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.
Understanding the oldest old.
Welcome to *Understanding the oldest old*.

In the course of our work with people in later life, we at Age UK have become increasingly aware of the importance of the group often called the ‘oldest old’, those in their mid-80s upwards. We have also found that not only is there a need for more research on this growing section of society, there is also a need for a clear summary of the evidence.

What was formerly a small number of exceptional individuals is rapidly becoming a whole new generation for families in this country, a ‘fourth generation’.

Often people talk about the ‘older population’ (aged 65 and over) as a homogeneous group. However, through our research, our contact with leading experts, and our engagement with older people, it has become apparent to Age UK that we all need to know more about people at the upper end, the ‘oldest old’.

We are concerned that all of us who make decisions concerning the welfare of this group need help to identify and understand the growing body of evidence about them. The aim of this publication is to present messages about what we need to know and do, based on research, to professional audiences, such as civil servants, national and local politicians, doctors, nurses, carers and care workers, care home managers, charities… the list could go on.

In addition to this book, we have dedicated part of our website to this issue, with in-depth materials, downloadable copies of this book and individual chapters, diaries from people talking about what their lives are like at this age, and more. We trust that you find our presentation of the evidence useful.

*M. Mitchell*

**Michelle Mitchell**
Charity Director General, Age UK
Among the messages emerging from the research conducted by the leading experts contributing to this book, several key points have emerged that all professionals making decisions about the oldest old should know.

**One**
Life is not over once you hit 85. In fact, most people over this age are rather independent, feel that their health is good, enjoy a good quality of life, and have more than a few years of life left.

**Two**
People get more diverse the older they get.

**Three**
Assumptions based on the younger old can be totally inappropriate for the oldest old.

**Four**
No matter what chronological age a person is, it is still worth treating health problems.

**Five**
Even the very old and frail need to get up and moving. There is never an age where it's best to sit and rest all the time!

**Six**
The social interaction needs we all have continue to be as important, if not more so, when we get to be very old.

**Seven**
Loneliness and isolation tends to increase the older we get, as we lose social networks, friends, and mobility. Even those surrounded by others, such as in a care home, can feel lonely; people may need to be supported and encouraged to participate and engage.

**Eight**
People still want to be involved in decisions about their lives, no matter how old they are.

**Nine**
Not enough is known about people in the fourth generation. More research is needed.
Contents

8 Foreword
    John Beard

9 Introduction
    Tom Kirkwood

10 Abandon preconceptions about the oldest old
    Alan Walker

12 Ignore age and look at the person
    Finbarr Martin

16 Rethink old age
    Rudi Westendorp

18 Learn from the oldest old
    John Starr

22 Understand the importance of social relationships
    Ann Bowling

26 Focus on outcomes in social care
    Ann Netten

28 Use the six senses
    Mike Nolan

32 Listen to and care about the oldest old
    Liz Lloyd

34 Know that loneliness is not inevitable
    Vanessa Burholt

38 Understand that we will still need care homes
    Julienne Meyer and Tom Owen

40 Maintain personhood
    Julian Hughes

42 Prevent, identify and treat depression
    Susan Bedford

46 Allow for some hard thinking at 85 and over
    Ian J. Deary
Help people live well with dementia
Alistair Burns

Realise that exercise is still key for the oldest old
Richard A. Ferguson

Minimise sedentary behaviour
Dawn A. Skelton

Maintain vision
Catherine Dennison

Keep teeth and mouths healthy
Paula Moynihan and Angus Walls

Support proper nutrition
John Mathers

Manage sleep
Kevin Morgan

Realise that multiple health issues are the norm
Marion McMurdo

Ensure age is no barrier to accessing health services
Iain Lang

Plan for better hospital care
Teresa Dowsing and Simon Conroy

Living long and ageing well: insights from nonagenarians
Maeve Rea

Know that incontinence is not inevitable
James Malone-Lee

Provide technology for all
Gail Mountain

Design for the fourth age
Jeremy Myerson

Recognise and prevent elder abuse
Gloria M. Gutman

See the need to know more
Tom Kirkwood, Joanna Collerton and Carol Jagger
Foreword

Today, in many parts of the world, people can expect to live into their 80s. This is one of the great triumphs of the 20th century. It is also a great adventure. For the first time in human history, it is becoming normal to experience ‘old’ old age. We can sometimes forget how different this is from the past. Indeed, when today’s 85-year-olds were born, there were fewer than 10 million people living on the whole planet who had reached a similar age. Yet by the middle of this century, there will be around 400 million people over the age of 80 globally, the vast majority living in what are today low- and middle-income countries. In the UK the numbers are just as dramatic. Today, the Office for National Statistics estimates that there are nearly 1.5 million people aged 85 and over. By 2050, this will have grown to 5 million.

The world that today’s oldest old live in is a very different place from the world they were born in to. But how do they experience it? How should we address the challenges they confront? How do we provide the care they need, and how do we break down the barriers that prevent their active participation in society? The answers can be surprising. Indeed, we may need to shed some of the preconceptions we hold about this fourth age if we are to create the sort of world we would all want to live in as a 90-year-old.

This book brings together a distinguished array of contributors to provide their insights on some of these questions. It is wonderful to read their stimulating thoughts. They provide a vision of the world we might create, and the path we will have to follow to get there. I would like to congratulate them and Age UK for illuminating our way.

John Beard MBBS, PhD
Director of the Department of Ageing and Life Course, World Health Organization (WHO).
Introduction

‘Today’s older people are the vanguard of an extraordinary revolution in longevity that is radically changing the structure of society and altering our perceptions of life and death.’ With these words I began the Preface to my book *Time of Our Lives*, published in the last year of the last millennium – a book which I was audacious enough to hope might even have messages for the politicians we elect to lead us into the ‘uncharted territory of a greying world’.

Who could have foreseen, in 1999, what the early years of the new millennium would bring in terms of other upheavals – the terrorism of 9/11 in 2001, the economic catastrophe of banking mayhem in 2008, and so much else? But the continuing dynamics of population ageing were entirely predictable, and the world’s population has continued to age as never before.

It would be nice to think that our success in defeating premature, preventable deaths would be hailed for the triumph it truly is. It would be cause for additional celebration if we had marshalled the same ingenuity that led to increasing lifespans towards making the most of society’s greater expectation of life. It would even be good if we had directed appropriate effort to understanding what life is actually like for the vastly increased numbers of people living to age 85 and beyond.

But we have done hardly any of the things necessary to prepare for the realities of population ageing, which is why this new book from Age UK is so timely and important.

Great voids exist in our information about the lives of the oldest old in today’s world, and much prejudice and misconception still obstructs the path of identifying and instituting the necessary changes. In this book are collected valuable pointers along the way of what needs to be done from experts who are still far too few in number.

It is time to do more.
Abandon preconceptions about the oldest old.

Key messages

Abandon the ‘deficit conception of ageing’ as a costly problem and think in terms of how policy can help to maintain and regain autonomy and independence, both physically and mentally.

It is never too late: even in advanced old age it is possible to restore some lost physical and mental capacity.

We need to overcome ageism and exclusion with regard to the oldest old.

Dignity and respect are critical: it is as easy for practitioners to boost self-esteem as it is to undermine it. Too often, policy-makers and practitioners hold ageist stereotypes about the oldest old. At best these are patronising and, at worst, they treat this group as being either a costly burden on the economy or just waiting for death. Where they exist, these attitudes must be abandoned because they are discriminatory, damaging, wrong in factual terms and completely out of step with the changing face of later life. Those aged 85 and over are the most rapidly growing section of the UK’s population and policy-makers and practitioners need to adjust equally quickly to this new reality.

There is now a huge body of evidence upon which to base a new approach, including the Growing Older Programme (www.growingolder.group.shef.ac.uk), the New Dynamics of Ageing (www.newdynamics.group.shef.ac.uk) and the English Longitudinal Study of Ageing (www.ifs.org.uk/ELSA).

This research evidence emphasises why we need to overcome ageism and exclusion with regard to the oldest old.
Heterogeneity
Just like every other section of the population, those over 85 vary widely in terms of demography, social and health characteristics. Ageing is unequal: more than three in four women aged 85 and over live alone, compared to two in five men. The oldest women are more likely than their male counterparts to rent accommodation (one-third vs one-fifth). Poverty is highest among very old women.

Variations in capacity
There is no clear evidence of a sudden decline in health at 85 and self-rated health is no different between those aged 80–84 and those 85+. Significant proportions of the oldest old are not severely disabled and can look after themselves. Even among those suffering severe activity limitations, self-care is the most common form of support.

Function not age
Ageing is not a matter of chronology but restricted activity. Most people begin to feel ‘old’ as a result of illness or disability. Rather than assuming that this is inevitable, because people are old, or permanent, actions are needed fast to restore function (physical and mental) or to re-skill by finding new ways to do things, such as opening jars. The evidence is clear, even among frail older people in their 90s, mild exercise can have beneficial effects both physically and mentally.

Dignity is crucial
An older person’s identity is threatened when their autonomy is restricted; for example, following severe illness or a fall. This undermines confidence and self-esteem and this is especially the case when personal care is required. In this situation, practitioners can work wonders by supporting people to regain some of their reduced capacities and by closely observing the Dignity Code (http://npcuk.org/wp-content/uploads/2011/11/NPC-Dignity-Code.doc).

The rapid transformation of later life and the growing importance of the oldest old demand that we abandon the ageism that stultifies policy in this field. Instead, this group needs to be fully integrated into an active ageing strategy that includes both prevention (at earlier stages of the life-course as well as into late old age) and fast remedial action when autonomy is threatened.

Alan Walker FBA, FRSA, AcSS
Professor of Social Policy and Social Gerontology and Director of the New Dynamics of Ageing Programme.
Ignore age and look at the person.

**Key messages**

The oldest old are more diverse in health than the younger old; they cannot all be treated the same.

Chronological age is a weak predictor of life expectancy and response to treatments.

Many illnesses associated with age can be treated or avoided, especially if the oldest old receive good co-ordination across services and specialities to offer the best treatment.

The oldest old have lived long enough to have acquired, on average, several specific conditions (e.g. diabetes, osteoarthritis and heart disease), a range of age-associated impairments of bodily and mental functions (like strength, balance and factual memory) and the trials and satisfactions of life events. But diversity grows rather than diminishes. Generally, the health and healthcare needs of older populations is related to proximity to death, rather than chronological age. Since there is wide variation of health and life expectancy, chronological age becomes a weaker predictor of need.
Individual differences have accumulated over the life-course, and socio-economic factors have a predominant influence. The sum total of problems or impairments means that individuals also differ in their ability to weather the next setback, illness or injury. Loss of reserve or resilience is called frailty, and this can be measured through a comprehensive assessment, which is more holistic than a list of diseases.

Intriguingly, while women are on average more frail than men of similar age, they survive longer, for reasons not yet understood. Social participation, with responsibilities as well as support, seems important in preserving resilience as well as wellbeing. Society, neighbourhoods and practical issues like physical access are therefore influential in enabling a healthier old age.

Age-attuning healthcare is a significant challenge to all health services. The approaches developed and proven of value to middle-aged people are inadequate. A multidisciplinary approach is needed, which crosses traditional service boundaries. For example, most operations are now performed on older people. The oldest old can certainly benefit. But the greater risks they face can be anticipated and ameliorated by joint working between surgeons, anaesthetists and geriatricians, so that chronological age itself need never be sufficient reason to deny possible benefit.

Difficulties in managing day-to-day tasks merits a medical assessment as well as a social care response. A proactive approach is needed, particularly for those with disability. This includes care home residents whose needs may change and frequently require specialist input as well.

Evidence is building about general measures to delay or reduce frailty. Regular physical activity is key, although many will be limited in the scope or intensity of what’s possible. Challenging balance and co-ordination, within safe limits, preserves functional mobility and reduces falls. For frailer individuals, this needs tailoring by health professionals.
Appetite and weight may fall in late life but protein needs remain high and advice on adjusting the balance of foods may be needed. There are no anti-ageing wonder vitamins, but many people who lose weight or eat too little will simply become deficient in some standard requirements, such as folic acid; and most housebound older people are short of vitamin D. This justifies routine supplementation or at least measurement to check whether it is needed, before it causes problems. Ongoing research is likely to identify additional treatments to address the problem of sarcopenia (smaller and less effective muscles).

Treatment for common conditions such as hypertension should be tailored for the individual. Evidence obtained from research using younger, fitter subjects needs to be factored with a mind to the older patient’s short- and long-term healthcare objectives. These are likely to change towards the end of life. The benefits of some treatments decline, but for others the absolute benefit may be greater for older people because of the greater underlying risk. However, the risks of adverse effects and burdens may increase in the presence of multiple illnesses or frailty. Polypharmacy (taking multiple medicines) itself increases the risk of adverse effects, so six-monthly reviews of indications and side effects are justified. Completing the circle, frailty increases the risks of polypharmacy.

Thinking about individual objectives and priorities naturally includes considering events towards the end of life. This proactive approach gives both doctor and patient a chance to plan for dignity and wellbeing, avoiding unnecessary treatments and the muddle that can otherwise arise in a crisis.
Those of us who reach 85 have, on average, at least five years more to live; it is worth paying attention to their health, needs and desires.

In this fourth age of life, risk factors of disease and markers of health are markedly different when compared to those at younger age, so we can no longer take accepted predictors of ill health as accurate in relation to the oldest old.

What we now need is a paradigm shift in our thinking: solutions that fit the younger old may not be appropriate for the oldest old.

The oldest old are rapidly increasing in numbers, a shining symbol of the sociomedical improvement of our societies. Life expectancy of men aged 85 is now about five years, long enough to envisage a personal master plan. Women already have a couple of years longer.

Insights from current biological and medical research reveal that this new dawn of our lifespan is far more plastic than we have yet appreciated. Therefore it shouldn’t come as a surprise that life expectancy increases by an extra one or two years per decade. Fortunately, self-rated life satisfaction beyond age 85 is at least as high as during our ‘middle’ and ‘third’ age, despite deficits in physical and mental functioning. Nevertheless, we need to address the versatile goals and ambitions as perceived by the oldest old themselves.
The leap forwards in preventing and treating disease throughout our prime years has contributed enormously to the length and quality of life that we now enjoy. While this was happening, however, we were not investing in our understanding of the consequence of this, e.g. in just a few generations, the age at which 10 per cent of the population is still alive increased from 70 to 80 years of age. Disease, morbidity and death in very old age actually occur in a ‘knowledge shadow’, as we have almost systematically excluded the very old from our research and have therefore too little data to fully exploit the potential of our present and future longevity.

In the Leiden 85-plus study we – and other investigators who have included very old people in similar observational studies – have shown that, among others, high cholesterol, hypertension (high blood pressure) and low thyroid hormone have lost their value for the over-85s to predict disease and disability, and have instead become markers of health!

Some argue that these very old are a rather selective pick of survivors who appear resistant against high cholesterol, hypertension and low thyroid hormone. This reasoning may be not false, but it does not explain the paradoxical finding of these biomarkers to predict longevity in the fourth age.

The oldest old are rapidly increasing in numbers, a shining symbol of the sociomedical improvement of our societies.

Use of biomarkers and associated interventions that may have to be reconsidered is as follows.

• The PROSPER study, a randomised controlled trial of cholesterol-lowering in (very) old people showed cardiac benefit but no survival advantage, a finding that is not at odds with the experimental data at middle age.

• It is as yet far from clear whether decreasing blood pressure in frail older people provides benefit and recent data suggest that it may well be worthwhile to study withdrawal of anti-hypertensive medication to protect the brain and cognitive function.

• Within the TRUST consortium, randomised experiments are ongoing to provide an answer on whether to treat or not to treat the (very) old with thyroid hormone, whereas we would not hesitate if they were younger.

To be able to enhance self-rated life satisfaction of the oldest old, we urgently need innovative strategies that appropriately address their needs and desires. These necessitate a paradigm shift in our thinking as diagnoses and solutions that fit the younger old may not be appropriate for the oldest old. When not addressed properly, life satisfaction and the length of life may even diminish.

The Leiden 85-plus Study: https://www.lumc.nl/con/2095/83047/86636/90106004730420
Learn from the oldest old.

Key messages

Health and social care professionals, along with policy-makers, should listen to the story of the lives of people aged 85 years or more. They have much to learn from the stories of those whose lives have gone well enough to have survived so long.

Even the very old generally rate their quality of life as good or very good.

Having a good late life depends a lot on events and actions in younger life, so healthy behaviours need to be encouraged in people at every age to optimise everyone’s chances of ‘good’ ageing.
For centuries our view of old age has been dominated by William Shakespeare’s dismal description of it in *As You Like It*:

Last scene of all,
That ends this strange eventful history,
Is second childishness and mere oblivion,
Sans teeth, sans eyes, sans taste, sans everything.

But over the last 50 years or so this picture has been transformed by mass population ageing. With so many more people surviving to old age, research on larger samples of older populations has become feasible and this research reveals that this period of one’s life is typified as much by continuity as it is by loss.

*If we want to have a good old age, we have to start young; that is, what is technically termed a life-course approach to ageing is required.*
Learn from the oldest old.

For example, in our studies of people born in 1921 in Scotland, we found that even approaching the age of 90, over a quarter of a person’s mental abilities can be explained by her ability when she was 11 years old; that is at least a quarter of how a person performs on tests of mental ability is fixed across eight decades of life (there is more on this in Professor Ian Deary’s article – see page 46). Similarly, more than half of the people we surveyed had their own teeth. We also measured their visual acuity, wearing glasses if necessary, and found this on average to be 6/9, which is the sixth line down on the standard Snellen chart of letters used by opticians. We did not measure sense of taste.

Given this picture of relative preservation of youthful attributes into old age, it is unsurprising that people aged 85 and over generally rate their quality of life as good to very good. In fact, physical limitations and losses are not particularly strong predictors of how someone will rate their quality of life at this age. Instead, aspects of mental wellbeing such as mood, personality and lifelong intellectual ability are the most important factors. And here is a crucial point: although mood may vary over fairly short periods, other aspects of our psychological being, such as our personality or mental abilities, are things that remain relatively fixed throughout our lives. Hence, if we want to have a good old age, we have to start young; that is, what is technically termed a life-course approach to ageing is required.

What is striking about Shakespeare’s ‘Seven Ages of Man’ is the discontinuity of each age, represented as separate acts of a play, as if one person exits for another to enter. But life-course studies, which now extend into advanced old age, show this to be fundamentally wrong: there are no discontinuities, it is the same ‘us’ in many ways at age 90 as at nine years old. As the physical health of younger members of the population improves, we can expect this to lead to physically healthier older members in due course. What is needed is attention to mental health: for example, we know that even mild levels of stress increase the risk of both dying early and dementia.

So Shakespeare got it wrong for the 21st century – no longer can old age be said to be a time of devastating loss, nor can we reckon our lives to be made up of separate selves, the infant, the schoolboy, the lover, etc. But maybe the play’s title still holds some truth for us: it is more how we consider the story of ourselves that determines our quality of life at 85 years and beyond – in Shakespeare’s words, it remains a matter of ‘As You Like It’.

To find out more about the research behind this article, go to www.ccace.ed.ac.uk
Understand the importance of social relationships.

Key messages

Be aware that social relationships are very important and should not be taken for granted. We all need to build and nurture our social relationships throughout life, so that we enter very old age with enough reserves of these to compensate for relationship loss due to deaths, frailty, or moving home.

Provide information about how older people can maintain feelings of being in control over their lives as they become frailer. This includes examples of how to cope or compensate for activities as these become more difficult to carry out.

Enhancing quality of life in old age is attracting increasing policy interest. Quality of life is an accepted measure of outcomes of government policies, including health and social care.

Our research on quality of life was unique in asking older people themselves, including very old and frail people, about their quality of life, rather than relying on ‘expert’ views.
We used the results to develop a questionnaire about quality of life, relevant to older people that can be used to measure effects of public policy.

• We found that the most important influences on whether we experience a good, rather than bad, quality of life in older age are one’s social relationships, and having social roles and activities.

Many very old, frail, people mentioned the importance of having someone for ‘companionship’, ‘to take me out’, ‘to make life bearable’; and of having social or voluntary activities, not just for their self-esteem, but to help them ‘keep busy’, in order to stop them worrying, feeling lonely, or dwelling on the past.

• The next most important influence on quality of life mentioned was having good health and physical mobility.

Other important influences included:

• enjoyment of one’s home, good community facilities, and feeling safe

• a feeling of wellbeing and contentment, feeling in control of life, as well as having an optimistic outlook (‘looking on the bright side of life’)

• having independence and control over their daily lives (to be able to continue to live independently in their own home, rather than residential care, was important to people)

• feeling they had enough money to pay one’s bills or to enjoy oneself (e.g. to be able to have day trips or holidays).

These were also the most important influences on their ratings of their own quality of life, on a scale ranging from ‘So good, could not be better’ to ‘So bad, could not be worse’.
What professionals can do

Facilitate provision of affordable venues, adequate and convenient transport, safe and well-lit neighbourhoods, to promote social contacts and activities, especially for older people who have become socially isolated, lonely, or increasingly frail.

Encourage continued participation in social, neighbourhood and civic activities – resulting social networks need maintaining to enhance social support as people become less physically mobile.

Promote to all age groups the importance of building up social networks throughout life to ensure that people have a stock of social resources in late old age.

Read more about the research. Download ‘Good Neighbours: Measuring quality of life in older age’ (PDF, 231KB) at www.ilcuk.org.uk/files/pdf_pdf_159.pdf, or go to the ILC publications site to read more about the project, including the questionnaire used: www.ilcuk.org.uk/index.php/publications/publication_details/good_neighbours_measuring_quality_of_life_in_old_age

In each of our studies, feelings of little or no control over their lives also statistically increased people’s risk – by over three times – of rating their quality of life as bad rather than good, compared with those who felt they had a lot to some control.

Having difficulty walking was also a risk factor for poor quality of life, but it was not as influential statistically as social support and feeling in control.

The risk factors for poorer social support included being in the oldest old-age groups, and being a member of an ethnic minority group.

Our results are consistent with an analysis of all published studies combined, showing that social relationships are as important as not smoking, having a healthy diet and exercising for mental and physical health, and for a longer life.

Understand the importance of social relationships.
Focus on outcomes in social care.

Key messages

Focusing on outcomes for the individual allows us to deliver appropriate care and support. These will sometimes challenge our assumptions about preferences and experiences. For example, very old people value having something to do, social contact, and control over aspects of their lives as highly as younger people.

These domains are equally important for life in the community and in care homes, including care homes that provide nursing.

Integration across health, housing and social care has considerable potential for improving older people’s lives and can be facilitated by joint responsibility for, and measurement of, quality of life outcomes.

Very old people are much more likely than younger people to need to make use of social care support. Social care plays a vital role in compensating for impairment and, despite budget cuts, there remains a policy emphasis on getting away from basic support to ‘higher order’ outcomes that are about maximising control and providing people with freedom to achieve their own goals. Alongside this there is a commitment to focus on and measure outcomes, especially patient or service user reported outcomes and experiences, evident in the National Outcomes Frameworks for health and social care.
It is important that we make use of the evidence about the experience and outcomes of health and social care that are beginning to emerge, partly as a result of these shifts, and that challenge implicit assumptions. Aspects of quality of life that are the target of social care (or social care-related quality of life) include very basic aspects – being clean and comfortable, food and drink, feeling safe, and a clean and comfortable environment.

However, the ‘higher order’ domains of occupation (having something to do), social participation, control and dignity are also very important to people. Research conducted to allow us to estimate the relative importance of these different aspects of outcome has shown that control and occupation are of particular importance to people and, critically, that not only are service user views on these no different to members of the population, there is no age effect. Thus the very old value feeling in control of their daily lives and spending their time in ways they value and enjoy as much as younger groups.

So how can we maximise the oldest old people’s sense of control and levels of occupation? People themselves and policy-makers tend to assume that older people will be able to exercise most control in their own homes. However, when the same question is asked of people supported in their own homes, in care homes and in extra-care housing (allowing for differences in levels of impairment), we found that older people living in their own homes felt less in control than those living in other care settings. In part this is likely to be related to their environment – from survey evidence it is clear that design of people’s homes is critical to social care-related quality of life. Moreover, in addition to the more accessible environments of communal care settings, there is the company of others. Isolation and loneliness are associated with lower feelings of control.

Turning to communal settings, other research has found that, again after allowing for levels of impairment, social care-related quality of life (including the domains of control and occupation) is lower in care homes that provide nursing than those homes registered just for personal care. Moreover, while star ratings reflecting the regulator assessment of quality of care were associated with resident outcomes in residential homes for older people, this association was not found in nursing homes. If anything the indication was that higher ‘nursing home quality’ was associated with poorer social care outcomes. More anecdotally, it is noticeable that newspaper headlines about poor hospital care of older people reflect just those domains that comprise social care quality of life: personal cleanliness and comfort, food and drink, and so on.

This suggests that integration across health, housing and social care has the potential to have an important impact on older people’s lives. However, it is going to be important that we do not assume that we know what will work – if good outcomes are to be achieved, joint responsibility for, measurement of, and use of patient- and service user-reported outcomes information will be essential.


Adult Social Care Outcomes Toolkit: www.pssru.ac.uk/ascot
The majority of older people are relatively fit and able, but frailty increases significantly with age. The ‘oldest old’ group therefore usually contains the frailest members of society, who are far more likely to require support from health and social services to maintain a good quality of life. Despite many initiatives over several years (for example, the National Service Framework for older people and the Dignity Campaign), serious concerns about the quality of care for frail older people remain.

Key messages

Current government policy for older people is underpinned by having ‘autonomy’ and ‘independence’, and services are evaluated by the extent to which they meet government ‘targets’. Such an approach fails to provide high-quality dignified care for the oldest old.

We need new approaches to delivering and judging the quality of care provision that focus on relationships between older people, family and service providers.

A relationship-centred model that promotes six senses (security, belonging, continuity, purpose, achievement and significance) for older people, staff and family carers creates an enriched environment of care with better outcomes for all groups.
An enriched environment is one in which each of these groups experience six ‘senses’:

**Security**
To feel safe, physically and psychologically.

**Belonging**
To feel part of a valued group, to maintain valued relationships.

**Continuity**
To experience consistency in care and relationships based on what matters to you.

**Purpose**
To be able to pursue valued goals and activities.

**Achievement**
To be able to realise these goals and to have your achievements recognised.

**Significance**
To feel that who you are and what you do matter.

Policy for older people promotes ‘person-centred’ care based on ideals such as autonomy and independence, and services are still largely judged by their ability to meet government ‘targets’. Consequently, frail older people are continually seen as problems, cast as ‘bed-blockers’ or ‘frequent flyers’, and work with such individuals is often not highly valued by young health and social care practitioners. Unless things change, this situation can only get worse as levels of frailty increase. If things are to improve, then there has to be a reconsideration of the values underlying both policy and practice, and the development of new approaches to both delivering and judging the quality of care provision that are based on ‘meaning rather than metrics’ (see Patterson et al., *From Metrics to Meaning: Culture change and quality of acute hospital care for older people*, 2011, available at: www.sdo.nihr.ac.uk/files/project/SDO_FR_08-1501-93_VO1.pdf).

Over the last 15 years a programme of research undertaken primarily at the University of Sheffield (but with applications across the four home countries) has developed and tested a differing model based on ‘Relationship-centred Care’ and underpinned by the ‘Senses Framework’. Rather than promoting independence, this approach recognises that people of all ages are generally interdependent and that it is the nature and quality of their relationships, not only with family and friends but also with service providers and service systems, that are of central importance.

Within the context of service delivery this stream of work has demonstrated conclusively that an ‘enriched’ environment of care is created only when the needs of all relevant groups (older people, staff and family carers) are seen as important.
Several studies have shown that if frail older people experience the ‘senses’, in the environment in which they receive care, then their experience is significantly more likely to be positive.

Relationship-centred care and the ‘senses’ are being applied in numerous care settings throughout the UK; for example, they underpin Age UK’s My Home Life initiative and were explicitly endorsed in the influential Delivering Dignity report. As such, they offer a potentially valuable resource in ensuring that, when they need it, the ‘oldest old’ receive the quality of care that they deserve.

Read more about the Senses Framework at http://shura.shu.ac.uk/280/1/PDF_Senses_Framework_Report.pdf

Lloyd et al., ‘Identity in the Fourth Age: Perseverance, adaptation and maintaining dignity’. Ageing and Society, published online 6 August 2012 (DOI: http://dx.doi.org/10.1017/S0144686X12000761)

Listen to and care about the oldest old.

Key messages

When we reach the fourth age, skilled help is crucially important and this requires sustained investment in practitioners’ social as well as technical capabilities.

Skilled help is highly valued by older people and when it is given in a respectful and responsive way, it sustains a sense of dignity and identity.

But remember too that the oldest old vary in their views and preferences and these needs are often neglected. Caring about is as important as caring for.

The importance of listening to each and every older person cannot be overemphasised.
Living in the fourth age is a challenge that most of us who work with older people face. Individuals must balance their continuing wish for independence with the growing evidence that their health and mobility are declining as they face death at a near but uncertain time. Declining health poses a threat to people’s identity, particularly when dementia is involved. It disrupts ordinary routines, cherished activities, and social relationships. Uncertainty and a sense of precariousness reverberate in the lives of the individual and their families.

There is no single recipe for the provision of health and social care. The only consistent message from research is that older people vary in their views and preferences. Regrettably, there is overwhelming evidence that, because of pressure to contain the cost of services, the emphasis has been on physical needs to the neglect of psychological and social needs. This is counterproductive because isolation, loneliness, depression and anxiety have an adverse effect on physical health.

At this time of the life-course, decisions of major importance must be made, such as whether to remain at home or move to a care home; to give someone Lasting Power of Attorney over decisions relating to one’s care; or trust someone with control over one’s finances. Such decisions are hard to make: people need time and their views might change with changing circumstances. The support of skilled professionals is crucial and is more productive when such decisions are approached as a process, rather than as a one-off.

Family and friends play a vital role in supporting people in the fourth age, but no assumptions should be made that they will be a reliable source of care, as they might be unable or unwilling to provide for all of a person’s needs. Sustained family relationships can enable older people to continue to make a valued contribution and enhance their dignity. Skilled practitioners have an important role to play, providing information and support to individuals and their families. A little support can have a big impact.

The fourth age is a time of bereavement and loss, which reduces older people’s circles of support and help as well as exacerbating a sense of precariousness. The need then is not only to be cared for but cared about. In care homes or in people’s own homes, having someone sit and listen is highly valued. This is a challenge because practitioners’ busy schedules mean that they lack the necessary time and their training has prioritised technical rather than social skills. When care is reduced to the minimum, the message that people in the fourth age are a burden is reinforced. The importance of listening to each and every older person cannot be overemphasised, because it is through responsiveness to individuals’ views and preferences that a sense of identity and dignity can be sustained throughout life to the point of death.

Read more about this at www.newdynamics.group.shef.ac.uk/assets/files/NDA%20Findings_8.pdf
Know that loneliness is not inevitable.

Vanessa Burholt, PhD
Professor of Gerontology and the Director of the Centre for Innovative Ageing at Swansea University.
Her research is on social and support networks, intergenerational relationships, loneliness, attachment to place and migration of older people. In summary, her interests focus on older people’s relationships with others and with places.

Key messages

Loneliness is not inevitable in the oldest old, but it is more common.

The public and private sectors have a role in helping older people to maintain long-term relationships and to develop new ones.

Loneliness can speed up cognitive decline and memory problems. Visits from friends are important in the face of the risk of dementia.

The proportion of people who report loneliness in their ninth decade and beyond is greater than the proportion of older people who report loneliness between 60 and 85 years.
Loneliness is not an inevitable part of old age, but once someone reaches the ninth decade certain life transitions are more probable and increase the risk for loneliness. However, practitioners and policy-makers can try to proactively combat loneliness for people in their 80s and over.

Loneliness is a personal experience. It stems from unpleasant feelings linked to a shortfall in the desired level or quality of social contact with others. Loneliness should not be confused with being alone or living alone. Some people can be isolated but not lonely, others isolated and lonely, while some may not be isolated but still lonely.

Research has shown that fewer than one-fifth of people aged 85 and over report that they feel lonely often or all of the time. On the other hand, more than one-half of the same age-group report that they are never lonely. Despite the low levels of loneliness reported by the oldest old, the proportion of people who report loneliness in their ninth decade and beyond is greater than the proportion of older people who report loneliness between 60 and 85 years. This is because certain life transitions influence loneliness. Although loneliness can occur at any age, for people over 85 there is a greater chance that they will have retired and have less or no contact with former work colleagues, that they have been widowed, and that friends and/or family have moved away from the local area or died. Poor health can also make it difficult to go out and keep in touch with friends and family.
What can be done?

It is important for friends and family to keep in contact with each other throughout the life-course, but the relevance of this becomes more obvious in later life.

Some older people will move into supported living environments. Recent research has shown that residents in supported living environments want to maintain long-term friendships that have been forged across the life-course. Although the development of a socially connected community within a supported facility may be important to managers, for those residents who have long-term friends in the community, support to facilitate visits or other forms of communication between them may be more important.

In the face of dementia, it is important for older people to maintain friendships through face-to-face visits.

Some older people will experience poor physical health. Regardless of residential environment, when distance or poor physical health makes visiting difficult, phone calls, emails, Skype, Facebook or writing letters can keep relationships alive, but some older people may need support in using new technologies.

The prevalence of dementia increases by age, from 20.3 per cent for those aged 85–89 years to 32.5 per cent for those aged 90 years and over. Research has shown that loneliness can speed up cognitive decline and memory problems. In the face of dementia, it is important for older people to maintain friendships through face-to-face visits. Professionals can be a key source of advice to friends and family on effective means of communication.

Some older people will outlive their long-term friends. Older widows consider social activity an effective way to combat psychological distress associated with the loss of a spouse. However, certain disadvantages – such as economic disadvantage, poor health, inability to drive, and living in a remote or rural location – can impact on an older person’s ability to participate fully in society. An older person may not able to replace intimate long-term relationships that may span several decades; however, new friends can provide different but fulfilling emotional relationships.

Consequently, the public and private sectors have a role in helping older people maintain long-term relationships and develop new relationships by creating age-friendly communities that are accessible, with affordable and appropriate transport and communication solutions, local interest groups and social activities.

For further information on ‘good practice’ with regard to social activities and interventions that can combat loneliness in old age, visit: www.campaigntoendloneliness.org.uk

Know that loneliness is not inevitable.
Understand that we will still need care homes.

Key messages

Despite efforts to transfer more care into people’s own homes, this will not be possible for, nor desired by, everyone. Therefore the number of care home places is likely to double in the next 30 years.

To deliver good care, residents, relatives and staff need to be in a positive relationship with each other. Managers need to ensure that care workers feel supported, valued and respected. If not, they are unlikely to offer dignified care to others.

Residents should be given more voice, choice and control about what happens in care homes and placed at the centre of all decision-making.

For many of us, care homes will be an option that we will have to consider at some point in the future. Far from being a thing of the past, it is likely that the number of care homes will have to double over the next 30 years. While alternative models of care are emerging, there is no evidence to suggest that these will ultimately replace care homes in delivering 24-hour support to our frailest and most vulnerable citizens, including people with severe dementia.

It has never been so important for society to actively work with care homes to ensure that they can provide the quality that we would expect for ourselves and those we love. Care homes are often viewed as ‘islands of the old’ and a ‘place of last resort’ rather than as a vital part of the care continuum. In the recent White Paper, *Caring for Our Future*, the Government said it will support the work being led by My Home Life and national care-provider organisations to work with their members to connect care homes to their local community.

Care homes are our future.
So how can we help care homes deliver quality? My Home Life is a UK-wide initiative led by Age UK in partnership with City University and Dementia UK to promote quality of life in care homes for older people that has the support of all the key stakeholders in the sector. It began as a small project pulling together best practice in care homes and is now seen as a social movement for change. It is evidence-based, relationship-centred and seeks to make a difference by focusing on the positive.

There is no doubt that recent economic pressures are significantly impacting upon many care homes and a proper funding model is needed. Care homes are looking after increasingly frail older people, typically at a quarter of the cost of hospitals. There is also evidence to suggest that care homes often feel undervalued and viewed with suspicion by both the community and statutory agencies. Positive relationships are at the heart of best practice and we need to be mindful that if people don't feel respected, they are unlikely to offer dignified care to others.

Research suggests that for relationships to be good between older people, relatives and staff; each party needs to feel a sense of security, belonging, continuity, purpose achievement and significance (read more about the Senses Framework in ‘Use the Six Senses’ by Mike Nolan, page 28).

Care homes are our future. They should be structured around the needs of the individuals they care for, rather than the routine needs of the organisation. Older people want to be recognised for who they are, involved in decision-making about their care and how the care home is run and feel a sense of connection with staff. They want to be helped to adapt to their changing circumstance, to improve their sense of wellbeing and to be guided to a peaceful death, where appropriate.

Care home managers have a vital role to play in leading change and creating positive cultures in which relationships can flourish. They need our support to respond to the demographic challenge and to help the workforce develop new ways of working.

Find out more about care home research: download The Changing Role of Care Homes at www.cpa.org.uk/information/reviews/changingroleofcarehomes.pdf
Maintain personhood.

Key messages

Going into long-term residential or nursing care is a major event in anyone’s life and is a threat to the older person’s civil liberties.

All those involved in making decisions about going into long-term care, including the older person, need proper support – advice, education, training and time – if the rights of the oldest old are to be protected.

Personhood is what it is for the individual to be the unique person that he or she is. It persists throughout our lives. Understanding it can encourage respect and enhance the dignity of the oldest old.

Oldest-old people are at risk of requiring long-term care in residential or nursing homes. As we become frailer, either physically or mentally, the risk of being put into such an institution increases. Care homes can seem like the modern equivalent of the old poorhouses or asylums. Their residents are largely forgotten by society. Despite bad publicity and some scandals, however, many care homes are making efforts to improve the quality of the care they provide by, for instance, introducing more meaningful activities.
But given that many people who go into care lack capacity to make the decision for themselves – for example, because of dementia – it must be made properly. It must be the right decision for the person and it must be made in accordance with the law. Many people go into care from hospital. But busy hospital wards are not the best places for these decisions to be made, because they will often require time and space for the options to be considered, both by the older person and by the family.

Decisions made in the community can also be difficult, especially where there are tensions within families. Those who make these decisions, who should include the older person, need considerable support. If the wrong decision is made, older people – who may not have an effective way of making their wishes known – may be deprived of their liberty, which undermines a basic human right. In the future, we need to see real alternatives to institutional long-term care, where more attention can be paid to the individual.

It is tempting to think that concepts such as ‘personhood’ are too theoretical to be of practical use. But, actually, our understanding of what it is to be a person is the basis for much that we do in health and social care. Well-meaning relatives will sometimes say that someone is no longer the person he or she once was. Others go so far as to say that a condition such as dementia can stop you being a person at all. It is certainly true that illnesses can change our personalities. But we need to understand personhood in a broader fashion.

First and foremost, we are never isolated. We are always situated – we stand – in our personal stories, which will include our families and our social or cultural histories. Part of what makes the person unique is the nature of the social interactions that only this individual has and that go to make up his or her standing as a person. To support the person, then, we need to support and pay attention to the surrounding social structures, which can enhance or detract from the person’s standing. Taking a broad view of personhood means that we should pay attention to everything about the person, from his history to her biochemistry. But, in particular, we must recognise our mutual interdependence: none of us is an island and our inclinations to care are rooted in our connections as persons.

Professor Hughes’s recent books include Thinking Through Dementia (which is very relevant to the issue of personhood: http://ukcatalogue.oup.com/product/9780199570669.do and Alzheimer’s and Other Dementias: http://ukcatalogue.oup.com/product/9780199596553.do

Another work of relevance is the co-edited book Supportive Care for the Person with Dementia: http://ukcatalogue.oup.com/product/9780199554133.do. For further details of Professor Hughes’s work, please see: www.ncl.ac.uk/ihs/people/profile/julian.hughes

Our understanding of what it is to be a person is the basis for much that we do in health and social care.
Prevent, identify and treat depression.

Key messages

Depression in over-85s needs good-quality assessment. Severe depression is a life-threatening condition. Older people with depression need screening for physical illness, optimisation of any physical problems and review of medication.

Management of depression requires the availability of a range of interventions (social, psychological and pharmacological), with the patient fully involved in making informed decisions. Although access to drug treatments is widespread, resources for psychological and social interventions are limited.

Older people in residential and nursing care need more input and an enriched environment to prevent and manage depression.

Susan Bedford MD
Worked as a specialist in Old Age Psychiatry for 20 years in the NHS, providing management and assessment of people over 65 (many over 85) with mental health problems until her retirement from this role in 2012. She has also been involved in research into Old Age Psychiatry Services.
When is depression an illness?

Depression is an emotion that few avoid altogether. It is a normal reaction to the difficulties faced by almost all of us and is part of the human condition; indeed it may form a useful impetus for change. However, when depression is pervasively and persistently present for more than several weeks, it can be regarded as a depressive illness. Only when normal depression reaches a severity of affecting day-to-day function would it be regarded as illness.

The prevalence of depressive illness is less than of depressive symptoms. The prevalence of depressive illness in recent studies shows intriguing variation in different countries according to the Eurodep Study: in Munich the prevalence was 23.6 per cent in 85-year-olds while in Iceland the prevalence was only 8.8 per cent in 88–89-year-olds. This interesting difference may point to some societies being more likely to predispose their citizens to depression. In some environments such as nursing homes the prevalence of depression can be much higher. Depression is often associated with physical illness, bereavement, institutionalisation and isolation.

What studies clearly show is the high prevalence of depressive illness in the older age groups. There is less good information for the very old than for younger old, but a very interesting longitudinal study in Leiden is looking at this group of over-85s. There is also evidence that interventions – social, psychological and pharmacological – will improve depressive illness and help prevent it in this age group.

In this country, organisations such as Age UK have provided highly effective interventions such as day care, engaging activities, singing, and benefits advice (financial hardship is a major worry for many older people). At a European level there has been funding to explore and develop health promotion for older people (www.healthproelderly.com).

Symptoms of severe depression in over-85s can be less obvious because physical symptoms may be most obvious; for example, poor appetite, weight loss, pain and tiredness may be part of a physical problem but can also be caused by depression. Anxiety is also often a distressing feature.

Symptoms of severe depression in over-85s can be less obvious because physical symptoms may be most obvious.
Assessment needs to include an evaluation of physical health, plus a review of medication as this can contribute to tiredness and depression (one example is beta blockers). Cognitive ability should also be sensitively assessed as impairment is present in around 20 per cent of this age group, and may suggest the presence of dementia. Blood tests are useful to exclude common problems such as anaemia, hypothyroidism, diabetes, renal impairment, and possibly B12 deficiency.

Following assessment, a care plan must be agreed with the patient, bearing in mind that in rare cases of the most severe depression with risks of self-starvation and suicide or with very distressed and agitated behaviour, the person needs intensive and usually in-patient treatment.

Depression can be successfully managed, but preventing recurrence may need ongoing effort in terms of social engagement and keeping active, and in some cases antidepressant drugs.

There is evidence that there is widespread access to antidepressants; for example, in Bradford a study of general practice found 13.6 per cent of over-75s were on antidepressants. But access to psychological therapy and social activity needs improvement.


An article about the Eurodep Study is here: http://bjp.rcpsych.org/content/187/1/35.full.pdf

The mnemonic SAD FACES gives an easy way to remember key symptoms of depression:

- **S** - Sleep disturbance with early wakening
- **A** - Appetite (with weight loss) and Anhedonia (the inability to gain pleasure from enjoyable experiences)
- **D** - Dysphoria/depression
- **F** - Fatigue
- **A** - Agitation/anxiety
- **C** - Concentration impaired
- **E** - Esteem (feeling worthless or guilty)
- **S** - Suicidal ideas or plans
Allow for some hard thinking at 85 and over.

Key messages

The oldest old should have access to appropriate physical and mental activities, at home and in residential care. These will help the brain to think well.

Educating carers in the range of changes in people’s thinking skills over time can help to improve communication and outcomes.

Delirium is common in this age group; it is important not to confuse this with dementia.

‘Cogito ergo sum’: ‘I think, therefore I am.’ That’s what Descartes wrote. But what does a 17th-century French philosopher know? Well, he wasn’t far off the mark. When we get older, we want to be reasonably healthy and mobile, happy, and connected with family and friends. And we want to be able to think and remember.

When older people are asked what they fear most about later old age, it is losing their thinking skills. Our ability to think and remember is at the core of what we are as individuals. It’s the importance of these skills that has kept me studying the effects of age on thinking during most of my academic career. And here is some of what I have learned, which I think policy-makers and people working with the oldest old should know.

The brain is a factory: it makes knowledge. There are two ways to test how good a factory is: we can test the machines to see how fast and well they make things; or we can go to the warehouse and inspect the quantity and quality of the products the machines have already made. So it is with the brain: if we want to see how well it is working we can ask a person to do some new thinking, or we can ask them what they already know.

The good news is that the brain’s warehouse of information ages quite well. Our knowledge and things like vocabulary and learned skills, including some number skills, often stay pretty well intact even into very old age.
Allow for some hard thinking at 85 and over.

For most people, the machinery will be a bit slower and less high in quality. For most of us, our thinking machines – that help us to remember, to organise our thinking, and to get around new environments – won’t be as good as they were.

But that matters less than you might think. The research studies that show us that the sorts of thinking that the brain machinery is less good at after 80 are mostly done by giving people tests that make them work as mentally hard and fast as possible. But we hardly ever do that, just like we hardly ever drive a car at its top speed (up a steep hill!). If even the oldest people keep their health, their thinking skills will mostly be fine for the driving equivalent of getting around town, and driving pleasantly in the country. They might not do so well in a Grand Prix race, though.

My research studies have had the privilege of being able to study people’s thinking skills in old age after they had had their thinking skills tested as children. What we have learned is that there is a strong tendency for the childhood bright sparks to be top of the class in old age, and for the modestly endowed children to be the less bright in old age. But that does not apply to everyone, and there are some things that seem to help people to jump a few places up the class in older age.

The old saw that there is ‘A sound mind in a healthy body’ has some teeth. Older people who don’t smoke, who are more physically active and fit, and who are generally healthier tend also to have better thinking skills. So, although it is good for its own sake, keeping the body healthy can have mental benefits too.

And, while we are on the topic, it is very important to be aware of something called delirium. It is a common, transient state of mental clouding and confusion and poor attention that older people can experience when the body is under stress as, say after an operation or even during what seems to be a mild infection. Delirium tends to clear, and it is important not to confuse it with dementia.
Allow for some hard thinking at 85 and over.

To think and remember, we need to see and hear. Like the rest of us, the oldest of us find that making new memories, thinking quickly, and making complex decisions are much harder if they can’t make out the stuff they are thinking about. So, to help them give their brain the best chance of doing its job well, we need to do what we can to keep their vision and hearing as clear as possible.

I am always asked if doing mental work like crosswords and Sudoku are good for the brain. People ask me if they will lose it if they don’t use it. The scientific studies are not clear about whether brain training works. But I do know this. People who engage in mental activities have a richer mental life. So, no matter how old they are, people should do mental stuff – and I don’t care if that is Bingo or Shakespeare – because it is fun and because it keeps the brain active.

In our own studies of people over 80, we found that most people were highly satisfied with their lives. More than that, people’s satisfaction with their lives had nothing to do with how intelligent they were. So, once again, our aim should be to help people keep their brains in as good repair as they can.

But some will get dementia. There’s no getting away from it, being in the mid- and later-80s brings with it a greater risk of dementia. Dementias are the set of diseases that cause damage to the brain and ruin our thinking skills, especially our ability to make new memories. Even in the early stages of dementia, though, people retain quite a bit of their stored knowledge and so can, for a while, preserve their personal warehouse of the past even when the machinery is working much less well. And, to be positive, many people even in very old age will not get dementia.

Most people will get right through their lives having adjusted to their different ages. Those who are lucky enough to get to a relatively healthy ninth decade will have a unique treasure trove of knowledge and memories that should be the envy of anyone unfortunate enough to be younger. There is much less need to keep the brain-factory running at full pelt when the warehouse is richly packed.

To read more about this research, visit www.lothianbirthcohort.ed.ac.uk and www.ccace.ed.ac.uk

Our ability to think and remember is at the core of what we are as individuals.
Help people live well with dementia.

Key messages

Care of dementia is the most important social and health challenge of this century. It is particularly common in people over 85.

A quarter of NHS beds are occupied by people with dementia and two-thirds of people in care homes have dementia.

People can live well with dementia and their carers can be supported, but only if there is joint working across governments, the health service, social care, the voluntary and independent sectors and the wider community.

Dementia affects more than 800,000 people in the UK, a number which can be multiplied by two, three, or four when counting the numbers of carers (including family members), and costs the UK £23 billion.

The National Dementia Strategy entitled Living Well with Dementia was published in 2009 and is an ambitious five-year plan to transform the lives of people with dementia and their carers. Specific important outcomes include: increasing the diagnosis rate from the current 42 per cent by working with primary care, raising awareness and providing memory clinics; improving the care of people with dementia in hospitals by incentivising diagnosis; enhancing care in care homes; building on the 50 per cent reduction in potentially harmful antipsychotic drugs achieved; and supporting carers to allow people with dementia to live at home.

Building on the five-year National Dementia Strategy of 2009 and working closely with the Alzheimer’s Society, the 2012 Prime Minister’s Challenge on Dementia identified specific areas aimed at improving the quality of life for people with dementia and their carers.
**Timely diagnosis** – only 42 per cent of people receive a diagnosis, the benefits of which include: an explanation of worrying symptoms; empowerment of people by allowing planning for the future; and avoidance of admission to care in a crisis. The provision of information to primary care is important concerning diagnosis and the availability of memory clinics, where specialist advice can be sought, are universally available.

**Dementia in hospital** – a quarter of NHS beds are occupied by people with dementia and care is often poor. Best care in hospitals is being incentivised with the aim to improve the detection of people with dementia when admitted.

**Dementia in care homes** – two-thirds of people in care homes have dementia. There are many examples of good practice in homes; a Care Home Compact (as part of the Prime Minister’s Challenge) is being signed up to by the major care home providers and is incentivising good-quality care.

**Reduction in antipsychotics** – these are often given inappropriately for agitation. A 52 per cent reduction in their prescription over the past five years has been achieved.

**Support for carers** – this is essential in allowing people to stay at home. Carers are being supported, including with the provision of respite care.

The Prime Minister’s challenge on dementia offers a unique opportunity to push the agenda for dementia further and faster with three working groups. First, Health and Care. Second, Dementia Friendly Communities. Third, Better Research. Among the initiatives in Health and Care is improving the diagnosis rate across the country, improving the quality of care in hospitals, providing better local information on services for people with dementia and their carers and getting dementia into regular health checks for older people.

Dementia Friendly Communities involves making dementia everybody’s business and gaining support from organisations to make their processes more dementia-friendly. Better Research includes making more money available across the board from basic science to social care.

For more information, including the Dementia Strategy and Dementia challenge, see the Department of Health dementia website: www.dh.gov.uk/health/category/policy-areas/social-care/dementia
Realise that exercise is still key for the oldest old.

Key messages

Chronological age does not necessarily explain differences in health and physical capability. Many people in their late 80s do as well as others in their 60s.

Even the very old and the frail can benefit from exercise and physical activity.

Physical activity programmes have been proven to bring a wide range of health benefits and enhance quality of life.

The age-related decline in function of our body systems (e.g. cardiovascular, immune, skeletal muscle and bone) has profound effects on our capability to live in good health and with a good quality of life. The benefits of exercise and physical activity for people over 65 is well known and there are now UK-wide guidelines on the amount and type of physical activity we should all aim to do as we get older. Older people should aim to be active daily. Over a week, activity should add up to at least 150 minutes (2½ hours) of moderate intensity activity in bouts of ten minutes or more. Older adults should also undertake physical activity to improve muscle strength.
However, chronological age does not necessarily explain the differences in health and physical capability of older people. Many people in their late 80s do as well as those in their late 60s or even younger. Indeed, the oldest person to complete a marathon is 101 years of age (with a very respectable personal best time of 5 hours and 40 minutes). However, it is more likely for some people in their early 70s to have a functional status more expected of a 90-year-old and become increasingly frail as they get older.

Frailty is a state of vulnerability associated with increased level of disability, risks of falls, hospitalisation, cognitive deficits, and psychological distress, the prevalence of which increases with age. The good news is there is emerging evidence supporting the health benefits of exercise and physical activity in frail older people. For example, studies have shown that a variety of physical exercise programmes can lead to improvements in cardiovascular fitness, muscle strength, mobility and balance, as well as psychological aspects, including mood and cognitive function. All these factors will ultimately lead to an enhanced quality of life.

Despite these encouraging signs there is still a lack of research that will allow us to specifically define the nature of exercise and physical activity that should be undertaken. Nevertheless, this should not prevent us from encouraging physical activity and exercise as a safe and effective tool in promoting and maintaining optimal health levels in frail older adults. Any exercise or physical activity programme must of course be dependent on the person’s own individual capabilities and the amount of exercise taken should be gently increased progressively and consistently over time. Even something as simple as minimising the amount of time spent being sedentary (sitting) for extended periods may be a good start and also confer health benefits for frail older people.

Physical activity guidelines for older adults, including frail older people, can be found at The British Heart Foundation National Centre for Physical Activity and Health: www.bhfaactive.org.uk/olderadultsguidelines/index.html
Minimise sedentary behaviour.

Key messages

Research-based physical activity guidelines for the oldest old are needed. The amount recommended in current guidelines for older people are not achievable and indeed may not be necessary for most of those aged 85 and over.

Those working with the oldest old should regularly encourage and support older people to break up their sitting periods, even if just to stand for a few minutes.

Older people spend over 75 per cent of their waking day sitting, more than any other age group. The older we get, the longer we sit. Prolonged sitting time is also related to other unhealthy behaviours, such as lack of fruit and vegetable intake. Long periods of sitting are associated with poor health, regardless of how physically active a person is at other points in the day.

In an analysis of more than 3,000 older people participating in a large National Health and Nutrition Survey, using sensors that recorded periods of sitting, both professionals and older people were surprised at how often they were spending long times sitting. Over half of all surveyed had at least one sitting period of over four hours in a one-week period. Yet most, when asked, said they never sit for that long without getting up and moving. Those aged over 85 were twice as likely to sit for extended periods. Yet, in as little as 20 minutes of sitting, there are noticeable effects in blood-test markers of cardiovascular health.
Single bouts of prolonged sedentary behaviour, such as days of bed rest, have well-known adverse physical and mental health effects, which is why doctors rarely recommend bed rest. However, recent research has shown that sitting for more than three hours a day can reduce life expectancy by two years, even if a person regularly exercises, and watching TV for more than two hours a day can shorten life expectancy even further. For the oldest old, an increase in life expectancy may not be a motivating factor to break their patterns of sitting. However, the lack of movement during long periods of sitting is known to temporarily affect older adults functionally through increased joint stiffness and fatigue. This can in some instances discourage standing, but for others standing regularly reduces back and joint pain.

In 2011, the four Chief Medical Officers from across the UK published new Physical Activity Guidelines for Older People. However, the recommendations for the amount of activity the older population should aspire to in order to improve health are potentially unattainable for most of those aged 85 and over. The recommendations include accumulating 150 minutes a week of moderate intensity activity (such that you are slightly out of breath or warmer than usual), a further two sessions a week of activities that challenge your balance and another two sessions of activity that improve your strength.

The final main recommendation was to break up long periods of sitting, but the report was unable to specify how long a ‘long period of sitting’ was, as there has been so little research in this relatively new area. There are many ongoing studies that will answer not just this, but also what determinants of an individual’s health and social history, environmental and cultural influences and even their cognition, brain size and IQ might have on their future sedentary behaviour.

Interestingly, the notion that minimising and/or breaking up sedentary behaviour could contribute to a more active lifestyle has been a motivating recommendation for older people, because it is readily achievable and capable of being started instantly without cost or pre-planning.

This has important implications in the future health of older people. How often in care settings, both nursing homes and hospital, do older people remain completely sedentary for the whole day, perhaps only once or twice being encouraged by professionals to move around a bit. For this vulnerable age group, what harm are professionals doing if they don’t encourage or support older people to break their sitting times? What effect is this having on their mental and physical health on top of the effects of ageing? Important questions that, at the moment, we just do not have the answers to.

Physical Activity Guidelines for Older Adults: www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_128146.pdf
Maintain vision.

Catherine Dennison BSc, PhD
Head of Research – Health and Social Care with Thomas Pocklington Trust. Pocklington provides housing and support services for people with sight loss in the UK. It also funds and manages a programme of research centred on alleviating the effects of sight loss.

Key messages

Policy-makers and politicians should include eye care in outcome frameworks for services that work with the oldest old, e.g. general practice and care homes, should include eye health in their outcome frameworks.

Practitioners and care-givers need to encourage and support the oldest old to have a sight examination as regularly as their optometrist recommends, which may be annually.

Many older people believe that deteriorating sight is inevitable and nothing can be done. However, even in very old people, a high proportion of sight loss is preventable and/or treatable.
There are almost 2 million people in the UK who are living with sight loss that has a significant impact on their daily lives. Losing our sight is increasingly likely as we get older. One in every three people over the age of 85 has sight loss. Many older people believe that deteriorating sight is inevitable and nothing can be done. However, even in very old people, a high proportion of sight loss is preventable and/or treatable.

Refractive error (problems with focusing) can be corrected by wearing appropriate spectacles. Sight examinations are free to those over 60 and support with the cost of glasses is available for those on low incomes. Those working with the oldest old should encourage regular, usually annual, sight tests, and be on the lookout for deterioration in the interim. If a resident is unable to attend an optometrist’s practice, a home visit can be arranged. Support to ensure that the correct spectacles are worn is crucial, especially in care homes where 50 per cent of residents are wearing the wrong ones.

Cataract surgery, to replace a cloudy lens causing blurred vision, is a common NHS procedure that can be done with local anaesthetic. The average age of cataract patients is 75 years. With careful assessment and support, cataract surgery is still possible for those with dementia and can have benefits.

Other eye conditions such as diabetic retinopathy, age-related macular degeneration, and glaucoma can be helped through early diagnoses and treatment. Regular sight examinations are essential to detect potential problems. When an individual has another health condition such as hearing loss or dementia, adapted tests, special equipment and a modified examination help ensure to the best results. Crucially, other health conditions, such as stroke and dementia may cause vision problems.

For those experiencing untreatable sight loss, support to come to terms and make adjustments to daily living can make a difference to staying safe and maintaining independence. Older people with sight loss are at greater risk of falls, depression and isolation. However, a wide range of professionals have the potential for positive intervention. Low-vision professionals, such as vision rehabilitation officers, and local sight-loss societies can help with adapting the home environment; for example, by improving lighting and training in the use of magnifiers; enabling daily tasks; and accessing social and leisure activities. Occupational therapists, care home and nursing staff all have a role to play in enhancing quality of life.

Pocklington has existing guidance on adapting the physical environment to better meet the needs of older people with a visual impairment, and has commissioned new advice on how design of residential settings can take account of co-occurring dementia and sight loss. See www.pocklington-trust.org.uk. RNIB and Age UK have a guide to adapting older people’s services to support sight loss: see www.rnib.org.uk

1 in 3 people over the age of 85 has sight loss
Keep teeth and mouths healthy.

Key messages

Most people aged 85+ have at least some of their natural teeth.

Preventive dentistry is essential to their health care needs.

Preserving oral health has a positive impact on eating, general health and social wellbeing.

Good oral health is important for quality of life, requiring oral comfort and hygiene, an ability to chew and swallow foods and the absence of oral disease.

Maintaining good oral health in later life is important for health and wellbeing. Poor oral health can profoundly disturb eating and speaking and is associated with under-nutrition. Furthermore, teeth play a prominent role in easing or inhibiting social activity in the oldest old. Frailty may disturb past routines like everyday oral health practices and going to the dentist.

Complete loss of teeth and their replacement with dentures used to be the norm with age but is becoming an exception. The proportion of those aged 85+ with no natural teeth declined from 80 per cent in 1988 to just 30 per cent in 2009, with significant implications for oral healthcare.

With over two-thirds of the 85+ population retaining at least some natural teeth, prevention of decay is paramount. The gums recede with age, exposing the roots of the teeth, which are more prone to decay. The flow of protective saliva is often reduced because of medicines taken to manage chronic disease. Traditionally the sugar content of foods provided in residential care is high – but limiting sugar consumption is an important caries preventive measure for all age groups. Good oral hygiene and exposure to the protection of fluoride (through twice-daily brushing with a fluoridated toothpaste and through water fluoridation) are vital.
Wearing dentures can impact negatively on quality of life, with increasing difficulties managing dentures as facial muscles weaken and dentures become ill fitting with time. This causes problems with eating and speaking, which may complicate the management of frailty. Denture wearers are less comfortable eating with others and avoid social interactions due to eating problems. This may be worse when a person in residential care is faced with social dining.

People over 85 are also prone to a dry sore mouth due to reduced salivary flow or wearing dentures. A dry mouth increases the risk of oral infections. Research shows that frail older people, especially those with physical impairments, often have gum disease due to difficulties with oral hygiene. A dry mouth coated in plaque can be a major reservoir for the bacteria that cause pneumonia.

Good oral health is important for quality of life, requiring oral comfort and hygiene, an ability to chew and swallow foods and the absence of oral disease. Some impairment with age is to be expected. With increasing frailty it is often necessary for carers to provide personal oral health care along with other aspects of bodily hygiene; dentists can advise carers on appropriate techniques. Dentists may identify a range of problems in the mouth that could be treated; care plans need to be tempered by an appreciation of a patient’s tolerance to care, to an acceptable level of oral health impairment and their autonomy.
Oral health should be managed as part of general health, with oral health professionals being members of the multidisciplinary management team. Furthermore, primary health care personnel and both formal and informal carers should be trained in the delivery of oral health care for older people.

Care pathways for older people should include assessment of their disease risk as well as their ability to access care, which can be impaired because of mobility. Dentists and other members of the dental team may be able to provide domiciliary care services for the frail and homebound. Access to care may also be limited by financial constraints as dental charges continue to be payable beyond retirement age, unlike any other aspect of NHS health care.

The bottom line is that there has been little research on the nutritional needs of the oldest old. Neither the major national authorities in the UK, USA or Australia nor the EU (through the European Food Safety Authority (EFSA)) provides any specific nutritional guidelines for people aged 85+. The Food and Nutrition Board, Institute of Medicine (IOM) in the USA and the Scientific Advisory Committee on Nutrition (SACN) in the UK offer recommendations for those aged 70+ years and 75+ years respectively. However, to a large extent, these recommendations are based on evidence from younger adults with unknown relevance for the oldest old.

Those aged 85+ are a very diverse section of the population, ranging from relatively healthy, active individuals to very frail individuals with multiple diseases and disabilities. This diversity creates both practical and conceptual difficulties in undertaking research on the nutritional needs of the oldest old and in making recommendations with wide applicability. The nutritional needs of the oldest old have been identified as a research priority by the British Nutrition Foundation’s Task Force report, *Healthy Ageing: The role of nutrition and lifestyle.*
What we know already

Food is a key contributor to enjoyment, health, and wellbeing at all stages of the life-course and remains important for physical, psychological and social wellbeing in the oldest old. The amount of physical activity undertaken by the oldest old is a major determinant of energy needs, so that those who are least active – through frailty, disability or disease – are most at risk of nutrient deficiencies because they eat less food. Meeting the nutritional needs for some nutrients may be a particular challenge for those aged 85+ years. For example, poor appetite may lead to inadequate protein intake, which is a risk factor for the development of sarcopenia (loss of muscle mass and function) and, therefore, physical frailty. Synthesis of vitamin D in the skin is reduced by age per se and by lack of exposure to sunshine (e.g. for those who are housebound) and low vitamin D status contributes to the risk of several age-related diseases and of low mood and depression.

Vitamin B12 uptake from the gut is impaired in those with atrophic gastritis (a common stomach problem in older people) and vitamin B12 deficiency can damage the nervous system, leading to balance disturbances and, possibly, more rapid cognitive decline. Further, some drugs, widely used by the oldest old, have adverse effects on the sense of taste, on appetite or on nutrient use by the body.

What we hope to learn

Prospective studies, such as Newcastle 85+ Study, which are investigating the relationships between nutrition and health of the oldest old, will help to fill the evidence gap by identifying eating patterns, and measures of nutritional status, which are associated with better, or worse, health and wellbeing. However, there is an urgent need for sustained investment in this research area to provide the robust scientific data on which recommendations of the nutritional needs of those aged 85+ can be made with confidence.

To find out more, please visit:
www.ncl.ac.uk/iah/research/areas/biogerontology/85plus
www.nutrition.org.uk/nutritionscience/life/older-adults
Kevin Morgan  BSc PhD  
Professor of Gerontology and Director of the Clinical Sleep Research Unit at Loughborough University. He graduated in psychology from the University of Ulster before completing his doctoral research into the psychopharmacology of sleep and ageing at the Department of Psychiatry, University of Edinburgh. Since then he has developed broad research interests in health and psychological wellbeing in later life, focussing specifically on the causes and treatment of insomnia.

---

**Key messages**

For many people in the fourth generation, excessive daytime sleeping and prolonged periods spent in dimly lit environments represent a particular threat to sleep quality.

The importance of good sleep quality to the maintenance of health and personal wellbeing does not diminish with age.

Sleep problems in the fourth age can be prevented, or effectively managed, through optimal activity levels, cognitive behavioural strategies, regular exposure to daylight (or bright artificial light), and sleep hygiene.

Sleep difficulties lead to fatigue at any age. But among very old people, fatigue can rapidly impact physical stability, mood and self-management skills, leading to an increased risk of falls, withdrawal and self-neglect.
Sleep patterns change whether we are growing up, or growing old, with sleep typically becoming shorter, lighter and more fragmented throughout middle age and later life. This trend continues into the fourth age when, in addition to structural changes in night-time sleep, the 24-hour distribution of sleep may also be affected.

For many in their eighth and ninth decades, the bi-phasic pattern of daytime wakefulness and night-time sleep typical of earlier adulthood gives way to a multi-phasic pattern, with recurrent episodes of sleep during both the day and the night. These changes are not necessarily problematic. However, reduced depth of sleep, together with a weakening of the circadian (24-hour) rhythm, makes very old people particularly vulnerable to chronic insomnia (persistent problems getting to sleep, staying asleep, or experiencing unrefreshing sleep).

The research evidence shows that this vulnerability can be further increased by:

- health factors (e.g. acute illness episodes, chronic discomfort or pain)
- situational factors (e.g. disturbances of routine such as brief hospitalisation)
- lifestyle factors (particularly reduced activity levels, excessive daytime sleeping and reduced access to daylight).

Sleep difficulties lead to fatigue at any age. But among very old people, fatigue can rapidly impact physical stability, mood and self-management skills, leading to an increased risk of falls, withdrawal and self-neglect. It follows, therefore, that appropriately managing sleep and insomnia can make a substantial contribution to health, safety and wellbeing in the fourth age.

**Chronic sleep problems should not be regarded as either an inevitable or an acceptable part of later life ageing.**
Managing sleep in the fourth age

While the evidence indicates that hypnotic medication, when consumed for very short periods at the lowest possible dose, can be effective in managing some sleep problems among the oldest old, the risk of hypnotic-associated injurious falls is also greatly elevated. On the other hand, psychological and physiological approaches are safe, effective and well tolerated among those in the fourth age.

Psychological approaches make the assumption that important behavioural and cognitive contributions to sleep onset have been reduced or lost, but can be amplified or reinstated by systematically changing habits, attitudes and sleep routines. Key targets, here, are reductions in excessive daytime sleeping and night-time worry, and the preservation of healthy bed-time tiredness. In trials these approaches show sustained benefits among the majority of treated patients, with both therapist-delivered and self-help methods effective among very old people with chronic health conditions.

Physiologically, bright light is presumed to compensate for the ageing-related loss of vasopressin-secreting neurons in the suprachiasmatic nucleus. Stimulated by light input direct from the retina, these neurons are key regulators of the 24-hour sleep–wake cycle. Exposure to bright light appears to re-activate these neurons, helping to re-establish a regular sleep–wake rhythm. Of course, the best source of bright light is daylight (even when it is overcast), so regular outdoor excursions make valuable contributions to sleep quality in later life. Brighter indoor lighting, and seating closer to windows, is also effective in regulating the ageing circadian rhythm. Where a severe circadian disruption is identified, prescription melatonin (a non-sedative hormone) can be effectively used in conjunction with light exposure.

Finally, all of these approaches can be enhanced by ‘sleep hygiene’, self-help practices to promote better sleep (particularly regular bed-time and daytime routines, reduced caffeine and fluid consumption in the evening, and moderate alcohol use). The appropriate medical management of pain and discomfort can also make a significant impact. Chronic sleep problems should not be regarded as either an inevitable or an acceptable part of later life ageing.
Realise that multiple health issues are the norm.

Key messages

Most healthcare, clinical education and research focuses on single diseases, while most of their oldest patients have several.

Treatment of diseases in isolation is inefficient, leading to duplication and fragmentation of care.

The prevalence of multiple health problems increases steeply with age, and these individuals often need more GP consultations and more complex and structured care than those with single conditions.

Multiple health problems (multimorbidity) are more common in older people. By the age of 65 years most people have more than two health problems, and this rises steeply in the over-85s. People living in deprived areas are more likely to have multiple health problems.

Recent research has shown that even young and middle-aged people in the most deprived areas had rates of multimorbidity equivalent to those of people 10–15 years older living in the most affluent areas. This is important because people with multimorbidity have reduced quality of life and worse health outcomes than do those without. People with multiple health problems are also the main users of healthcare.

Expenditure on health care rises steeply with the number of chronic conditions that a person has, so increasing multimorbidity generates financial pressures. More efficient ways must be found to manage people with several health problems, who account for 78 per cent of GP consultations.

Clinical evidence and guidelines are created largely for individual diseases, and most clinical trials systematically exclude the multimorbid and people over the age of 75 (or even younger). Research funders should ensure that trials are carried out in more representative populations and that applications proposing to apply arbitrary and unjustified age restrictions should be rejected as unethical.
Marion McMurdo MBChB, MD, FRCP (Edin, Glas, Lond), FSB
Professor and Head of Ageing and Health in Ninewells Hospital and Medical School at the University of Dundee. She also chairs the UK NIHR Age and Ageing research network. She divides her time between leading her research team studying novel approaches to delaying the onset of disability in later life, clinical work as hospital consultant in medicine of old age, and teaching. She gives regular public lectures on aspects of healthy ageing.

The dearth of research in the oldest old means that practitioners are unable to draw on the results of good-quality research in the management of such patients. A result is that people with multiple health problems can be prescribed multiple drugs (polypharmacy), each of which is recommended by a disease-specific guideline. This leads to an overall drug burden that can be difficult for patients to manage, and potentially harmful. Polypharmacy is common in the oldest old, but is not always wrong; as such people are also at risk of the under-prescription of beneficial drugs, as well as prescription of inappropriate drugs.

Polypharmacy is strongly associated with drug-related hospital admission, which accounts for 11 per cent of hospital admissions in old age. Complex drug regimens are part of the treatment burden experienced by people with multiple health problems.

Existing approaches focusing on patients with only one disease dominate NHS clinical care. Yet treatment of diseases in isolation is inefficient, leading to duplication of care, or fragmented care. And for patients, repeat requests to attend multiple clinics are inconvenient and perplexing.

People with multimorbidity have reduced quality of life and worse health outcomes than do those without. People with multiple health problems are also the main users of healthcare.
Ensure age is no barrier to accessing health services.

Key messages

The oldest old encounter problems accessing and using health services because of:

- organisational problems (e.g. poorly designed communications)
- health problems (e.g. multiple health problems mean that some are overlooked)
- age discrimination (e.g. denial of treatment solely based on age).

All these problems can be solved – policy-making and service redesign across the board must take into account the needs of the oldest old and involve service users at all stages of planning and provision.

The oldest old often face difficulties accessing and using health services. There are three reasons for this, which often overlap:

- unintended consequences of service delivery, which fail to take into account the needs of the older population
- factors related to general health, which tends to be poorer than that of younger people
- age discrimination.

Iain Lang PhD
Consultant in Public Health at NHS Devon, Torbay and Plymouth, and a Senior Lecturer in Public Health in the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for the South West Peninsula (NIHR PenCLAHRC), based at the University of Exeter Medical School.
The unintended consequences of the way the health service is organised includes things like the scheduling of appointments, location of facilities, and means of communication. Individually or in combination, challenges like these can make it hard for the oldest old to find, to get to, or to use health services. For example, the oldest old are more likely than younger adults to face challenges accessing services that cannot easily be reached by public transport. People who have difficulty seeing and hearing, or who have neurological or cognitive problems (such as dementia), often have special needs in relation to communication that are not considered by service providers.

The general health of the oldest old is often, though by no means always, poorer than that of the general population. They often have multiple health problems and there is mixed evidence on the consequences of this – some research suggests people with multiple problems are more likely to receive treatment for each condition because they are already in contact with health services, while other studies suggest additional problems may be overlooked. What is clear is that people who have dementia, in particular, are much less likely to receive high-quality care for other conditions: for example, they are likely to be kept in hospital longer than necessary.

The oldest old can be at risk because of polypharmacy (see page 68 in this volume) yet sometimes do not receive drugs that could help them because (a) prescribers are anxious or uncertain about giving potentially toxic drugs to people they consider particularly vulnerable, and (b) many trials of drug effectiveness, efficacy, and safety explicitly exclude the oldest old, so there is limited evidence of whether they work and are safe for older people.

A persistent worry among those interested in the health and healthcare of the oldest old relates to age discrimination in service provision. There are recurrent concerns that access to and receipt of services and therapies among older people are shaped by age instead of need – if this happens, then it is, of course, the oldest old who are most affected. Repeated attempts to prevent this form of age discrimination have not prevented repeated assessments finding that it still occurs.

A central aim of the 2001 National Service Framework for Older People was to eliminate age discrimination in health services and the Framework set out a series of milestones and standards to achieve this. But, for example, a recent investigation – jointly carried out by Age UK, the Royal College of Surgeons, and MHP Health Mandate – found age unfairly used as the basis of denying services in relation to surgery for cancer, hernia repairs, and joint replacements, with people more likely to receive needed surgery before the age of 75 than after. The authors found that discriminatory age ‘cut-offs’ for receipt of surgery were used and the needs of the oldest were often dismissed, based on assumptions that their problems were an inevitable part of ageing. Tightening of the legal rules about age discrimination in the NHS was introduced in 2012 with the aim of outlawing assumptions about fitness for referral based solely on age and of ensuring that the wellbeing and dignity of older people are promoted. It remains to be seen how effective these measures will be and health commissioners, providers, and policy-makers must be vigilant to ensure age is no barrier to accessing health services.
Plan for better hospital care.

Key messages

In order to improve hospital care for the fourth age we need to ensure that patients are treated:

- in the right bed (which might be their own)
- with the right plan for their care
- for the right amount of time
- with the right support for discharge.

Traditionally, healthcare professionals working in hospital front-door services, such as Accident and Emergency, have worked on a ‘see, treat, move’ basis. The aim was to quickly understand the main reason a person has come to hospital, treat it the best we could at that time, and move on to the next patient.

This model of care fails the oldest old in society as they are often coping with a multitude of physical, mental health and social problems. As such they rarely come to hospital with one single ‘problem’ to solve. A holistic overview is needed to pull together the pieces of the jigsaw and look at the person as a whole to provide appropriate care and treatment.

In order to try to improve care for these patients delivered through front-door services and provide guidance for healthcare professionals treating them, The Silver Book was launched in June 2012.

A core focus of The Silver Book is to highlight the skills, knowledge and attitudes needed by healthcare staff to ensure that they are better able to assess, manage and support very old or frail people. This includes appropriate communication, assessment and risk management skills, and improved understanding of services available within the community. The Silver Book considers all the healthcare professionals a person living in their fourth age might come into contact with in an emergency situation and suggests standards and responses for each service.
The Silver Book also recommends ways to try to reduce the number of very old patients who are admitted to hospital who could be treated elsewhere (such as home sweet home!) and improve the experience of those who do need to be admitted to hospital. As an age group, these patients make up a smaller number of those actually arriving in the emergency department, but once there they are far more likely to be admitted and stay in hospital for longer. And, once admitted to hospital they are not only at high risk of falls, fractures or infections, but when ready to leave they are more likely to be discharged to care homes rather than returning to their own home, and to be readmitted to hospital within a short space of time.

The reasons for readmission in the oldest old are not completely understood, but what little research there is suggests that, as they are probably due to a combination of physical, mental health and social factors, a simple solution seems unlikely. Recent research by Age UK in this area (Older People’s Experience of Emergency Hospital Readmission, 2012) advocated developing good practice on what older people and their carers might expect on discharge from hospital, which could be developed in a similar way to The Silver Book.

Challenging times lie ahead for health services throughout the world. The economic recession and ageing population are conspiring to produce a perfect storm. Healthcare providers are having to commit to radical cost-cutting at a time when demand for services is soaring. Initiatives such as The Silver Book should be encouraged, efforts focused on getting things right for patients and a move towards delivering safe and appropriate care as close to the patient’s home as possible.

More details of The Silver Book can be found at: www.bgs.org.uk/index.php?option=com_content&view=category&layout=blog&id=207&Itemid=888
Living long and ageing well: insights from nonagenarians.

Key messages

The oldest old often ‘feel younger’ than their age; they still want to engage with life and people.

In addition to physical and mental health, personality may be a factor for longevity.

People who survive to this age can tell us a lot about achieving a long, healthy life span.

‘I don’t feel 90, just 21 and a wee bit.’

This is how Ethel, who is 93 years, laughingly replied when asked what age she felt. Her sister Maud (95), of the same frame of mind, quipped:

‘I would like to try and reach 100 – and over it.’

Lillian celebrated her 100th birthday last week and laughingly reported:

‘I danced up until I was 99... I loved waltzing and dancing; I did all the jiving!’

While Norman at 92 years young, supposes that his:

‘plain diet – not too much sweet stuff or sugar’

contributed to his longevity.

Dorothy in her 93rd year is ever positive, saying:

‘[I] always made the best of things.’

Samuel (95), ‘going on 25’, writes books as he is:

‘interested in people and interested in life.’
Ellie (100), also enjoys:

‘Meeting people. The “craic” is always good – we laugh a lot.’

But when considering the future, she reflects:

‘I don’t look ahead, only from day to day. I worry a little, just a little, about what is going to happen if I get any less able because I would hate to go into a home and sit with a lot of people around a room – I think that would make me die, it really would. I like talk and I like to know what is going on in the world.’

Theresa (93), also thinking ahead, says:

‘I live from one day to another’

but adds:

‘My family are all very good. All very good.’

Ellie (100), recognises the importance of family genes:

‘I suppose it was the family I was born into – my mother’s female relatives all lived into their 90s. I can remember cousins and aunts, all were 90 and over... the men don’t live so long.’

Ellie’s wisdom, garnered from 100 years of life experience, has observed the differential mortality between the sexes – a question that scientists still cannot answer.

These are some of the wonderfully interesting insights that present-day 90-year-old brothers and sisters across Northern Ireland shared with us, when we asked them about the secrets of their longevity.
Across the world scientists are increasingly focused on understanding the reasons why some people live long and well and age more slowly. Do their genes tell the whole story? Or are genes and epigenetic genome moulded by environment before and during life, and by our beliefs and behaviours throughout life?

Understanding how to age better is fascinating science but has personal and societal benefits and underpins public policy about better ageing. The insights from 90-year-old participants from the Genetics of Healthy Ageing (GeHA study) help us to recognise how genes, lifestyles, behaviours and beliefs have contributed to good-quality ageing. We do well to listen and learn from their collected distilled wisdom.

**Key findings from my study**

90-year-olds thought that maintaining mental and physical interests and a family history of longevity or genes were important predictors of good-quality ageing.

Determination and hard work was another major theme important in survivorhood.

Nonagenarians valued the ‘love and support of good families and children’ and that was their wish for their children too.

Nonagenarians mostly felt younger than their years. They accepted the finiteness of their existence and ‘at peace with living for today’.

A self-deprecating sense of humour, optimism and adaptability twinned with a feisty independence defined the successful ageing personality.

Nonagenarians are telling us the same public health messages that today we recognise as the building blocks for good-quality health.

Nonagenarians have adopted beliefs and behaviours throughout life that seem to have ‘nurtured’ genes inherited through ‘nature’.

About the research: nonagenarian participants from the GeHA and BELFAST studies have contributed their insights to these research findings published as *Super Vivere: Reflections on living long and ageing well* by Maeve Rea and Susie Rea, Blackstaff Press/Amazon. 2011.
Know that incontinence is not inevitable.

Key messages

We should be a very sceptical about the accepted dogmas on urinary tract infection. Urinary incontinence is not a ‘normal’ or an ‘acceptable’ consequence of ageing.

There is a point to treating very old people for urinary tract problems, because they respond to treatment so very well, and untreated disease creates misery with health, social, and financial consequences.

Urinary tract infections that can cause incontinence can be painless in the very old, and urinary infection tests used in clinical practice are not very accurate – over half of the time they give false negative results.

If you look at the results of the numerous clinical trials that have been conducted on the treatments of urinary incontinence, particularly urgency and urge incontinence, it is very striking that older adults are the group that respond best. In fact, if you seek evidence of the efficacy of a new drug for urge incontinence I always advise examination of the data from older adults. If it does not work for them, it is very unlikely to work for others. Thus the notion that bladder symptoms are an irremediable consequence of ageing is nonsense. We should be treating these problems in older people with energy because the results can be truly remarkable.

In the future we are going to have to learn to adopt different attitudes to urinary tract infection, which is a most important problem of late life and a cause of much suffering. For many years, dogma has dismissed much urinary tract infection in the older adult as inconsequential. There has been a misplaced faith in the accuracy of the tests used to detect urine infection in routine clinical practice. There is an understandable concern about the use of antibiotics and the consequences of prolonged exposure. Some may worry about treating urine infection on the symptoms in the face of negative tests. But such challenges must be faced with integrity.
The symptoms of urinary infection can be more subtle than many assume. A significant, painless urine infection can occur and cause a general sense of being unwell, fatigue, weakness and confusion. These symptoms are most relevant to the oldest old person. A painless urine infection can cause incontinence and frequency of urination during the day and the night. It is probable that undetected and untreated urine infection is responsible for a great deal of mischief.

Our research is starting to clarify the failings in the traditional methods of assessing older people for urinary tract infection. The hidden messages in the symptoms that people describe are being decoded. Newer, better methods of making a diagnosis are being developed. The pathology of urinary infection in the older adult is being mapped. New, safe but assertive antibiotic regimes are being tested with very promising results. We are also contributing vigorously to education programmes so that the current beliefs and assumptions can be challenged and new alternative ideas, grounded on scientific evidence, promoted.

Because I work as a clinical scientist I am very privileged in being able to witness the results of implementing novel methods for managing lower urinary tract symptoms in older people. I am delighted by what I see and have never before felt so encouraged by what is likely to be achieved in the management of this core problem of late life in the years to come. However, it will require all of us to change our beliefs and reject many cherished practices.
What views do we hold on this topic and are they informed? Most people can cite examples of older people not coping with commonly encountered technologies such as mobile phones and computers. Do our anecdotal accounts reflect how older people are appropriating technologies in their lives and even if it does, how might this change in the near future?

The Knowledge Transfer consortium that I lead (www.equal.ac.uk) held a photography competition in 2012. The aim was to challenge commonly held assumptions of how older people interact with tools and technologies. Entrants were asked to submit text with their image to explain its relevance. We were not surprised to receive photographs that showed older people of all generations enjoying readily available devices such as computers, iPads, ebook readers and gaming consoles for leisure, as well as using technologies in the workplace. There were also examples of adaptation of commonly encountered technologies to meet needs. The winning images have been exhibited at receptions in each of the four UK parliaments, as well as at a number of other events, where they have stimulated considerable discussion.

Key messages

Current assumptions and preconceptions about the inability of the oldest old to use the latest technology need to be challenged – everyone can use technology if they are adequately and consistently supported to do so.

As technology develops, even the oldest of us are beginning to use ‘mainstream’ devices, possibly reducing the need for specialist telecare products in the future.

Provide technology for all.
There are other examples from services and from research that challenge current thinking. For example, I am also leading a randomised controlled trial of group friendship through teleconferencing. This is for people aged 75 years and over, with a particular focus upon those who are less able to leave the house. It is notable that Skype is being increasingly used by older people living in care settings, as well as by those living in the community, to maintain communication with family and friends. In Sheffield we are also exploring the potential of iPads for people with dementia living in the community, following on from the work of Dawn Brooker and colleagues who looked at use of this technology in care settings. All the above examples use technologies that can be readily purchased and used in the home and/or community. They also illustrate use of technology for socialisation and leisure.

Evidence from the work of the SUS-IT Consortium demonstrates that older people can use commonly encountered technologies successfully, including the internet, if supported on an ongoing basis. Nevertheless when considering the oldest old, and particularly those who are frail, the most likely scenario of technology use involves specialist (telecare) devices to assist with the maintenance of independence, enable security and support and provide family carers with reassurance that the person is safe. It is notable that since dementia became a policy priority, there has been a burgeoning of such devices.

Telecare can enable people to remain at home who might otherwise be unable to do so. However, will this remain the case? As everyday technologies become more usable, sophisticated and ubiquitous, will the demand for specialist equipment decrease, with their functionality being replaced by readily available devices? Will older people be enabled to use the multifunctionality that many existing devices offer, thereby fulfilling leisure needs as well as needs for safety and security?

To find out more, see:

- photography competition on older people and technology: http://lefttoourowndevices.org.uk
- telephone/teleconferencing friendship researcher: http://www.shef.ac.uk/pliny
- SUS-IT website: http://sus-it.lboro.ac.uk
**Design for the fourth age.**

**Key messages**

Design is a fundamental factor in maintaining quality of life for the oldest old.

Care homes need to be designed as homes and not medical institutions.

The oldest and most dependent of us still require design that preserves dignity.

How we plan and shape our physical environment – and the products, systems and services within it – will determine levels of independence, dignity and self-respect during the last stages of life. Too much design for those in later life is accidental or incidental, and uncaring as a result. We need to pay more attention to design improvements and innovations that will enhance daily life and support clinical care for those over 85.

Better design can make a difference in a number of key areas of challenge for the oldest old.

While the majority are still living independently, this age group is likely to have severe multiple minor impairments such as loss of dexterity and visual acuity, making it very difficult to open everyday food packaging. Design of packs needs to be reconsidered to make life easier – currently too much emphasis is placed on the conservation and integrity of the food inside the pack and not enough on how to open the pack itself. New developments in materials science could be explored to improve usability.
This age group is likely to be managing chronic conditions and following a strict medication regime. So new ways to manage medications should be designed with better feedback for user and carer, making it easier to comply with the drugs programme. In particular, medication packaging could play a greater role in helping and guiding older people to take their drug at the right dosage, at the right time and in the right sequence.

There will almost certainly be more drivers over 85 on our roads in the near future. Designers in the car industry have already begun to anticipate this with simpler in-car instrumentation, self-parking cars and even automatic-braking cars, and we can expect more innovations of this type. Our streets also need to be redesigned to accommodate greater numbers of older pedestrians, many using walkers or wheelchairs, and to combat high levels of fear of crime among older people.

This age group is likely to have left the workplace before the digital revolution, so access to and understanding of new technology is difficult, leaving much of this cohort digitally excluded. Digital service providers should do more to ensure that the over-85s can get online. Designers might explore the use of pre-digital archetypes such as chalk boards, TV sets, framed mirrors and picture books as simple, familiar interfaces to the new world of the internet, as learning new things is difficult for the oldest old.

Digital inclusion has an impact on other areas of life for the over-85s, such as maintaining a social network or managing household finances. Much more design attention needs to be given to how older people engage with online social networks or manage their bank account now that the familiar world of chequebooks and bank statements is being removed.

Once inside the care home, hospital or hospice, the dependent oldest old still require well-considered design that preserves dignity. Care homes in particular need to be designed as homes and not medical institutions. The care home dining table that is too low to allow the wheelchair user to draw up close to eat, requiring a carer to spoon-feed the meal to a person who could otherwise eat independently, is simply a disgrace caused by bad design. It is also one of countless examples I have seen of the oldest age being denied the quality of life that can be achieved by a simple focus on design that is fit for purpose.

Helen Hamlyn Centre for Design, Royal College of Art: www.hhc.rca.ac.uk

Design with people: this web-based resource has been created by the Helen Hamlyn Centre for Design at the Royal College of Art to share ways to design with people: www.designingwithpeople.org

We need to pay more attention to design improvements and innovations that will enhance daily life and support clinical care for those over 85.
Recognise and prevent elder abuse.

Key messages

The causes and consequences of elder abuse are complex.

Elder abuse is about as common as dementia.

Interventions must not undermine the victim’s right to self-determination but, where cognitive capacity is compromised, safety must take precedence.

‘Elder abuse’ is the name given to a group of harms perpetrated against older people. Types include:

• physical abuse – beating, burning, spitting on, restraining using ropes, belts, drugs or other chemicals

• emotional/psychological abuse – verbal or non-verbal behaviour that reduces a senior’s sense of self-worth or dignity

• financial abuse – theft, fraud, forgery, extortion, sale of assets, wrongful use of power of attorney

• sexual abuse – assault, harassment and exploitation

• neglect – intentional or unintentional failure to meet the needs of persons who are dependent.

The oldest old need to be protected from rapacious relatives and others in a position of trust who would cheat them of their hard-earned savings and assets or who would physically, psychologically or sexually abuse or neglect them.
At the same time, it must be recognised that the causes and consequences of elder abuse are complex, and that interventions must not undermine the victim’s right to self-determination – which may involve choosing to maintain a relationship with the abuser. The caveat is cognitive capacity. Where it is compromised, the safety of the older individual must take precedence.

To date, much effort by governments and charities has been directed to awareness-raising. The time is now to move from awareness to action. Action includes attacking the ageism that underpins elder abuse and tolerance of it. For too long we have made excuses – ‘the caregiver is stressed’, ‘he has a substance abuse problem’, ‘she was fired from her job’. For too long we have blamed the victim – ‘she should have been nicer to her daughter’, ‘she should not have given Power of Attorney to her nasty son’. We need to take the same zero-tolerance stance as for child abuse – that it is simply not acceptable.

How common is elder abuse? Until recently, it has largely been a hidden problem. Prevalence rates, however, are about the same as for dementia – 3–10 per cent for ‘domestic abuse’ – that is, abuse that takes place in private households. It’s harder to estimate the rate for institutions as few methodologically sound studies have been conducted to date. The picture that emerges from the available evidence is, however, disturbing. It indicates that 80 per cent of nursing home staff have witnessed abuse – most commonly psychological (yelling and swearing) and to a lesser extent physical – most commonly excessive restraint of residents. While it’s possible that large numbers of staff could have witnessed the abusive behaviour of a small number of sadistic caregivers, it’s difficult to explain away the fact that across studies between 16 and 54 per cent of staff self-report engaging in psychological abuse and 10 per cent in physical abuse.

An important point to note is that the impact of elder abuse lasts far beyond ‘the event’. Physical abuse can be especially serious because older people’s bones are thinner and take longer to heal. Even minor injuries can cause serious and permanent damage. Loss of income and assets due to financial abuse can rob older people of their autonomy and choices, including their capacity for self-care, and living under the threat of abuse can result in earlier mortality.

With respect to risk factors, a number of studies show abusers to be dependent on the victim in some way (e.g. for housing, financially). However, risk factors appear to be different for the different types of abuse, or at least to have different weighting. For example, in the case of physical and psychological abuse, perpetrator characteristics and quality of the victim–perpetrator relationship appear more important than victim characteristics.

In financial abuse and neglect, victim characteristics are more predictive than perpetrator characteristics. Also, there may be transitions in risk factors. For example, if a woman remains functionally independent, the risk factors for abuse mirror those for intimate partner violence. If she becomes dependent, they mirror those of caregiver abuse and neglect. Marital status and living arrangement also need consideration. For example, the abuser may be a spouse or family member if the victim lives with others; a stranger if they live alone. In institutions, in addition to possible staff–resident abuse, seniors may experience resident–resident abuse, with one or both cognitively impaired.
See the need to know more.

Key messages

More research needs to include people aged 85 and over. They can successfully be included in studies.

The majority of 85-year-olds self-rate their health and quality of life as good, and a significant fraction (20 per cent for both sexes combined) have no significant functional limitations with respect to activities of daily living.

The information that informs our work on the ageing and health of the oldest members of society is drawn chiefly from the Newcastle 85+ Study, led from Newcastle University’s Institute for Ageing and Health, and from other studies with which we have been involved.

We formed this study because far too little information is yet available about the health, wellbeing and circumstances of those aged 85 and older, in spite of the fact that this is demographically the fastest-growing sector of the population. Teasing out the complex factors contributing to health in old age is a key challenge in planning for the health and care needs of today’s and tomorrow’s populations, in order to maximise health and quality of life in old age and minimise dependency.

The reason for the lack of comprehensive information about those aged 85+ is that they have generally been excluded from surveys and other studies on the grounds that they are likely to be frail, cognitively impaired and generally harder to contact than younger age groups. Yet the experience of the relatively few research studies that have specifically targeted those aged 85+ has shown that they can be successfully included in research, provided that the research methodology is appropriate to this potentially vulnerable population.
The Newcastle 85+ Study aims to do the following.

1. Assess, in great detail, the spectrum of health in the oldest old.

2. Examine the associations of health trajectories and outcomes with biological, clinical and social factors as the cohort ages.

3. Identify factors that contribute to the maintenance of health and independence.

4. Advance understanding of the biological nature of human ageing.

We have made these findings, among other things.

• Advanced old age is, as is commonly expected, found to be accompanied by significant prevalence of age-related diseases. For example, most 85-year-olds have between three and six chronic diseases. Yet by far the majority of 85-year-olds self-rate their health and quality of life as good, and a significant fraction (20 per cent for both sexes combined) have no significant functional limitations with respect to activities of daily living.

• Although only 8 per cent of 85-year-olds require 24-hour care, future growth in the numbers aged 85+ suggest a substantial increase in the numbers requiring 24-hour care. Without innovative solutions to delivering better care at home there will also be a proportionate increase in demand for care-home places.

• There exists enormous diversity among those aged 85+ with respect to all aspects of their health, wellbeing and circumstances.

Participants were visited in their own home by a research nurse to complete a multi-dimensional health assessment comprising questionnaires, measurements, function tests and a fasting blood test. Assessments have been conducted at baseline and during three follow-up visits at around 18, 36 and 60 months. General practice medical records have been reviewed at baseline and at 36 and 60 months for data on disease, medication and use of general practice services. In addition, participants are ‘flagged’ with the NHS Central Register, which provides details of the date and cause of death; it is planned to track the cohort until the last survivor has died.

Teasing out the complex factors contributing to health in old age is a key challenge in planning for the health and care needs of today’s and tomorrow’s populations.
The study is also expected to provide extensive data on the value of multiple molecular and cellular biomarkers in predicting and explaining individual differences in the health of very old people. This increased understanding of the underlying biology of ageing will potentially contribute to new insights into how the ageing process acts as the single largest risk factor for a great number of diseases and for age-related frailty and disability.

The Newcastle 85+ Study is now publishing a growing stream of research findings, which is contributing a much better informed picture of the health and challenges faced by today’s older people. As we follow the participants further into old age, the results will be become ever richer.

Yet perhaps the best finding of all is summed up in the words of one of the research nurse team:

‘We have helped our participants search for lost glasses, opened stubborn jars, changed light bulbs, searched for escaped budgies, learnt a little Braille, fixed hearing aids, taken out hair curlers and admired endless photographs of grandchildren and great grandchildren.

‘We have peered into participants’ mouths, exposed their chests, poked needles into their arms, examined the contents of their fridges, made them blow into a cardboard tube until they’re blue in the face and asked them hundreds of personal questions.

‘Throughout all this they have responded with patience, good humour and at times grim stoicism, which is typical of their generation and which makes it a privilege and a pleasure to continue to be part of this study.’

To find out more about this subject, go to: www.ncl.ac.uk/iah/research/areas/biogerontology/85plus

---

**Tom Kirkwood** CBE, FMedSci, PhD
Director of Newcastle University’s Initiative on Changing Age.

**Joanna Collerton** BmBCh
Principal Clinical Research Associate.

**Carol Jagger** PhD
AXA Professor in Epidemiology of Ageing.

All are part of, and writing on behalf of, the Newcastle 85+ Study Team.
Acknowledgements

With grateful thanks to the Age UK Royal Berkshire Committee for generously sponsoring this book.
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.