing are important too, and they are often high and positive in older people.

If we deal, first, with thinking skills (cognitive abilities) in older age, what do we know about those who have more efficient skills in older age? We know that they tend to be the people who always had more efficient thinking skills, going back to childhood. But that explains only about half of people's differences. There is a large research effort aimed at understanding what explains the remainder. This search covers many possibilities, including, genetics, health, lifestyle etc. What we know is that there are relatively few well-established factors that appear to offer some protection against age-related deterioration in cognitive functions. Not smoking seems to be a good thing, being physically fit and healthy – avoiding cardiovascular disease and diabetes, for example – does too. These are small effects, but they do seem to be detectable. There are some small genetic influences

too, to age-related cognitive changes. When I say they are small effects, I mean that they are unlikely to make a big difference to any one person, but they could be quite important if there was a general population change in them. Some aspects of people's lifestyle – such as whether they engage in social and intellectual activities and some aspects of diet – at first appear to relate to cognitive skills in older age, but on closer inspection actually turn out to be things that are done by people who were brighter originally. Not surprisingly, cognitively fitter people tend to have better-looking brains, with slightly larger brains, more intact brain connections, and less of the accumulated damage that we tend to see with age. Many people ask about the evidence for physical fitness training and the training of mental skills, and whether they help the ageing mind. There are some trials of both of these, and there have been attempts to put the evidence of the various trials together and summarise the evidence. Overall, it looks like both have some limited and positive evidence. But I would say this: **first, there are many good reasons – other than thinking well – to keep physically fit, so one should do that any way; and do, if you like, train your thinking skills, because I can't imagine its doing any harm, but do it in a way that you enjoy.**

The chapters by Marcus Richards and John Starr, respectively, introduce what we call the normal and pathological aspects of cognitive ageing. Normal cognitive ageing is what I discussed above, i.e. what happens to older people who are otherwise well. By pathological ageing,

I mostly mean the dementias, the most common of which is the Alzheimer type which comes on after age 65. Also quite common is so-called vascular dementia, which is more common in people who have had mini-strokes and other problems of the vascular system. The two often co-exist. There are other, less common types of dementia. In between normal cognitive ageing and dementia are states with names like 'mild cognitive impairment'; these try to detect those people who are not doing as well as their healthy age peers, but do not meet the medical criteria for dementia. Sadly, though, this 'mild' cognitive impairment brings with it a higher risk of dementia in the following few years. There is a quite a discussion in academic and medical circles about how and whether we should separate normal cognitive decline from pathological states, or whether we might see them as a continuum. On the one hand, we do see some risk factors shared by people who develop dementia and those who are on the worse end of 'normal' cognitive ageing. Both are more likely to have the e4 version of a gene called Apolipoprotein E, and are more likely to have had illnesses such as Type II diabetes, cardiovascular disease, and delirium. This has led some doctors to recommend people, in middle and older age, to take good care of simple things like controlling their blood pressure, trying hard to avoid diabetes, taking more exercise, and attending to other aspects of healthy living. At the population level, these might make a good difference to cognitive ageing.

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**Although health and cognitive skills are important, they are not the whole story when it comes to ageing. Feelings of wellbeing are important too, and they are often high and positive in older people.**

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I am often asked whether the mental/cognitive tests we apply to people in the laboratory have relevance to everyday life. I think there are three things worth pointing out here. First, a good battery (that's what we call them) of cognitive tests should examine as many important mental skills as possible; there are many, and some might be strong while others have slipped a bit. Second, they do seem to have practical relevance because healthy older people – those who do better on laboratory cognitive tasks – are also better at managing their everyday household affairs. Third, do bear in mind what I said above about there being some mental skills that don't decline much with normal ageing. Furthermore, remember that, when a psychologist or doctor is testing mental skills with a standard test, they are trying to find out how well you can perform at best. In real life, we don't often have to perform at that level; most of the time we can 'cruise' along mentally at the equivalent of 30 mph rather than having to race à la Formula one. Just as our other not-as-good-as-they-once-were parts of the body still tend to prove serviceable in older age, so, also, the brain will mostly do the job we need it to, unless we want to start, in older age, toward being a Nobel-prize-winning physicist or a chess champion.

It is easy to imagine being older, with well-preserved thinking skills, yet lacking mental wellbeing. I can imagine the reverse situation too. Each of those states would have poignancy; being sharp but unsatisfied, versus being blunted but chipper. Higher wellbeing and good cognition share this: they are both associated with living longer, though we don't know why. Despite the changes that age brings – not least its proximity to more-likely-dying – most older people report high states of wellbeing. Dr Catharine Gale discusses the knowns and unknowns of mental wellbeing, and the things that foster it. Regarding the latter, one again finds a parallel with cognition in so far as there are contributions from how-we-used-to-be and how-we-are-right-now. That is, our long-term personality traits, or dispositions, have an influence on feelings of wellbeing. If we have always tended toward lower mood or anxiety compared with our peers,

those dispositions are likely to persist into older age. But life happens to us, and affects our more transient mood states, and those can influence wellbeing too. The trick here is to recognise which things will pass, allowing us to revert to our usual level of serenity, and also to look out for remediable states – such as a depressive illness that can be fixed. And that goes for cognition too: sometimes it may be that a fix-able physical illness is limiting it.

It is worth ending by sharing with you how researchers think about the ageing person in general. We sometimes use the word 'resilient' to discuss the sort of person whose body and mind are robust to life's knocks and can stay on track despite them. There are those who can 'bear the whips and scorns of time,' and whose cognitive skills, physical health, and mental wellbeing bounce back after an illness/accident/stressor/ etc. that would bring down a flimsier frame or disturb a more delicate self. In looking for the secrets of the resilient older person, the scientists are catching up with the idea that has been around probably for as long as older people have: they want to know what it is that contributes to those whom have always been called 'hale and hearty'. That is not to say that we should all be alike, but it would be nice to know why some people's physical frames, computing powers, and positive sense of self age relatively undaunted. If we are not born like them, we hope at least that we can unveil their secrets and copy them.

#### **References and further reading**

There is a good range of useful articles on these websites:

[www.ccace.ed.ac.uk/students-training/review-articles](http://www.ccace.ed.ac.uk/students-training/review-articles)

[www.nia.nih.gov/health/featured/memory-cognitive-health](http://www.nia.nih.gov/health/featured/memory-cognitive-health)

[www.nia.nih.gov/health](http://www.nia.nih.gov/health)



We should **prevent**  
**our discussion** of  
older age being **solely**  
**about decline.**

# Cognitive and mental health

## Cognition

### Key messages

- While some aspects of cognitive function tend to decline with age, not all necessarily do. Many people continue to learn and develop a rich set of cognitive skills into old age.
- The association between the chronic physical diseases of ageing and cognitive decline need to be understood by health professionals and the public alike and a preventive approach taken to maintain cognitive health.
- Our health behaviour is important. There are things people can do at any age to maintain or even improve their cognitive function, such as taking regular exercise, eating a healthy diet and not smoking.

### Introduction

Cognitive function is shaped by factors operating across the whole of the life course, with implications for the accumulation of cognitive reserve and the development of mastery and wisdom. Since cognitive function shows a high degree of stability over time, it follows that influences on cognition at any stage of the life course are capable of indirectly influencing cognitive functioning at subsequent stages.

### The measurement of cognitive function

In children, cognitive function is commonly measured as general ability, often divided into correlated verbal and non-verbal skills. A categorisation more commonly applied in adulthood is crystallised and fluid ability. The former refers to the acquisition and use of knowledge (for example general knowledge and the meaning of words), whereas the latter is concerned with unrehearsed reasoning and problem-solving. Typically, fluid ability declines with age and disease, whereas crystallised ability is generally preserved. In the adult years, other age-sensitive cognitive tests are also administered, for example within the domains of memory, executive function and speed of processing, but we should not overlook 'everyday cognition' such as planning, communicating and managing day-to-day demands and circumstances.





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## Poverty can negatively affect cognitive development, with particular implications for ageing if this becomes prolonged over the life course.

### Origins: genes, foetal growth and childhood

The heritability of general cognitive ability is approximately 30 per cent in early childhood, rising to as much as 80 per cent in older adults. Consistent with this, a large genome-wide association study (GWAS) showed that a substantial proportion of individual difference in general cognitive ability is due to genetic variation. In addition to effects of the DNA sequence, genetic influence also occurs through epigenetic alteration of gene expression during interaction with the environment. Some evidence suggests that this alteration occurs in human neurocognitive disorders.

Birth weight across the full population range, which reflects rate of foetal growth and duration of pregnancy, is associated with cognitive development in childhood, independently of social origins. This association is almost certainly due to common physiological causes, such as endocrine regulation. However, the overall influence is modest, and effects may be substantially confounded by maternal cognitive ability.

A range of maturational and health-related variables are positively associated with cognitive development, including postnatal growth (independently of birth weight), motor development, and exposure to important micronutrients. As with prenatal exposures, however, confounding by maternal cognitive ability is a serious issue. On the more social side, the role of the caregiver is important for cognitive development, since the reciprocal interaction involved helps to provide a 'scaffold' for language structure and function. On the other hand, poverty can negatively affect cognitive development, with particular implications for ageing if this becomes prolonged over the life course. Mechanisms responsible include long-term exposure to sources of stress, physical ill-health, low cognitive stimulation and affection from parents, and poor material environmental conditions. The latter includes neighbourhoods with poor quality of services, control of noxious or hazardous exposures and community responsibility for individuals.

## Use it or lose it? Education, work, and training

Schooling teaches specific knowledge, practical skills for the workplace, refines other cognitive skills, socialises the individual for success, and shapes confidence and motivation. It provides a readily identifiable credential that selects the individual into the workforce. While cognition is an important determinant of educational achievement, education thus is capable of augmenting cognitive skills net of this.

An analogous process occurs at work. Kohn and Schooler's studies show that, while cognitive ability is a determinant of intellectually demanding work, work complexity is also beneficial to cognitive function, as is upward occupational mobility. It follows that loss of work may be a risk factor for accelerated cognitive decline, unless compensatory activities are taken up. This is the disuse or 'use it or lose it' hypothesis, tentatively supported in the context of retirement, although further studies are urgently required now that extending working age has become a policy issue following the global economic downturn and the ageing of the population. The disuse hypothesis is, however, most commonly identified with advice to keep mentally active over the life course, which shows positive associations with cognitive function in later life, independently of education. This raises the controversial issue of cognitive training. There is little question that performance specific to a cognitive training task will improve with practice; less clear is whether there are 'transfer effects' to more general tests of cognitive function.

## Health and health management

Many chronic physical diseases of ageing are associated with cognitive decline, above all those which increase risk of cerebrovascular disease. Thus, awareness of prevention and management possibilities for conditions such as hypertension and Type II diabetes are vital for healthy cognitive ageing. This is an important message both for health professionals and for individuals for their self-management of cognitive as well as physical health. Indeed, low functional health 'literacy' among individuals can be fatal; in a

large population-based study, more than one error in comprehending a fictitious medicine label was associated with a forty per cent increased risk of all-cause mortality. Caution should be exercised since some of these associations between physical diseases and cognitive health operate the other way around as well, i.e. prior cognition predicts risk of the disease; this does not rule out the possibility of a two-way interaction between physical disease and cognition, but does suggest that estimates of the latter may be inflated if such a factor is not controlled.

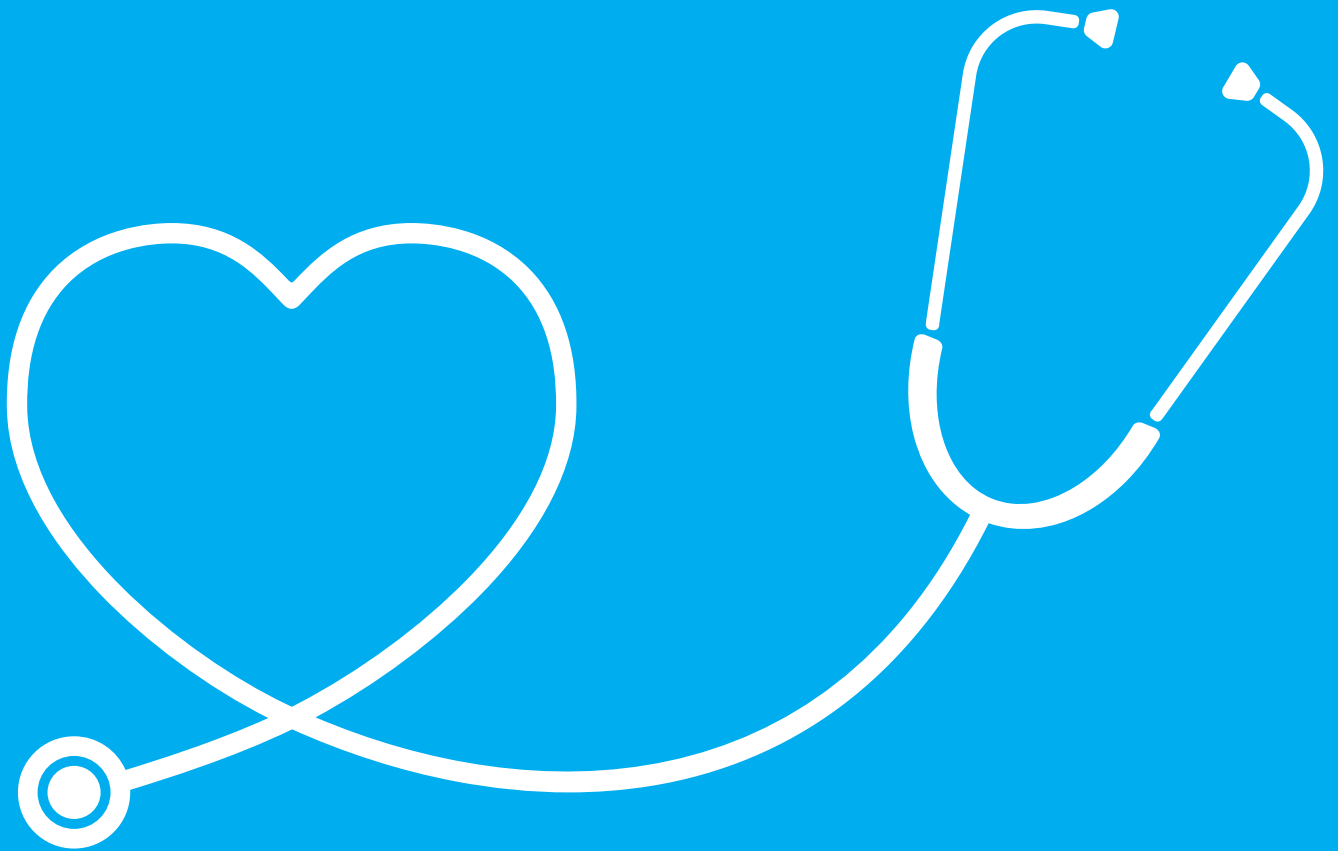
An equally important aspect of health self-management is health-related behaviour; for example physical exercise, light to moderate alcohol consumption and avoidance of smoking are protective of cognitive function in ageing. Biological mechanisms responsible include neurogenesis with exercise, and reduction of inflammation and oxidative stress with alcohol and avoidance of smoking.

## Conclusion

Rowe and Kahn famously listed six myths of ageing, one of which is that 'you can't teach an old dog new tricks'. While age-associated cognitive decline of course occurs, for example in the intentional recall of information bound to time and place, many people continue to learn over the life course, and continue to develop a rich set of cognitive skills. The accumulation of cognitive 'reserve' is an investment, beginning with an endowment (genetic), which can accrue over the life course and can be drawn against in times of emergency (brain disease and injury), although indeed it can also be depleted.

### References and further reading

This material is based on Richards M and Deary IJ. A life course approach to cognitive capability. In: Kuh D, Cooper R, Hardy R, Richards M, Ben-Shlomo Y (Eds.). A life course approach to healthy ageing. Oxford: Oxford University Press, 2014, pp. 32-45.



Many **chronic physical diseases of ageing** are associated with **cognitive decline**, above all those which increase risk of cerebrovascular disease.

# Cognitive and mental health:

## Dementia



**John Starr** is an NHS consultant and Honorary Professor of Health and Ageing at the University of Edinburgh, and Co-Director of the Medical Research Council Centre for Cognitive Ageing and Cognitive Epidemiology.

### Key messages

- Dementia has many causes. Alzheimer's disease is the most common but by no means the only one.
- Determining the cause of dementia is important for planning the right kind of treatment and care.
- Diagnosis enables a wide range of supports to be put in place to enable the person to live well with dementia and retain maximum autonomy.

### What is dementia?

Dementia is a state when changes in the brain cause someone's mental abilities to decline faster than what would normally be expected due to ageing alone AND this decline impacts on that individual's day-to-day life in terms of what she or he is able to do and/or how she or he behaves. There are many causes of dementia but the commonest, accounting for 60 per cent of cases, is Alzheimer's disease. This disease, and others that cause dementia – such as vascular dementia and fronto-temporal dementia – are sometimes known as different types of dementia. Conventionally, dementia is classified into young onset if it starts before the age of 65 years and late onset if it starts at age 65 or over. Although this classification is arbitrary in terms of the underlying causes of dementia, it does have some relevance in terms of the impact of the condition because young onset dementia is more likely to affect the ability to work and look after young children.

### Is it just normal ageing or dementia?

Memory, particularly of recent events, is the mental ability that is most commonly affected by dementia in its early stages. Scores on tests of recent memory also decline with age. However, a hallmark of dementia is that mental abilities other than recent memory are also affected. If there is concern about someone's memory, health professionals often administer a brief test that evaluates recent memory, but also other mental abilities. These tests have normal cut-off values that can be adjusted for someone's

age and education; when people score below these 'normal' cut-offs, more detailed testing of mental ability is often undertaken, together with questions about how the person is managing daily activities and any changes in her or his behaviour to make a diagnosis of dementia. When a diagnosis of dementia is made, doctors will generally order blood tests and some form of brain imaging to determine the cause of the dementia.

### **Why is it important to determine the cause of dementia?**

There are many causes of dementia. It is important to determine the cause because some are potentially reversible (e.g. a build-up of fluid in the brain, which may occur due to head injury or certain diseases, can be reversed by inserting a shunt to relieve this), some are treatable with drugs (e.g. Alzheimer's disease) and some have implications for family members because they are inherited (e.g. Huntington's disease). Moreover, knowing the cause helps to predict the likely course of the dementia and what symptoms to expect in the future because different causes (types of dementia) affect people in very different ways. This advance information can be very helpful to close family and other carers.

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**It is highly likely that all of us will either develop dementia or be involved in the care of someone with dementia: dementia affects us all.**

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### **What happens when someone is diagnosed with dementia?**

Diagnosis facilitates a range of supports being put in place. In Scotland, for example, everybody who receives a diagnosis of dementia is allocated a named key worker who works with a five pillar model of post-diagnostic support:

- Understanding the illness and managing symptoms
- Planning for future decision making
- Planning for future care
- Supporting community connections
- Peer support

How this implemented depends very much upon the person with dementia, their family and the local context. In addition, there are some key actions that will be initiated by the doctor making the diagnosis:

- Asking about driving – informing DVLA and insurance company
- Asking about wills and powers of attorney
- Deciding on specific drug treatment
- Inviting the person to consider participating in research/being on a dementia case register
- Review of general physical and mental health

The overall purpose is to help the person live well with dementia and minimise any impact on her or his autonomy.

### **Am I likely to develop dementia?**

Most people will not develop dementia. However, the incidence of the common causes of dementia increases exponentially with age so that the lifetime risk for any younger person now approaches one-in-three. Given this, it is highly likely that all of us will either develop dementia or be involved in the care of someone with dementia: dementia affects us all. Women are more likely than men to be affected. Some rarer causes of dementia carry substantial familial risk. For Alzheimer's disease, the commonest cause of dementia, first degree relatives are at increased risk if their relative developed the disease before the age of 75. There is evidence that dementia risk accumulates over the life

course, so ensuring a good education and good nutrition in childhood, adopting a healthy lifestyle in adulthood (exercising well and avoiding obesity) and limiting psychological stress are all recommended. There is evidence that the risk of dementia can differ by two–three times depending on where you live, but the reasons for this have not yet been determined.

### **What is new in our understanding of dementia?**

Recent genetic and molecular research has enabled us to classify the causes of some dementing illnesses much more exactly. Previously, it was thought that everyone who had Alzheimer’s disease had an abnormal protein called amyloid deposited in their brains. New scans that light up the amyloid in the brain have shown that a substantial proportion of people with the symptoms of Alzheimer’s disease do not have this protein. On the flip side, post mortem studies show that a fair percentage of people with the changes of Alzheimer’s disease in their brains were free from any symptoms when they were alive. This suggests that resilience to symptoms may be just as important an area to target as resilience to abnormal brain changes. Scientists are also making links between dementing illnesses that affect the frontal and temporal lobes of the brain and a range of other neurological conditions, opening up a whole new area for potential treatment and research.

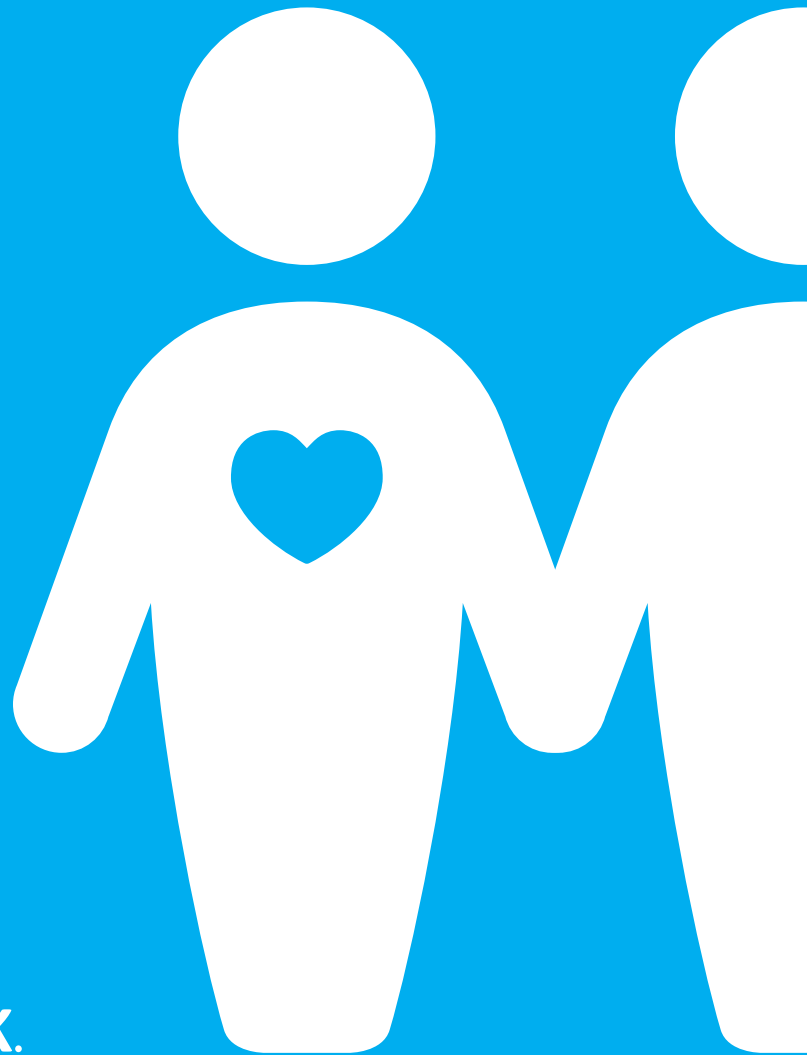
### **Conclusion**

In 2013, there were around 815,000 people with dementia in the UK, only five per cent of whom were under 65. It is likely that there will be over two million people with dementia in the UK by 2051, representing the major challenge to our health and social care systems in the decades ahead. Dementia has just become the commonest cause of death among women in England and Wales. Dementia, then, is something that is likely to touch all our lives.

#### **References and further reading**

See the excellent resource - applicable to the UK - on the Alzheimer Scotland website [www.alzscot.org/information\\_and\\_resources](http://www.alzscot.org/information_and_resources).

In 2013, there were  
around **815,000 people**  
**with dementia in the UK.**



# Cognitive and mental health:

## Mental wellbeing

### Key messages

- Mental wellbeing is important because it affects our health, how we engage with life, how we cope with challenges and how well we age.
- In later life, mental wellbeing is linked to health, recovery from illness and maintaining independence.
- Wellbeing can be improved by actively engaging in pursuits we enjoy, such as social and physical activities, and having valued goals and a positive attitude.

### What is mental wellbeing?

Mental wellbeing describes our mental state. For example, how happy we are feeling, how well we are coping with day-to-day life, how engaged we feel with the world around us, and the extent to which we feel our lives have meaning and purpose. As these examples suggest, mental wellbeing has many dimensions that are inter-linked. So, in general, people who report feeling happier are likely to feel that they are coping well with life, are more socially engaged and have a stronger sense of purpose in life, and vice versa.

Our personalities play a major part in determining our typical emotional tone; in other words, whether we tend to experience or evaluate life as generally positive or generally negative. Some scientists believe that we each have a 'set point' for mental wellbeing – determined in part by genes – and that, although our wellbeing may fluctuate in response to circumstances, we get used to changes in circumstances so any alterations in wellbeing tend to be short-term and we revert to our normal level of happiness. Others believe that individuals differ in how they adapt to changes in circumstances and that 'set points' for mental wellbeing can change.

### How does mental wellbeing change with age?

To be certain how mental wellbeing changes as people get older, we need to question the same individuals about their mental state at intervals over many years. No such very long-term studies have yet been done. However, a few studies have examined the mental wellbeing of the same individuals over periods of eight to 20 years. The researchers found that wellbeing remained, on average, remarkably stable over time in young





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## There is a large body of evidence showing that happier people tend to live longer.

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and middle-aged adults, but tended to start declining once people reached their mid-70s. This is consistent with findings from studies of people re-surveyed at intervals over years that symptoms of depression become more common in later life.

The causes of lower mental wellbeing in older people can be multiple. Widowhood, illness, difficulties in activities of daily life, loss of vision or hearing, and the onset of physical frailty have all been linked with a decline in mental wellbeing. The few studies that have examined whether lower cognitive ability leads to a decline in mental wellbeing have found little evidence for this. Little is known about the potential effect of poorer physical function – such as walking speed or grip strength – on mental wellbeing. One study using data from five cohorts of older people from across the UK found that poorer performance on objective tests of physical function was consistently linked with lower mental wellbeing around 10 years later, though the size of the effect was small.

Living with a partner who has problems with activities of daily living, dementia or physical illness can also have an adverse effect on mental wellbeing. Caregivers of physically disabled people living at home may face high levels of emotional and physical strain, and levels of distress tend to be higher the greater the time spent providing care.

### Significance of mental wellbeing

Maintaining mental wellbeing in the face of the changes and losses of later life may have implications for health. There is a large body of evidence showing that happier people tend to live longer. This link between happiness and longevity is found in adults of all ages but seems to be particularly strong in people over age 65. There is also evidence that happier people tend to recover better from illness. For instance, studies have shown that people who have had a stroke or heart attack tend to make a better recovery in terms of mobility, cognitive status and functional status if they scored higher on measures of mental wellbeing before their illness. However, these links between happiness and longevity or recovery from illness seem to apply primarily to people who were in good health at the time wellbeing was assessed. Most studies of people who

are already in poor health have found that higher mental wellbeing does not seem to be linked to living longer or to recovery from illness.

Older people with higher levels of mental wellbeing may be at an advantage when it comes to maintaining the ability to carry out everyday activities and living independently. There is evidence that individuals with higher mental wellbeing are less likely to develop problems with activities of daily life – such as dressing, walking across a room, bathing, eating or getting in or out of bed – or instrumental activities of daily life – such as shopping for groceries, making telephone calls, taking medication and managing money. Some studies have found that, among those older people who have difficulty with an instrumental activity of daily life, it is those who have higher mental wellbeing who are more likely to recover. People with higher mental wellbeing are also at reduced risk of becoming physically frail in later life.

### Maintaining mental wellbeing

So, is there anything people can do to improve their mental wellbeing? As an individual's wellbeing is partly determined by their 'set point' for happiness and their life circumstances, there has been considerable scientific pessimism as to whether it is possible to bring about sustainable increases in wellbeing. But one important determinant of individual wellbeing that is amenable to change is 'intentional activity' – pursuits that we actively engage in. Regular participation in social activities and involvement with one's community, such as voluntary work or membership of local groups, has been consistently shown in many studies to be associated with high levels of happiness and satisfaction. There is evidence from randomized controlled trials that being more physically active can improve mental wellbeing. Other intentional activities that have been linked to higher individual mental wellbeing in randomized controlled trials include striving towards a valued goal, putting effort into worthwhile activities, looking at the bright side of things or 'counting one's blessings', appreciating and savouring life, and doing acts of kindness.

### Conclusion

Mental wellbeing is highly rated by young and old alike. Getting older can pose particular challenges for maintaining a strong sense of wellbeing. Yet there is also evidence that retaining a high level of mental wellbeing may help us age 'more successfully'. Understanding how older people can be helped to be happier and more fulfilled in later life may have far reaching benefits not only for them but for society.

### References and further reading

- Gale, C.R., Deary, I.J. and Stafford, M. A life course approach to psychological and social wellbeing. In: Kuh, D., Cooper, C., Hardy R, Richards, M. and Ben-Schlomo, Y., eds. A life course approach to healthy ageing. Oxford: Oxford University press, 2013, pp 46–64.
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Getting older can pose particular challenges for maintaining a **strong sense of wellbeing**. Yet there is also evidence that retaining a high level of mental wellbeing may **help us age 'more successfully'**.



# Who Cares?

## Older family carers, their experiences and needs



**Hazel Morbey** is a Research Fellow in the Division of Health Research, Lancaster University.

### Who are older carers?

We hear more and more about the growth of ageing populations, and the subsequent increase in numbers of older people who need support from family carers. We hear less about the needs of older family carers themselves, who also often live with long term, multiple health conditions of their own. With policy drivers that promote support, care and dying in people's homes, many older people co-exist in relationships characterised by complex health and welfare circumstances. In these scenarios, who is 'carer' and who is 'cared-for' often collapses in what are shared relationships of reciprocal, fluctuating caring roles and mutual need.

Carer profiles are changing, with **carers over the age of 65 years the fastest growing carer age group**, and those over 85 years the most likely to provide more than 50 hours of caring per week. This includes care for people with the most intense care needs for enduring and degenerative conditions such as cancer and dementia. A quarter of these carers will themselves be over 75 years. While family care continues to remain the domain of women in mid-age cohorts, of note in an ageing context is the growth in numbers of older male carers, especially of those supporting family members with dementia, and of

older female carers from all ethnic groups, who provide high intensity care (of 20 hours plus a week) for family members in their own and in other households.

Who cares in older age is also a matter of definition, and it is as well to remember that older people in life long relationships do not necessarily self-define as carers. Rather, they are spouses, partners, siblings, sons, daughters, aunts, uncles etc. As such, those who provide care in older age may be less visible, which can result in their needs remaining hidden and unaddressed.

### Experiences of older carers

Older carer characteristics indicate the dual experience of many older family carers as both providers and receivers of care. In this position, older carers are faced with acknowledging and attending to their own health needs while at the same time supporting their family member with theirs. Indeed, at times, the needs of older carers may be greater than those of their family member, or may go unmet if the carer is unable or reluctant to seek support.

Spheres of care are all-encompassing and care tasks can be extensive. Those performed in the home by family carers are increasingly complex and demanding.

**Care can range from the provision of specialist diets, medical treatments and giving medicines and personal care, to operating technical equipment, understanding disease, care, and treatment-specific information, and following health professionals' nursing instructions. In addition, any and varying degrees of emotional support, financial management, arranging and attending appointments, navigating health and social care organisations, and lifting and moving are but a few care tasks carried out by older carers. Many carers will undertake these tasks while living with their own long term health difficulties, which might include painful, life-limiting or degenerative conditions.**

Others again care from a distance, providing a crucial organisation and co-ordination role for family members who live elsewhere; this can involve considerable time, expenditure and paid work/lifestyle compromises.

Many older carers may be new to the role of carer following a sudden or later life decline in the health of their family member. However, as people with learning and physical disabilities live longer, parental care extends to life-long caring for adult children. Conversely, people with disabilities will increasingly offer caring roles for ageing parents, as they themselves age. Similar reciprocal and multiple caring roles are seen when older carers in lower age cohorts provide support and care for grandchildren and parents. This so called 'sandwich generation' may also be in paid employment; a scenario set to increase with the rise in pension age and for those in economic hardship who remain in paid employment for longer.

### **Needs of older carers**

The above list of caring tasks (which is not exhaustive) clearly indicates that the needs of older carers should be viewed as wide-ranging and varied, at times complex and extensive, but also fluctuating according to their family member's, and their own, health-related circumstances. Given this variable nature, it is important to emphasise the key components of support for family carers. These should include timely interventions and multi-sphere assessment that are performed alongside, and which take account of, the cared-for person's health and support circumstances.

## **Older carer needs when they provide end of life care are especially intense.**

Raymond has a primary caring role for his older brother Bill, 73 years of age. Bill has a diagnosis of cancer and attends the local hospice regularly. Raymond has diabetes, a chronic organ disease requiring surgery, and joint problems causing considerable pain, with imminent planned joint replacement surgery. Raymond is prescribed specialised treatment that cannot be obtained from his GP and he travels some distance by taxi to obtain this from a hospital. Raymond experiences sleep problems and feelings of being unable to cope as his own and his brother's health deteriorates. Bill takes a caring role for Raymond during periods of his health improvement.

Blanche, 71, cares for Lily, her sister, 64, who has a diagnosis of two cancer illnesses. Lily has learning and physical disabilities and has received life-long care from Blanche. In addition, Blanche cared for another sister, also diagnosed with a learning disability, until her death some years previously, and both parents who she more recently nursed through terminal illnesses, until their death.

Emotional support is a critical component of older family carer needs. This can underpin all spheres of need, but often emerges as secondary to needs of a practical nature, e.g. gardening, cooking, home maintenance, shopping. Older carers have described valuing friendship models of support, where connection to flexible support services can be maintained over time and are responsive when there is increased need. Family carers' psycho-social-emotional needs are highlighted when we consider the greater number of years they care for family members, who now survive more life years with long term and multiple disease conditions.

Empirical research shows how older male carers can find it particularly difficult to acknowledge emotional aspects of their caring role, and there may be an emphasis on their practical support needs by care practitioners providing services, resulting in a two-fold limited understanding of their needs. In a similar way, we have limited awareness of the specific needs of older family carers from black and Asian minority ethnic households and people in same sex relationships.

Carer research is burgeoning, but a particularly desirable emphasis is for studies that understand carer coping and adaptation strategies, that can account for family carers as both givers and receivers of care, and that promote empowering perspectives of the role.

## Older carers and end of life care

End of life and palliative care health policies increasingly direct the location of these areas of care provision towards home and family. Most people in the UK die from chronic conditions, with two thirds of these people over 75 years. This involves upwards of half a million carers in end of life care and support, many of whom will be older themselves. Older carer needs when they provide end of life care are especially intense. They may be involved in complex medical treatments in their own or relatives' homes, they might manage extensive patient symptoms including distress and pain, they may mediate extended family relations and they can support their dying relative's decisions and wishes. While there is potential for satisfaction and meaning to be realised in this end of life caring role, alongside this is the reality of bearing witness to the decline and death of a close family relative, and adjustment through a bereavement period. The performance of an end of life caring role and undertaking associated care tasks is conducted in the relatively less visible home environment, where older carer needs can go unseen, unrecognised and unmet. Essential to caring in this life phase are accessible support and care services that are appropriately timed, responsive and affordable, and that recognise the dual position of older family carers as potential recipients of care as much as they are valued and valuable care providers.

Alice, 69 years, was primary carer for her husband Arthur of 75, who was diagnosed with cancer and acute heart failure. Alice supported her husband in his decision to discharge himself from hospital as he wanted to die at home. This was a sudden decision and no services were in place on his arrival home or planned for his future care. Alice sat up with him every night as he could not be left unattended. She was exhausted. Support services put in place included the Marie Curie night sitting service, day time volunteer sitting visits, and referral to social services for assessment. Arthur died within a few days of these arrangements having been made.

## Conclusion

The relations of family care in older age are often complex, reciprocal and variable. Older carers and their cared for family members can co-exist in mutual caring relationships, that see older carers inhabiting dual roles whereby they both meet, and have their own, care and support needs. Older people providing care are likely to be experts in their family member's needs, preferences and wishes. They require appropriate and timely assessment, accessible services, and they deserve acknowledgement, understanding and respect.

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**Most people in the UK die from chronic conditions, with two thirds of these people over 75 years.**

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## References and further reading

With thanks to Professor Christine Milligan<sup>1</sup> and Professor Sheila Payne<sup>2,3</sup> for their kind permission to draw on co-authored family carer literature and empirical research:

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# Resilience

There are several definitions of resilience, but it is generally agreed that resilience is the capacity of springing back or rebounding after a negative force or effect. In physics, it describes the power of an object to resume its previous shape after being subject to pressure. It is different from coping, as it can denote getting back up on your feet and even flourishing.



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Researchers into old age have been interested in what factors influence why some people are more resilient than others after taking a hit; why some are quickly back up on the same 'track' as before – or along a different pathway, but 'moving forward' – whereas others never fully recover.

This chapter sums up research on resilience in middle-later life that Age UK has been developing over the past two years.

## What makes up resilience?

Resilience is widely thought to be the result of resources on which people can draw. There have been numerous attempts at measuring resilience – the resilience 'scales' – which combine a diverse list of resources that can be grouped under the following main headings:

- Psychological, financial or health resources ('internal' resources)
- The network of friends and family relations and the available services from private, public and voluntary institutions ('external' resources).

So far, we have described resilience in general. However, personal experiences are never lived through a theoretical vacuum. Unexpected blows may come from different angles and in different guises and strengths, and they may affect people in different aspects of their lives. Therefore it is crucial to define which life events and which outcomes we are interested in. For example, life events such as redundancy or widowhood are unlikely to affect all people in the same way. Regarding outcomes, we may think of bouncing back after a time of withdrawal from social activities or of frequent drinking to dangerous levels.



## Our research

We used data from almost 6,000 people who were between 50 and 64 years old in 2001/02, and followed their data collected until 2011/12, from the English Longitudinal Study of Ageing (ELSA).

We were particularly interested in this age group, the 'future pensioners', who in a recent report we referred to as 'Generation R'; 'R' stands for risk, resilience and readiness for ageing.

The research covered the following life events:

- Widowhood
- Onset (or worsening) of disability, measured using Activities of Daily Living (ADL)
- Retirement

and a number of outcomes:

- Withdrawal from civic participation (anything from neighbour associations to church to volunteering in charitable activities), social participation (attending art groups or classes, a gym, a social club, etc), and cultural participation (going to the cinema, theatre, etc).
- Reduced quality of life, measured as a combination of people's self-perceived control of their lives and environment, freedom and autonomy, fulfilment of potential and pleasure from their lives
- Increased feeling of loneliness
- Reduced use of the internet
- Reduced levels of physical activity
- Not meeting up with friends and family as often as used to

With regard to resources, we concentrated on financial and health resources. Financial resources include income, housing and other assets, and an estimate of the pension 'pot'. We measured health resources by diagnoses of various conditions (high blood pressure, angina, myocardial infarction, congestive heart failure, heart murmur, arrhythmia, stroke, arthritis, high cholesterol, cancer, etc.) and any existing disability.

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# An individual's age seems to be a factor when it comes to bouncing back after reporting feeling lonely, having no control of things, or withdrawing from voluntary activities.

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ELSA does not include many psychological aspects that the literature has identified as associated with resilience. However, it does include questions about agency (feeling that things that happen to the respondent are out of their control, for example), meaningfulness of life, and orientation toward novelty (like choosing to do things never done before). We created an index of psychological resources with these items which we included in the analysis.

Given that we looked into the same people over 10 years, the study sheds light on which resources act as a protective shield, preventing bad outcomes when stressful life events occur, and which resources are associated with resilience – that is, if the bad outcomes do happen, which resources help people to bounce back.

## What we found

From our results, what we think happens is this: a negative life event occurs, which can cause one or more negative outcomes in a person (such as depression, disengagement from activities, etc). Some resources may help to lessen negative outcomes, or even allow a person to avoid them altogether. However, if a person does experience negative outcomes, then resilience is the ability to recover from them.

Financial and health resources protect people from bad outcomes in the event of widowhood, redundancy or disability. Of course, more resources cannot prevent these negative events, but we found that the better the health and the more financial resources people have, the lower the negative outcomes of these events.

For example, widowhood makes people feel lonelier and reduces the feeling of control, self-realisation and pleasure, but higher financial resources and better health counteract these negative effects over time.

Similarly, we found that retirement is associated with reduced use of the internet and physical activity of individuals with low financial and health resources. And the onset of disability or an increase in the number of difficulties with ADL or IADL are associated with:

- Reduced social and cultural engagement
- Reduced quality of life across its four domains
- Reduced use of the internet or email
- Reduced physical activity
- Reduced frequency of social interactions with friends and relatives.

All these adverse outcomes are much reduced or even completely offset if financial and health resources are high.

So, financial and health resources appear to have good protective value: good, but not perfect. Regardless of financial resources or the absence of any diagnosed medical conditions, some people do exhibit the negative results of stressful life events. However, they do not make people more resilient to any of the events in any of the outcomes we studied.

An individual's age seems to be a factor when it comes to bouncing back after reporting feeling lonely, having no control of things, or withdrawing from voluntary activities. Within the 50–64 year-olds in the study, older respondents were less likely than younger people to go back to the place where they used to be before losing their partner, being made redundant, or retiring.

Furthermore, psychological resources and education also play a role: higher scores in our index of psychological resources and higher levels of education are associated with higher resilience to loneliness and also with withdrawal from engaging in voluntary activities.

We do not know what the future may hold for people approaching retirement, but we know that some will face the loss of their partners or their jobs. Furthermore, most will retire from paid employment at some point, with all the potentially challenging life changes this could bring about. We know that people react differently to these life events – some are badly affected for years if not the rest of their lives, whereas other people bounce back.

Our analysis lets us conclude that sound financial and health resources in middle-age are good protectors against the negative outcomes from these stressful events. They cannot prevent things from happening, but they can preclude or reduce the negative effects.

However, if loneliness, lack of control, withdrawal from civic, social or cultural activities, or other negative results become a reality, then getting back on your feet is not a question of finances and health. Financial and health resources are good for preventing negative consequences, but not good predictors of resilience.

#### **References and further reading**

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# Commentary

For some considerable time, Age UK has been concerned about the increasing numbers of older people who are living longer and experiencing increasing vulnerability. Indeed, one of our previous volumes – *Improving Later Life: Understanding the oldest old* – highlighted the corollary of exceptional longevity, namely the transition into vulnerability. But where there is vulnerability, we may expect to find resilience. And so we have presented in this volume a valuable collection of papers written by a range of authors, all authorities in their own field, who have given us precious insights into the two sides of the ageing coin.

We have attempted to crystallise the issues into four broad areas, each of individual significance but all of them interdependent. We defined these areas as social engagement, resources, care-giving, and physical and mental health.

## Social Engagement

Kate Bennett opens her section with an approach analogous to that of the medical world: Osler's dictum, which may be paraphrased as, 'listen to your patients, they are telling you the diagnosis'. By the same token, by listening to older people, much unnecessary and inappropriate interference might be avoided: 'most older people, as younger people, know when they need help'. Equally, we need to refute the assumption that chronological age is the sole criterion for intervention. Growing older is never a simple process, there being large inter-individual differences – and this generalisation applies no less to vulnerability.

The recent plethora of evidence about the grave disadvantages for older people of experiencing social isolation and loneliness is salutary. The consequences have been described as more harmful than smoking, obesity and alcoholism. More importantly, they are wholly avoidable, a message that needs to be reinforced to those who are cutting the resources available for supporting marginalised and hard to reach older people.



**James Goodwin** is Head of the Research Department at Age UK, and a Visiting Professor at Loughborough University.

An equally important message, from Michael Murray and Katie Wright-Bevans, is that the provision of services should enable older people to improve, wherever possible, the extent to which they can maintain their independence and social participation.

## Resources

As Martin Knapp points out, it is important to question the assumption that resources – and resourcefulness – decline with age. Partly as a result of our success in removing the default retirement age, there are now over one million people aged over 65 who are still in employment, simultaneously enabling many older people to maintain their social connections and income, and to reduce debt.

Increasingly, the provision of services is being devolved to the internet, which serves to marginalise the 4.8 million older people who are ‘off-line’. They are also put at a considerable disadvantage in financial terms and through distancing from friends, relatives and family who have moved away.

The challenges of maintaining many older people in their own homes are now critical as the employment of a new model of integrating health and social care takes hold. The Department of Health’s policy is to move the focus away from large tertiary care centres (hospitals) towards the GP and community care. Age UK recognises the need for the adaptation of homes, for integrated care in the community and for the use of technologies which can enable better health care at home. Many local Age UKs now provide ‘home support’ services, some built in to our new integrated care models that are being piloted in several areas of England.

The environment outside the home is of equal importance in enabling older people living in their homes to take advantage of neighbourhood resources available to them – and to reduce their vulnerability through fear of crime, lack of access to transport and opportunities for social engagement. The Age Friendly global movement (of which Age UK was a founding partner) has been instrumental in compelling local authorities to address these issues. Further, there is now an incontrovertible and compelling evidence base for the importance of good urban design in supporting ageing in the community.

## Health

We are now recognising the inescapable and exponential relationship between increasing longevity and the risk of ill-health. This relationship is evidenced by the increasing number of diagnosed medical conditions with age (co-morbidity) and the continued ‘over-medicalisation’ of older people (poly-pharmacy) – the reduction of which, fortunately, is currently under trial in a number of major research projects. The mean number of medically diagnosed conditions for those over 85 is now five and the median number of prescriptions eight.

Yet it is arguable that older people in such circumstances may paradoxically be regarded as ‘well’, if their conditions are managed in such a way that they are symptom-free and able to manage activities of daily living independently. It is therefore unsurprising that measures of ADLs and IADLs are good predictors of outcomes indicating older people’s vulnerability. However, both James Nazroo and Christine Milligan remind us that the older population is quite heterogeneous, and that the trajectory of health in life is greatly influenced by a complex array of personal, lifestyle and environmental issues, including socio-economic

disadvantage. The subtle ways by which the environment influences the experience of ill-health must surely curb the temptation to view both frailty and disability as simply medical conditions.

At this point it is worth revisiting the idea of 'risk reduction'. The preventative agenda is attracting increasing attention, as governments seek to ease the pressures on the provision of health and social care. We see this attention especially in intractable areas like dementia, where risk reduction (as opposed to prevention) is now much more highly emphasised, though there is a need for more evidence-based guidance.

## **Cognitive and Mental Health**

Of all the areas which challenge us in later life, changes in our cognitive health must rank among the highest. Huge momentum has been generated by the G7 Dementia Summit, held in London in 2013, from which an international programme of funded research and a considerable increase in public interest are developing. Age UK has played a central role in developing the issue of life-long cognitive health as a distinct paradigm by which to understand and deal with the pathologies of older age.

Undoubtedly, general interest has been propelled by the reported widespread fear of cognitive decline and dementia, plus, for governments, the huge current and projected costs of providing for dementia care. But before I make some observations on where progress in dementia and cognitive decline is likely to be made, it must be pointed out, in company with our authors, that most people as they age will not become incapacitated by either condition. Having said that, maintaining mental wellbeing in a wider sense is absolutely a priority, as the influence of mental wellbeing on longevity and physical health is indisputable, though not yet widely appreciated.

In spite of what must look like a heavy dose of pessimism, there is likely to be, in the next five to 10 years, considerable improvement in the way in which cognitive decline and dementia are prevented or slowed down, diagnosed and treated. One emerging theme presented in this volume is the requirement to understand more about cognitive decline across the life-course and the associated modifying risk factors. The reduction of risk will be a highly productive area of communication. We will undoubtedly see the issue of brain ageing break into the public consciousness, in the same way that cardiovascular health has permeated everyday understanding over the last 20 years or so. Such a transition will be of immense benefit to public health. It is an area in which Age UK is fully engaged.

## **Care**

Whenever I hear the press and media stigmatising older people for the burden they place on society, I am reminded of the almost half a million older people who provide full time unpaid care for a member of their family, and also of the comment made by a carer on the Department of Health Dementia Programme Board who said (I paraphrase): 'Whenever dementia is diagnosed there are in fact two diagnoses: one, you have dementia; and two, you are now a dementia carer'. This sentiment puts into context the estimated figure of 815,000 dementia sufferers in the United Kingdom – and also the four million older people who suffer from chronic long term illness.

## **Resilience**

Resilience is a complex and controversial concept, interpreted so differently by many observers. But, if loneliness, lack of control, withdrawal from civic, social or cultural activities, or other negativities become a reality, then 'getting back on your feet' is not merely a question of finances and health. To put it another way, though financial and health resources may protect against the negative consequences of adverse events, they are not good predictors of resilience.

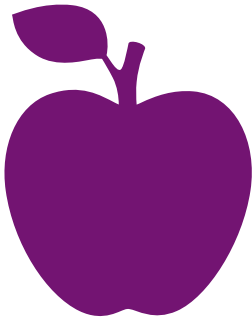
If we are to generate improved resilience amongst 'tomorrow's pensioners', then we have a long journey ahead, building up their health and financial resources, providing help and support, and generating opportunities for personal and collective improvement. It is a difficult enterprise on which we embark: today's older people and tomorrow's pensioners are equally deserving of our attention.

## **Conclusion**

The rapid advance of today's message of healthy and active ageing has to be tempered by what research now reveals about vulnerability: what it is, what are the predisposing conditions, how we can slow down its trajectory and how we can mitigate its effects. As the older population grows, particularly the oldest old, these are increasingly important issues. At Age UK we are in the fortunate position of working closely with our research colleagues in many disciplines and, as a result, are more widely informed than most. We can deliver the messages derived from their research to decision-makers and practitioners, so that the lives of older people are transformed and continue to be transformed, for the ultimate betterment of society. This is what I consider to be the real meaning of research impact.

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