BMA

Growing older in the UK

A series of expert-authored briefing papers on ageing and health

'Growing older in the UK'

This series of briefing papers explore a range of topics relevant to supporting and improving people's health and wellbeing as they grow older in the UK. They have been authored by external experts and are published under the auspices of the BMA board of science. Details of the membership of the board are available at bma.org.uk/about-us/how-we-work/ professional-activities/board-of-science/people
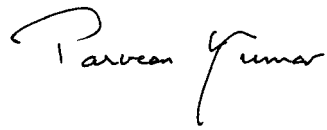
Foreword

I am delighted that the Association is developing a focus on the health of older people. Statistics in these briefings highlight that our society is ageing, yet too commonly, the health needs of older people can go unmet. It is essential that we focus greater attention on supporting the process of growing older, and strive for a society in which everyone can look forward to a healthy later life.

By asking external experts to author this series of briefing papers, the BMA is seeking to explore some of the key issues faced by us all as we grow older. We also need to challenge ourselves, as doctors, to think about the individual actions we can take to support older patients and to help create an environment which supports healthy ageing. I am therefore enormously grateful to the authors who have kindly contributed to each of these papers.

Beyond the challenges and barriers identified in this work in old age, we should not forget the major contributions that older people make to society. Far too often older people are regarded as a 'problem' rather than an 'opportunity' of what they can provide from their vast experience and maturity. As part of the BMA's work in this area I would like to help see the perception of older people shift away from being viewed as passive or dependent consumers of finite resources. I would like to see a society where older people are valued, and where everyone is supported to maximise their potential as they grow older.

I hope that these briefings will serve as a foundation for the BMA and others to pursue further work, and that they will help contribute to the development of a wider focus on supporting the health of us all as we age.

Professor Parveen Kumar
BMA board of science chair

Background and introduction

The BMA has a key interest in contributing to the development of effective policies to support improvements in health. Doctors are all too aware of the substantial pressures facing underfunded health services across the UK; from an unsustainable workload, and the workforce crisis in general practice, to unprecedented demand facing accident and emergency services. Contributing to these pressures, in-part, is the complexity of supporting the health of a population that contains a greater proportion of older people, more likely to suffer from multiple long term health conditions. The challenges doctors face in supporting people's health as they grow older can often be further exacerbated by fragmented health services, and poor coordination between health and social care.

Ageing: Exploring the terminology

A number of terms associated with growing older can vary in their meaning in different contexts. While 'ageing' broadly describes growing older as a process, it can be viewed from a purely chronological perspective, or also as a biological process whereby accumulating molecular and cellular damage leads to gradual deterioration of function over time.[1] Similarly, there are many different ways of defining 'older people', and perspectives on what constitutes being 'old' can differ widely.

Statistics on ageing often categorise 'older people' as being above a certain age. For example, the ONS (Office for National Statistics) commonly quote data on individuals aged over 65,[2,3] and those aged over 85 have been described as the 'oldest old'.[2] The WHO (World Health Organization) have defined an 'older person' as someone 'whose age has passed the median life expectancy at birth',[1] which in the UK is currently 81.2 for men and women combined.[4] Whilst categorisation by age can be useful practically and for understanding broad trends, significant differences exist in the age people consider to be old, and the loss of functional ability (or 'functional decline') typically associated with ageing is only loosely related to a person's chronological age.[1] Functional decline is linked to frailty, which has been defined by the British Geriatric Society as 'a distinctive health state related to the ageing process in which multiple body systems gradually lose their built in reserves'.[5] Frailty is a distinct — though potentially overlapping — concept from multimorbidity, which can be defined as the co-existence of two or more long term conditions.[6]

This series of briefing papers are not necessarily intended to refer to one specific age group, to focus solely on the 'oldest old', or only on those with specific health conditions. Each of the briefing papers adopts a different perspective depending upon the topics covered. Exploration of the social determinants of health, for example, includes discussion of the cumulative experience of social, economic and environmental circumstances throughout life and their impact on health in older age, starting from before birth. Discussion of health and social care services, on the other hand, adopts a more specific focus on getting services right for those older people with long term conditions.

In 1986, the BMA published *All our tomorrows: Growing old in Britain*.[7] In the 30 years since, the median age of the UK population has increased from 35 to over 40 (**Figure 1**), with the proportion of the population aged over 75 increasing from 6.5% to 8.0%, and now totalling over 4.5 million people.[8] This is a trend broadly reflected throughout Europe (**Figure 1**). It is projected that the population over 75 in the UK will double in the next 30 years, and by 2040 nearly one in four people will be aged 65 or over.[9] These demographic changes have been driven — at least in-part — by significant improvements in life expectancy, which in the UK increased from 70.0 for men and 76.0 for women in 1980, to 79.0 and 82.5 respectively by 2013.

These improvements in life expectancy are a cause for celebration, though too often these extra years of life are spent in poor health and/or social isolation. A comprehensive public policy approach is therefore required to ensure the health and wellbeing of a population that includes a greater proportion of older people.

Action in this area needs to extend to more than just the absence of disease; it should look to support the ability and opportunity for people to play an active role in society and shape their own lives as they grow older. A policy framework intended to support 'healthy ageing' must also seek to ensure people can fulfil their potential and flourish in older age.
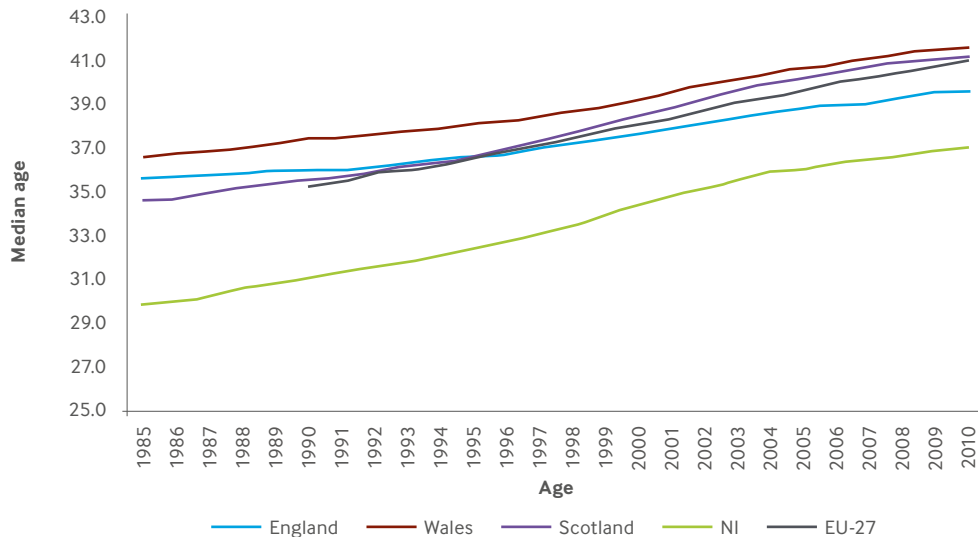

Figure 1. Median age by UK country and in the EU 1985-2010.[2]

Healthcare that meets the needs of older people

In general, older adults access health services more frequently than younger individuals. In England, for example, people aged 65 or over account for approximately one in six of the population but one in two hospital bed days and a third of all outpatient attendances.[10] This reflects similar trends in health services across the rest of the UK.[11,12,13] In Great Britain in 2011, the proportion of people aged 16-44 reporting a limiting long term illness was 12%, compared to 47% in those aged 75 and over.[14] It is therefore essential that health services meet the requirements of older individuals. Yet when surveyed, 52% of people aged over 65 in the UK agreed that those who plan services do not pay enough attention to their needs,[9] and shortfalls in care have been highlighted for a number of common age-related diseases.[15]

Healthcare systems tend to focus on single conditions;[16] frequently lack co-ordination between health and social care;[17] may be difficult to access, and can fail to deliver fully 'person-centred' care — taking into account individuals' needs, circumstances and preferences.[18,19] These services also often do not adequately support the mental health and wellbeing of older people. A significant proportion of older people in hospital have mental health conditions, and it estimated that 22% of men and 28% of women aged over 65 suffer from depression, yet an estimated 85% of older people with depression receive no help from the NHS.[9] There is a continuing need to explore the potential for greater integration between health and social care and between different parts of the health service,[a] as well as to ensure sufficient access to these services, including in rural communities.

Negative perceptions of older people that may be prevalent in wider society can commonly be reflected within healthcare settings.[20,21] The language surrounding the health of older

a   Further information on the BMA's wider work on integrated care is available here.

people frequently aligns with ageist stereotypes,[20,22] and despite age being a protected characteristic under the Equality Act,[b] ageist attitudes may influence the care older people receive.[23,24] Too commonly the economic and social contributions older people make to society go unrecognised.[25,26] Older people are often portrayed as a 'burden', as a 'passive' group with high dependency.[26] It is important to challenge these assertions, to recognise the value older people add, and to focus on seeking to ensure people can continue to make these contributions as they grow older. Only a small proportion of older people in the UK are dependent on others for care,[27] and it has been estimated that people over 65 make a net contribution to the UK economy of £40 billion, through, amongst other things, their taxes, spending, the provision of care and volunteering.[27, 28]

It should be recognised that professionals working within health services themselves are also ageing, may suffer from age related health issues, and are frequently carers. It is important that the NHS, as an employer, takes steps to adequately support an older workforce, to ensure healthcare professionals are able to maximise their potential as they grow older.

Supporting a life course approach to growing older in the UK

An individual's health as they grow older is significantly dependent on their health throughout their lives.[29] This is influenced by the cumulative impact of social, economic and environmental conditions in which people are born, grow, work, live, and age – the 'social determinants of health'. The development of a number of the long term health conditions that commonly affect older people – including cardiovascular disease, diabetes and dementia – can be affected by exposure to a range of modifiable risk factors.[30,31,32] Exposure to these risk factors accumulates throughout the course of a person's life, and can be significantly influenced by these determinants.[33] Healthy ageing therefore needs to be viewed as an active process – beginning from before birth – whereby people are supported to maintain their health over the course of their lives.
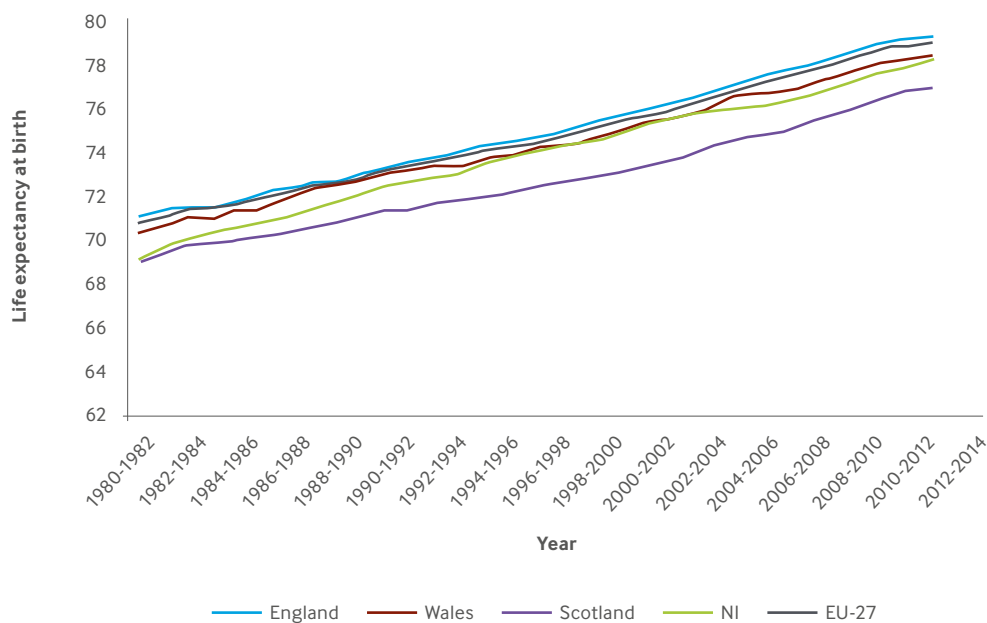
Figure 2. Life expectancy at birth by UK country 1980-2014.[34]

Despite overall improvements in recent years, there continues to be significant social gradients in life expectancy and healthy life expectancy throughout the UK.[35] Individuals living in the least deprived parts of England, for example, can expect to live for 7.9 years longer than those in the most deprived, and in good health for 16 years more.[36] Those

b   Further information on discrimination and the Equalities Act is available here.

living in Scotland, Wales and Northern Ireland continue to have lower life expectancy than individuals living in England (**Figure 2**). [34,37] A man aged 65 in Harrow could expect to live for a further 20.9 years compared with only 14.9 years for a man in Glasgow City.[38] Action to reduce health inequalities needs to extend beyond the health system, into social and economic policy that addresses the social determinants of health. This reflects that healthcare has a relatively limited impact on a person's overall health, which is largely determined by factors beyond a doctor's clinical influence. Action on reducing health inequalities – so that as individuals grow older they can remain healthier for longer – expands opportunities for them to make a positive contribution, be it through work, volunteering or fulfilling caring responsibilities.[9]

Maximising participation of an older population

The WHO have defined 'active ageing' as 'the process of optimising opportunities for health, participation and security to enhance quality of life as people age'.[1] This involves more than maintaining physical function, but reflects the importance of promoting the ability for individuals to continue to participate in 'social, economic, cultural, spiritual and civic affairs'.[39] To support this, concerted action is required to facilitate access to local services and amenities and to reduce social isolation among older people. It is estimated that 17% of older people are in contact with family, friends and neighbours less than once a week,[40] and nearly half of all people aged 75 and over live alone.[9]

Social isolation is linked to loneliness; in the UK, 10% of people aged over 65 report that they always or often feel lonely.[9] Social isolation and loneliness can have a significant impact on the quality of life and mental health of older adults – underlining the importance of identifying and reducing barriers to older people's participation in society.

Older people make substantial contributions to the UK economy, through employment, informal caring, childcare and volunteering.[28] Approximately 10% of people aged over 65 are in work in each of the four nations of the UK.[41,42,43] Over recent years there have been significant increases in the proportion of older people with caring responsibilities. The number of older carers increased by 35% between 2001 and 2011, and there are now over 1.2 million carers aged over 65 in the UK.[44] Despite the contributions older people make to society, they are often not valued for the role they play, nor receive sufficient support in doing so.[9] Long term caregiving can have a substantial impact on physical and mental health,[45,46] and the provision of adequate support is essential to ensuring the health, wellbeing and independence of older carers, and the people they care for.[46] Older workers can face substantial challenges in combining work and caring responsibilities in later life, which can have a significant economic impact,[47] and older jobseekers often face substantial barriers to employment.[48]

What action is required to meet people's health needs as they grow older in the UK?

The BMA board of science is publishing this series of expert-authored briefing papers setting out key issues and actions required to support and improve the health and wellbeing of people as they grow older in the UK. These cover:

— **older people and the social determinants of health** — highlighting the early life social, economic and environmental factors which shape health in later life, and assessing the impact of these factors during later life;
— **health and social care services** — exploring how the structure, delivery, and integration of health and social care services can best be developed to meet the needs of older people with complex and/or multiple conditions;
— **older people's mental health and wellbeing** — exploring some of the major issues associated with older people's mental health and wellbeing, and how this can be better supported and maintained;
— **living with long term conditions** — looking into the steps required to better support older adults manage chronic health conditions or disability;
— **the perception of ageing and age discrimination** — outlining evidence about perceptions of ageing in the UK and exploring their implications for the health and wellbeing, as well as exploring 'risk factors' at the individual, organisational and societal levels that contribute to ageism in health and social care;
— **supporting carers** — setting out ways of ensuring carers are properly supported, with a focus on those caring for older people, and older people who have caring responsibilities.

Each briefing paper sets out recommendations for policymakers and actions doctors can take to support the process of heathy ageing. They are designed to complement other work by the BMA on supporting healthy ageing. For example, the BMA's occupational medicine committee has produced a report on *Ageing and the workplace,* for publication in September 2016, which aims to provide an overview of the impact of ageing populations, discuss common myths and facts about ageing and health in people of working age and to provide information about the health and safety needs of older workers.

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1

Briefing paper

Older people and the social determinants of health

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Briefing paper (1): Older people and the social determinants of health

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Key messages:
— The cumulative experience of unequal social, economic and environmental circumstances throughout life contribute to health inequalities in older age.
— Many of the social determinants that influence the health and wellbeing of older people in later life are amenable to change.
— Preventative interventions, such as improving access to good quality environments, employment, housing, and social connectedness, are likely to see health benefits throughout the life course including in later life and are likely to ease demand on health services.
— Clear opportunities exist for doctors and other health professionals to become active in helping to address the social determinants of health through social prescribing, advocacy at a local and national policy level, working in partnership with communities and organisations, and integrating legislative levers, such as the Health and Social Care Act, 2012 and the Social Value Act, 2012 into NHS strategic frameworks and working practices.

Introduction

Later life inequalities
Older people from lower socio economic groups will likely experience worse health than those from higher socio economic groups and poor health will begin earlier in life.[1] The latest IHE (Institute of Health Equity) Marmot indicators (IHE 2015) clearly demonstrate men living in the most deprived areas in the UK can expect to live 16.5 years less than men living in the least deprived local authorities. For women in the UK the difference is 11.6 years.[2] This is largely due to social, economic, and environmental inequalities experienced across the life-course. Health inequalities can be widened, and additional inequalities created, once people reach old age, again influenced by social, economic and environmental determinants. Social class inequalities are found in the leading causes of early mortality among 65-74 year olds as well as older ages. This is not only unfair and unjust, but also very costly. Poor health and health inequalities create significant economic costs, estimated in 2009 at between £31-33 billion in lost productivity, £20-32 billion in lost taxes and higher welfare payments, and £5.5billion in direct NHS healthcare costs, in the UK every year.[3]

In this paper we first explore early life social, economic and environmental factors which shape health in later life, and then assess the impact of these factors during later life, and make proposals for action – with a focus on actions health professionals can take.

Life course drivers for ill health in later life
The cumulative experience of social, economic and environmental circumstances throughout life impact on health in older age and people from lower socioeconomic groups are more likely to experience health harming social, economic, and environmental circumstances which lead to poorer health outcomes. These can start as early as the pre-natal period and early childhood and continue throughout life.[4, 5]

Prenatal and early childhood
Disadvantaged mothers are more likely to have babies with low birth weight which impacts on infant brain development.[6] Foetuses adapting to low levels of nutrients permanently change their structure and metabolism which heightens risks of various diseases in later life, including coronary heart disease, stroke, diabetes and hypertension.[7] Maternal depression and economic deprivation can collectively and separately diminish cognitive and emotional development in children lessening school readiness, and affecting educational attainment and school grades.[8] Conversely, higher educational attainment and higher cognitive scores

are associated with less risky health behaviours (eg smoking, alcohol and substance misuse), better health outcomes, and longer life expectancy,[5] with less limiting, long term illness in older age. In the UK, figures suggest that only 52% of children have reached a good level of development by the age of five, and are school ready.[9]

Childhood: School and home life
Adverse childhood experiences also impact on health outcomes in later life.

Around half of the English population have experienced one or more ACE's (adverse childhood experiences), such as abuse or neglect, experience of domestic violence, mental ill health, criminality or parental separation. ACE's increase the risk of premature mortality in later life and a range of illnesses, including cancer, heart disease, lung disease, liver disease, stroke, hypertension, diabetes, asthma, and arthritis.[10-13] The experience of childhood trauma is significantly associated with poor mental health in later life.[14,15] The greater number of ACE's a child is exposed to increases the risks of poor outcomes in a range of life chances including health and life expectancy.[4]

Children from disadvantaged areas, living in poverty, and who experience family stress and/ or poor and harmful parenting are more likely to experience ACE's.[5, 10, 16, 17] Between 2013 and 2014 there were 3.7 million children living in poverty, around 28% of children in the UK.[18]

Housing conditions experienced in childhood may affect health in later life as well as during childhood. Children living in cold homes are more than twice as likely to develop a variety of cardiovascular and respiratory illnesses.[19] Poor housing conditions, including overcrowding, are also linked to childhood/adolescent depression, slower physical growth and slower cognitive development and limited educational attainment.[19-21] A report published by The Children's Society in 2014 found that around 3.6 million children thought their home was too cold in the previous winter, and around 1.3 million said their homes were damp or had mould.[22]

Higher cognitive development in childhood, maintained in adulthood, provides a greater 'cognitive reserve' to draw on in later life enabling people to cope better with the onset of mild cognitive impairment and dementia.[23,24] Higher cognitive development provides older people with a wider range of skills, abilities, and knowledge[25] and can delay onset and symptoms of cognitive impairment or dementia.[25] Therefore, low educational attainment can have long lasting consequences on health, limits the resources needed to cope with poorer health outcomes in later life, and effects lower socio economic groups disproportionately. By age 11, around 25% of children from the poorest quintile in the UK have not reached the expected level of achievement at Key Stage 2, compared to around 97% of children from the highest quintile.[26]

Employment and income
Being unemployed is damaging to health, and increases the risk of mortality, even for those in higher socio economic positions. The causal relationship between loss of employment or long term unemployment and poor health outcomes are mediated through issues such as increased tobacco use and alcohol consumption, and increased psychosocial stress and poor mental health.[27-29] Loss of employment can also result in long term earning losses, loss of psychosocial assets, social withdrawal, family disruption and lower levels of attainment and achievement in children of unemployed parents.[30] Unemployment, associated with low income and poverty [5] increases the risk of a variety of harmful social determinants of health, including poor housing conditions, debt, social isolation, fuel poverty, [19] inadequate diet,[31] and lack of access to green space [32] all of which increase the risk of mortality. Other research [33] has demonstrated the negative impact of involuntary job loss on older worker's physical functioning and mental health. However, not all work is protective of health. Poor work conditions, including exposure to hazards and the physical impact of manual labour and inconsistent work, cause high risk of poor mental health and physical health, including musculoskeletal problems, increased rates of long term illness, increased medication use, and lower recovery from illness.[5] Poor quality work, and unemployment have also been linked to suicide and other causes of premature mortality such as cardiovascular disease.[34] Adults who experience job strain are more likely to have diabetes, to smoke and to lead more sedentary lives, leading to increased risk of cardiovascular disease.[35] Poor quality or sporadic work, and

unemployment, prevents financial preparedness in later life, increases risk of early retirement, reduces standards of living in older age, and affects levels of social connectedness and physical activity for older people.[36-39] Between 2014 and 2015, around 2 million people in the UK were believed to have an illness or condition, either caused or exacerbated by current or previous job roles[40] and around 4.7 million work days were lost due to workplace injury in 2013 – 14.[41]

Housing

Around 34% of older people in England live in non-decent homes,[42] and those on low income are less likely to heat their homes adequately and more likely to experience fuel poverty and cold homes.[19] Living in a cold home is a predictor of poor mental and physical health, independent of other predictors such as education or income. Mould in the home, cold homes, and fuel debt are all indicators for experiencing common mental disorders.[43] There is a strong relationship between cold temperatures and cardiovascular and respiratory diseases, lower dexterity and higher levels of accidents in the home and minor ailments such as cold and flu. Fuel poverty negatively effects dietary choices.[19] Although the means of measuring prevalence of fuel poverty has been changed recently, it is estimated that 2.3 million English households were in fuel poverty, costing the NHS around £1.36 billion in related illness. In the UK, Excess Winter Deaths exceed the number of deaths caused by alcohol, Parkinson's disease, or traffic accidents every year.[44] In the year 2014/15 there were 36,000 Excess Winter Deaths in the over 75's age group.[45] The impact of fuel poverty on older people is explored further in the later section relating to Social Isolation.

Green space

Access to well-maintained green space impacts positively on both mental and physical health, and can offset the negative health impacts of poverty and low income. Access to green space is not evenly distributed across England. People living in the most deprived areas are less likely to live close to well-maintained green space and less likely to experience the health related benefits of green space. For example, the risk of adverse cardiovascular events might be increased by physical inactivity, by particulate air pollution, by social isolation and by heat-waves. Lower rates of all-cause mortality and circulatory disease mortality have been demonstrated in areas with greater access to good quality green space.[32]

Later life drivers for ill health and increased mortality

Employment and income

Physical and mental ill health, poor working conditions, redundancy, caring responsibilities and financial circumstances are all key indicators for unemployment and early retirement in later life and are all socially graded.[46] In England, older people living on low pensions and incomes can experience a gap between their financial resources and what is needed for healthy living, resulting in worse health and earlier mortality.[47] In the Health Survey for England 2005, older people from lower socio economic groups report worse general health, lower levels of fruit and vegetable consumption and higher levels of mobility problems and lower-limb impairment.[48] Similarly, the incidence of ischemic heart disease for older people is higher in the most deprived areas in England. Diabetes prevalence and uncontrolled hypertension are also inversely related to income.[48] Findings reported in the British Medical Journal found that people from lower occupational grades also experience a steeper decline in physical health than those occupying higher grades.[49] Inequalities are also found in self-reported health between occupational grades, and this inequality worsens with increasing age.[5] Inadequate income and living standards are also closely related to social disconnectedness and/or isolation in later life, leading to poor mental and physical health.[50, 51]

Social Isolation

One million older people in England report not speaking to anyone in over one month.[52] Social isolation is a key driver for poor mental and physical health in later life. Social isolation can cause loneliness, anxiety and stress and is a predictor for cognitive decline, impairment and dementia, even when controlling for symptoms of depression.[53, 54] Older people with weak social ties have a 50% higher risk of mortality than those who are socially connected.[55] Social isolation and loneliness are significantly influenced by poverty. Care givers are particularly vulnerable to social isolation and loneliness because of loss of earnings, leisure time, and the disability or symptoms of the care recipient.[56] Social engagement in later life

is protective against cognitive decline and dementia and can influence levels of physical activity, healthy eating, and other positive health behaviours.[57]

Older people on a low income are less likely to heat their homes adequately and more likely to spend increasing time at home as trips and visits with friends and relatives become unaffordable. Conversely, evidence shows that people were more likely to invite friends into their homes after improvements to warmth and energy efficiency had been made.[58,59] Older people are more likely to be fuel poor as they spend longer in their homes and require more heating throughout the winter months and are also often on lower incomes than other age groups.[60] Older people are also more vulnerable to colder temperatures, cardiovascular disease, trips and falls and respiratory illness during the winter months. Therefore older people living in a cold home have higher levels of mortality and morbidity than those in warm homes. In 2014/15 there were 36,300 excess winter deaths amongst people over the age of 75, while not all of these will relate to poor housing and cold homes, cold housing has been estimated to cause approximately 20% of excess winter deaths.[19,60,61]

Local environment
The quality of the local environment influences the health and mortality rates of older people. The risk of traffic accidents, and serious injuries, increases with age and older people have particular concerns about crossing busy roads with heavy traffic. Concerns over traffic inhibits social interaction and use of community facilities, and can lead to older people feeling excluded from public spaces.[62] A lack of appropriate amenities, lack of access to well maintained and resourced (toilets, cafes, walkways) green space, real or perceived crime levels, excess traffic, degraded pavements and roads, and lack of appropriate transport, can lead to low levels of physical activity and social interaction in older people.[32,63]

Older people living in poorer, deprived areas of England, will be disproportionately affected by these issues leading to socio-economic inequalities in the prevalence of illness and disease associated with low levels of physical activity and social isolation, including poor mental health, cognitive decline and impairment, and dementia.[64]

Black and Minority Ethnic Older Communities
BME (black and minority ethnic) communities in England are likely to have higher rates of poverty, poorer housing and neighbourhood conditions, lower education levels, and higher stress levels.[65] These determinants have an impact on the prevalence of disease within BME communities.

For example, BME groups are projected to experience a seven-fold rise in the prevalence of dementia as the population ages, in comparison to a two-fold rise in the rest of the population across the UK as a whole. BME groups in the UK are living longer, and the number of BME people over 80 is expected to almost triple. However, there is also higher incidence of risk factors such as high blood pressure, diabetes, stroke and heart disease [66] and there is a greater risk of BME communities experiencing poor health associated with socioeconomic circumstances throughout life and in older age, increasing the risks of poor mental health, cognitive impairment and dementia. Experience of racism, exclusion, and poverty are significant drivers for poor mental health outcomes in minority ethnic groups.[67]

Cancer, including lung cancer, causes the highest number of premature deaths among older adults.[68] One in four black men in the UK will be diagnosed with prostate cancer, compared to a national average of one in eight, and death rates for black males with prostate cancer in the UK is 30% higher than white men.[69, 70]

Gender
The income of women in retirement in England is, on average, around 57% of men's.[71] Fewer women (60%) have pensions than men (80%) and less women continue to work part time after retirement than men. Women tend to live longer with more limiting long term illnesses, affecting their ability to continue in employment. Single female pensioners are more likely to live in poverty and are more likely to reduce fuel use because of low income, exacerbating existing physical and mental health issues[72] and increasing the risk of social isolation, poor standards of living, and low levels of mental stimulation.

Women in England are more likely to experience poor mental health.[73] Although there is under diagnosis of depression in men, in later life women are more likely to become carers, experience the death of a spouse, move into residential care, or experience physical ill health, due to their longer life expectancy. All these events heighten the risk and likelihood of poor mental health. [74]

Women make up two thirds of all people currently with dementia in the UK,[75][76] women's longer life expectancy, and other gender specific social determinants, including low income and lower levels of access to education and employment throughout the life course, clearly increase risk of cognitive impairment and dementia.

Carers
There are around 3 million carers over the age of 50 in the UK and over 75% have some form of health concern themselves, with more than a quarter of older carers rating their health as 'not good'.[77] Older carers experience specific issues relating to their caring responsibilities, including lack of respite breaks, missed or cancelled treatment for existing health concerns, deteriorating physical and mental health, and a lack of physical exercise.[63,77,78] Depression and social isolation are two particular and common issues for carers, increasing the risk of mild cognitive impairment and dementia.[78] A separate briefing paper in this series on *Supporting carers* further explores some of these issues.

Proposals for action
Social determinants across the life course accumulate, inter-relate, and impact on the health and wellbeing of people in later life. Therefore, action on the social determinants of health, throughout the life course is needed to ensure that the social gradient found in life expectancy and healthy life expectancy is addressed. Interventions, such as improving access to good quality environments, employment, housing, and social connectedness, are likely to see health benefits throughout the life course including in later life. Many of the social determinants that influence the health and wellbeing of older people in later life are amenable to change and have the potential to improve health outcomes for older people. Ways that health professionals can support action on social determinants throughout life and particularly for older people, are described in the section relating to 'the role of medical professionals' below.

Pre-natal and early childhood
Breast feeding, good maternal mental health and educational attainment, stable households, adequate family income and decent, warm homes are all protective factors against low cognitive function in children. These conditions increase the likelihood that children will be socially, emotionally and psychologically school ready,[5,79] and able to build the skills, abilities and knowledge, known as cognitive reserve, to improve life chances over the life course and to protect against cognitive decline and dementia in later life.

School and home life
Early intervention and prevention is recommended, rather than reactive action once ACE's have already been identified. Action can be taken to address the risk factors of ACE's such as programs that promote social inclusion, or that work with families experiencing poverty, and can support improved parenting, and mitigate the stress and psychological impact of poverty. Holistic and flexible services work best to respond to the needs of families experiencing adversity.[4]

Working life
Creating accessible, good quality and well paid employment will promote healthy living standards, and good work-life balance. Employer's adherence to equality legislation, preventative measures to mitigate mental and physical health problems at work, flexible employment options, access to affordable childcare and improved working options for single and co parents will improve access to employment and conditions of work. Additionally, policies that promote financial preparedness in later life, the importance of social connectedness, and active travel to and from work, can all improve health outcomes in later life.

Later life

Employment options that take account of the needs of older people, in particularly those with disabilities, caring responsibilities, long term unemployed, and those with training needs can have a positive impact on the likelihood of older people accessing employment and improving their income in retirement. Flexible, part time options are beneficial post-retirement age.

Services that promote the health, wellbeing and independence of older people and, in so doing, prevent or delay the need for more intensive or institutional care, make a significant contribution to ameliorating health inequalities.[80]

Reducing social isolation in later life and increasing mental stimulation through improved housing conditions, age friendly environments, services and communities, improved living standards, and better access to life long learning opportunities can improve physical and mental health, including delaying the onset of cognitive decline by up to 1.75 years.[81-83]

Access to green space and physical exercise can prolong years of living independently, increase life expectancy, reduce the risk of disability, and impact on the general quality of life of older people, lowering the incidence of diabetes, cancer, migraine and poor mental health, and reduce risks of cognitive decline and dementia.[84,85]

Consideration of the role of medical professionals – including actions that doctors can take.

Clear opportunities exist for doctors and other health professionals to become active in helping to address the social determinants of health, either through collaboration with representative organisations, through direct actions with patients and communities, or through influencing local decision making and contributing to the evidence base.[86] Further reports provide additional analysis and recommendations regarding the role of health professionals in taking action on the social determinants of health. These include 'Working for Health Equity: The Role of Health Professionals' by the UCL Institute of Health Equity, 'Social Determinants of Health – What Doctors Can Do' by the British Medical Association, 'How doctors close the gap. Tackling the social determinants of health through culture change, advocacy and education' by the Royal College of Physicians and 'Doctors for Health Equity', due to be published in September 2016, by the UCL Institute of Health Equity.

Recommendation 1 – Workforce education and training

Health professionals can improve their knowledge and action on the social, economic and environmental factors which shape health by ensuring that knowledge and action is better incorporated into health professional training and education. Whilst recognising that the training and education curricula for health professionals is already crowded, training and education should also aim to improve the communication, partnership and advocacy skills of the workforce, and incorporate placements in organisations both within and external to the health service.[87] Opportunities to either improve existing training content, or imbed best practice regarding action on the social determinants of health, rather than add additional modules or appendixes to existing curricula, should be developed.

Recommendation 2 – Working with individuals and communities

Health professionals can build relationships of trust and respect with individuals, enabling them to take detailed and accurate social histories, and to refer patients to organisations outside of the health service to address the social determinants of health. Increasing the use of social prescribing will help address the root causes of health inequalities. Health professionals can also work collaboratively with communities, utilising patient social history information, to help health and other organisations better understand the needs of their local population, improve the uptake of services, and promote patient empowerment and self-efficacy.[87]

Recommendation 3 – NHS organisations

The NHS commissioning power can be used to the advantage of local communities, promoting employment opportunities, including through social value procurement. [88] NHS organisations can also utilise their role as managers and employers to ensure that staff employed by the NHS have good quality work with the appropriate training and support. The NHS can also promote a culture of fairness and equality through ensuring that strategies to facilitate action on health inequalities are implemented at every level throughout NHS organisations.[87]

Recommendation 4 – Working in partnership

Partnerships can be developed with organisations within the health sector and with external bodies. Within the health sector partnerships should be 'consistent, broad and focused on the social determinants of health.' Partnerships with organisations outside the formal health service, such as the partnership initiated in 2010 between Turning Point, a third sector substance misuse rehabilitation organisation and Camden and Islington NHS Foundation Trust, should be extended and facilitate integrated work to address the social determinants of health. Clinical Commissioning Groups are well placed, as locally based consortia, to incorporate health equity and social value into commissioning decisions, and to measure progress against them.[87]

Recommendation 5 – Workforce as advocates

Health professionals, where appropriate, can act as advocates for their patients, ensuring they have access to the most appropriate services to address the root causes of their physical and mental health needs. Health professionals can also work as advocates on a local and national policy level, sharing local population information and needs, and working to improve the social, economic and environmental conditions of patients. Health professionals can also advocate for change within the health profession, helping to create a greater focus on the social determinants of health and preventative strategies that reduce inequalities.[87]

Recommendation 6 – Using legislation

The Health and Social Care Act 2012, the 2012 Social Value Act and the Equality Act 2010, which includes age as a characteristic protected against victimisation, discrimination and harassment, provide opportunities to tackle health and other inequalities. Health professionals can use these Acts as levers to ensure that the reduction of inequalities in health outcomes is integrated into the strategic framework of the NHS, and into its working practices, and incentivised and monitored appropriately.[87]

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2 Briefing paper
Health and social care services that support the needs of older people

Author: Professor Jill Manthorpe – King's College London

Briefing paper (2): Health and social care services that support the needs of older people

Author: Professor Jill Manthorpe – King's College London

Key messages:
— Whilst there is substantial evidence that population ageing does not cause unsustainable inflation of health and social care budgets, cuts in local government services are deep and having effects on whole services. Cost and patient shunting practice are likely to undermine further the parlous state of local government finances.
— When talking about 'integration', it is important to clearly set out what is being integrated with what or whom.
— It is important to be mindful of the stresses inherent in services that do not know what is happening to their contracts or futures. Communities of practice or similar local initiatives can help practitioners understand each other's demands and pressures.

Introduction

'Imagine yourself without some or most of your basic abilities – the things
which you rely on in everyday life, often unthinkingly because they are
there, which go to make you a person in your own and others' eyes: imagine
yourself in this situation permanently or temporarily, from birth or at a
later stage of life: imagine yourself with or without ill-health as well as
a disability – with full or with limited ability to think or judge for
yourself, with or without a close carer, a caring relative, friend or
neighbour – with a reasonable income or not – resilient or worn down –
with needs, wishes, fears and anxieties, hopes , abilities, a contribution to make . . .
What help would you need for a reasonable life? ie, reasonable in your eyes?
– How would you want that help to be given?
– How would you want decisions to be made?
Answers to these questions help to define social care – a definition which
for each individual varies with the hugely variable circumstances of
ability, disability, life...'
(Plank, 2015)[1]

This briefing explores how the structure and delivery of health and social care may best be developed to meet the needs of older people in the UK (United Kingdom), focussing on England in the main. Health services and systems need to be designed to support older people with complex and/or multiple conditions – because their needs are often poorly met by the current arrangements in the NHS that focus on acute care. But other problems arise from the separation of responsibilities between the NHS and local authorities. The need for more integrated care is often presented as a magic solution to these problems and this briefing considers the need for caution about seeing any one organisational change as simple or easy to do. Within social care in in England in particular, there is not a lot of integration (there are over 25,000 care providers for example) and poor outcomes and experiences are often feared or reported.

A (brief) background

How did we get to this position? A short briefing paper is not a historical monograph but a bit of history helps. It helps in understanding the world we are in, but also what has been tried before, and, when working with older people, in understanding their expectations.

Many reports start with a standard history – going back to the founding of the welfare state – for obviously the setting up of the NHS is a pretty good place to begin; but others go back further and talk about continuities with the Victorian Poor Law and the establishment of workhouses and poor law hospitals and asylums. These are useful accounts. But in this briefing paper I am going to ask readers to look around the area where they work and see some of the past or listen to accounts of earlier systems.

First – in many areas there are NHS hospitals – whether teaching or acute, whether Foundation or Trusts. Most of them will be orientated to treatment for medical conditions that have enabled local populations to live well, to avoid disabilities and sickness that would have dominated the lives and worries of their parents or grandparents. They stand amid the ghosts of separate hospital provision for older people that was closed down – long-stay geriatric wards, poor law infirmaries, wards for the incurable, and wards or hospitals for mental illness, including what we would now term dementia.

Second, down local streets or on housing estates there will be large and not so large local authority (council) buildings – again some survivors of the Victorian age – in which local services were funded (by local taxation/rates) that evolved to include responsibilities for people who were too ill or frail or unable to care for themselves. The Second World War prompted many such services, funded by local authorities, to provide living accommodation for older people in hostels, help at home with housework and care for the sick (to enable women to work), home delivered meals, and other aids and assistance. Following the War, such services were permitted, then made mandatory, but from their beginning it was seen as a matter of dignity that people would pay for them. Later on local authorities were able to build day centres, sheltered housing, old people's homes, and develop their home help services. You may look for these and find some– but many have gone – closed or been sold/ transferred to other providers. Interestingly (but beyond the scope of this review), central government has renewed local authority's public health responsibilities.

Third, there are now huge private providers (and some not for profit providers) of care services, particularly home care and care home businesses. You will no doubt recognise some of the big chains – but in your area there are also small family owned businesses and some not for profit suppliers – some of these having their origins in provision for retired employees or in religious organisations.

There are four main implications of this – most pertinent to England but applicable to the rest of the UK. First we talk about social care as if it is one body; it is not. Second, it covers a wide range of services – ranging from specialist clinical services staffed by professionals, including some doctors, but also nurses and other allied professions to very small independent community groups running largely with volunteers, who may see themselves more as community groups rather than care providers. And third, while local authorities have some responsibility for shaping the market of social care and pay for some care services for some older people, they are not able to control what happens to any great extent. For example, in many care homes a majority of residents pay their own fees. And finally, the question of funding is complicated in social care. At the level of the individual there is local authority means-testing – often unpopular – but also social security benefits to cover the extra living costs incurred by disability and providing family care (some also means tested). There is a complicated mix of funding streams from central government – spanning direct grants to local authorities for social care but also housing and care services. There are government rules on how local authorities should spend their money and what they should set as thresholds for eligibility, and there is pressure to reduce public expenditure.

In Scotland, things are slightly different and one interesting development from devolution has been the 'natural experiment' occurring in social care between England, Scotland and Wales, with Northern Ireland having a long tradition of more integrated commissioning and services. In Scotland the Community Care and Health (Scotland) Act 2002 introduced free personal care as a legal entitlement for people aged 65 or over, although services which are not personal care are chargeable (eg housework, laundry or shopping).

It is not so much how things are organised but what happens in practice that has led to a chorus of demands again to 'do something' about the 'crisis' in social care. Key problems are social care quality; social care sufficiency and social care capacity. Again, just to provide concrete examples of this, you will find that there is high turnover among social care staff; many experience problems in getting enough home care support at the right time for people leaving hospital and you will likely hear that older people's needs are now not 'high enough' to get local authority social care support. A telling figure is that while the numbers of older people are rising, the numbers of older people receiving publicly funded social care support are falling.[7]

Currently there are two Commissions on this very subject proposed or underway,[2,3] and the 'crisis' of social care is reported as a reality in many circles,[4,5] or imminent.[6] Indeed, its very demise in the form of public funding has been prophesied.[7] For some, the term crisis is insufficient – social care is becoming a 'catastrophe'.[1]

We have been here before - in a mild sense. In 2014, the King's Fund published the interim report of the Commission on the Future of the Health and Social Care in England (the Barker report), '*A New Settlement for Health and Social Care*'.[8] It opened with a discussion of the history of relations between health and social services, called for "better integration," and predicted "hard choices" lay ahead. While the history provided by many report writers is a useful corrective to professional and public ignorance about how health and social care have evolved,[1,2] the Barker report followed others in being rather vague about the mechanisms of integration across disciplines, sectors, businesses and localities and was met by what Chris Ham, Director of the King's Fund, termed a deafening silence from the three main political parties.[9]

The weight of evidence – solutions and resolutions
While older people seem almost to be blamed for the crisis in care; there is substantial evidence that population ageing does not cause unsustainable inflation of health and social care budgets although it contributes to rising demand and greater expectations and may continue to do so among the 'younger old'. The main drivers of rising healthcare costs are improved technology and the costs of professional practice, not just ageing (see Evans et al 2001).[10] More than half of all NHS expenditure in England goes on those under 65, as does virtually half of social care expenditure (Barker 2014). Social care funders in local authorities (commissioners) have responsibilities for care and support for other age groups, and some of their needs and numbers are increasing, such as people with profound and complex disabilities who are now living into adulthood. For many local authorities this group present a major resource challenge even if the high eligibility thresholds for social care remain in local authorities.[11]

Tighter eligibility rules (in response to budget cuts and as a consequence of wanting to target services) have reduced access to publicly funded social care overall, so much so that there can seem little left to integrate. To take care home services as one example (and drawing on UK figures since there is not much difference between different regions/countries), 175,000 older residents (43.4%) paid the full costs of their care home fees in 2012.[12] A further 56,000 (14%), while being funded by local authorities, also relied on 'top-ups' from family or friends. Thus a total of 231,000 older residents were paying in full or in part from their own or their families' resources — that is, 57% of all (403,000) older residents of independent sector care homes in the UK. The remaining 43% of residents either had their fees paid in full by local authorities (143,000) or by the NHS's Continuing Healthcare scheme (29,000).[6]

As noted above, Fernandez and colleagues (2013) have shown that the number of older people receiving state supported community based social care in England fell substantially, by at least 31% between 2005-6 and 2012-13.[13] This has occurred without much public debate, just as the transfer of care homes from the public sector (local authority) to the commercial occurred quietly in the 1990s. For many care homes their relationships with primary care, let alone secondary healthcare, has been disappointing. For older residents there are feelings of being disenfranchised from the NHS once they move to a care home. A recent report from the Alzheimer's Society (2016),[14] drawing on a survey of care home managers, found that almost half of the survey participants thought the NHS was not providing adequate and timely access to services such as physiotherapy, continence services, and mental health services for their residents with dementia. Instances were reported by the managers and residents' families of care home residents being left bed-bound, incontinent, and sedated because the healthcare services were too slow in responding to their needs.

The view that a heroic restructuring of health and social care is needed has its adherents although most commentators focus on the short-term problems or crisis management.[1] There are mixed views about social care being free at the point of use — ranging from those in the baby boomer generation wanting to keep and pass on their generation's housing wealth while having their own care paid for by a third party, while others see it as firmly part of the social contract and a necessary ingredient of integration.[4] And, as the Scottish system of 'free' personal care shows, there are debates over what actually is personal care. There is greater consensus that long term or chronic underinvestment in social care means that social care services cannot keep up with hospital discharge, so causing delays, while split budgets lead to cost-shunting with inevitable disputes, complaints and inconsistencies, as occurs with Continuing Healthcare funding. The short term problem requires funding to be mobilised, especially for social care. The Barker report outlined the options available, from restricting the healthcare offer (no more tattoo removal), through increased co-payments (charges for general practitioner consultations and the like), to tax changes that reflect the unprecedented affluence of the older population.

So will integration be the answer? It is widely seen as so in England, and devolution in areas such as Greater Manchester is taking it to a different dimension by including health and social care.[15] Over a decade ago it was argued that the necessary ingredients for integration are close knit professional networks, a mutual sense of long term obligation, little concern about reciprocity, a high degree of mutual trust, and an acceptance of joint working arrangements as core business.[16] Last century (just) Leutz (1999) developed five rules that seem to have stood the test of time (see Box 1) and may be helpful to all those advocating the 'integration solution'.[17]

Box 1
Integration of services: Leutz's rules.[17]
— You can integrate all of the services for some of the people or some of the services for all of the people, but you can't integrate all of the services for all of the people.
— Integration costs before it pays.
— Your integration is my fragmentation.
— You cannot integrate a square peg and a round hole.
— The one who integrates calls the tune.

This may explain why when talking about integration in relation to social care for older people (and probably for other users of social care services) everyone needs to be extra clear about sharing understandings. A more sparingly use of integration might assist medical and social care colleagues to think about whether what is being discussed is alignment of health and social care (also termed co-ordination or even co-operation), the adequacy of services (both for individuals but for the whole health and care economy), and their affordability (which in social care, more than in the great part of the NHS, means actual payments by individuals as well as taxpayers). The Care Quality Commission recently reported hearing of many initiatives that aimed to deliver integrated care and indeed seeing some good practice. Yet, it observed, 'we did not find many examples of it working really well'.[18]

The role of medical professionals – including actions that doctors can take

The Barker report and others sketched out the range of choices necessary to improve health and care services for older people. These include restricting the healthcare 'offer' and extending co-payments which may raise more indignation than money.[19] Raising taxation to fund running costs and investment is likewise outside the remit of local professionals. These are the "hard choices" for politicians that will probably need all party agreements to make – a refreshed Barker report's 'new settlement' that the former Care Minister Norman Lamb is proposing.[3]

This briefing paper suggests three 'promising areas' for medical professionals. First the fostering of a sense that cost and patient shunting practice are likely to undermine further the parlous state of local government finances. As Plank's (2015) analysis of what is happening in one area (Cambridge) shows, cuts in local government services are deep and having effects on whole services, not just at the margins.[1] Support for local government managers sounds trite but it may be helpful to them. Second is to be careful about 'integration' being seen as the one-word answer to every problem – and particularly being careful to say what is being integrated with what or whom. Much social care for example is provided by family carers, who generally want services and professionals to talk with each other and to 'be joined up' but who do not want to be integrated themselves. And housing and care services, which are a major element of social care (sheltered housing, extra care housing, retirement villages, and hostels) are part of the mosaic of social care – not necessarily integrated but wanting to collaborate. Third is being mindful of the stresses inherent in services that do not know what is happening to their contracts or futures. Communities of practice or similar local initiatives can help practitioners understand each other's demands pressures – as a recent small drama performance in a rural area attended by GPs, nurses and care home managers illustrated (see Box 2).[20]

Box 2

Let's Talk is designed to stimulate discussion about working relationships that originated in the United States.[20] It has been adapted for the UK social care context by a social enterprise organisation, Dignity in Dementia. Let's Talk uses role play, workshop discussions and a range of other tools to challenge the traditional hierarchies played out in social care settings (known to impact adversely on quality and safety). Role play situations are devised and presented to a group of local professionals and service users and carers. For example a care worker might play the role of the GP or the GP a care home manager. The advantage of using this approach is that it dramatizes potentially difficult thoughts, practices and conversations and enables people to discuss them more objectively without blaming colleagues or getting heated.

Behind these micro-level ways of working at individual, team and practice level lie three 'monoliths' that shadow all solutions. They are not problems in themselves but get seen as problems rather than potential solutions. The first is the social care workforce, which like other healthcare workforces such as community nursing, is ageing and will need replenishing. In social care, even more than in nursing, migrants from the EU (European Union) and beyond, have shored up workforce shortages and high staff turnover. Is this sustainable? What will be the impacts of leaving the EU? Will the Living Wage attract and retain staff? Will the NHS 'poach' social care staff to fill its own vacancies? And what can unqualified and non-regulated staff be expected to do? Questions about duty of care and clinical responsibilities will be in sharper relief if increasing numbers of older people (and others) take up Personal Health Budgets. But there are wider issues about medical practitioners recognising the stress of working in social care among their patients.

Second are family carers – the lynchpin of care for older people. Medical practitioners have been given much advice about not ignoring family carers, being able to respond to them in a systematic way (eg by attention to their patient records systems enabling linking up of carer with the person they are supporting) as well as individually in person.[21] But carers sometimes say that they are under-recognised and that services that they are 'signposted' to do not exist or are not accessible. A separate briefing paper in this series on *Supporting*

carers further explores some of these issues. For medical practitioners involved in direct commissioning these areas are important to consider when making decisions in Clinical Commissioning Groups or locality forums.

And third, perhaps most importantly in any briefing paper about older people, are older people themselves. For medical practitioners there are numerous ways to hear their opinions of local and national influences on health and care, and their own experiences (such as through local Older People's Forums or Age UK or patient participation groups) (including HealthWatch (England), Community Health Councils (Wales), the Scottish Health Council and the Patient Client Council (Northern Ireland)) and patient surveys; there are also major local authority surveys which sometimes paint a more content picture than the crises reported. They too have an important part in ensuring that services meet the needs of older people by being active advocates, critical friends as well as supporting the NHS and care sectors through their volunteering and caring work today, and their current contributions and past commitments to the NHS.

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3 Briefing paper
Older people's mental health and wellbeing

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Briefing paper (3): Older people's mental health and wellbeing

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Key messages:
— By 2015, 850,000 people were estimated to be living with dementia in the UK. The emphasis in dementia services recently has been to increase the early identification and diagnosis of dementia. Services have been criticised for failing to keep pace with referral numbers and a lack of post-diagnostic support.
— In supporting older people with mental health conditions there is a need to consider the importance of 'triple integration'; integration of health and social care, primary and specialist care, and physical and mental health care.
— A continued focus is required on ensuring parity of esteem between physical and mental health. This should be reflected in the quantity, quality, and depth of teaching delivered on geriatric medicine and older adult mental health at undergraduate and postgraduate level.
— Other important principles are to take services to the person and support them in their own context, and to embed health promotion initiatives within services.

Introduction

The older adult population is increasing across the world, and is projected to increase from 530.5 million in 2010 to 1.5 billion in 2050, when roughly one person in six is expected to be over 65, double the current proportion of older people.[1] In 2014, in the UK (United Kingdom), there were over 11.4 million people aged 65 or over[2] with 1.5 million people aged over 85. The number of people aged 75 and over is projected to rise by almost 90% by mid-2039 with the number of people aged 85 and over set to more than double.[3] BME (black and minority ethnic) groups are estimated to contribute over 16% of the population of England, but currently constitute only 8% of those aged over 60:[4] an increasing population of older adults from BME groups is another important projected change. In Scotland the population of pensionable age and older is expected to decrease by 4% from 1.06 million in 2014 to 1.01 million in 2020, but then to increase to 1.36 million by 2039, an increase of 28% compared with 2014.[5] In Wales the projected increase in people aged 65 and over between 2014 and 2039 is 44%,[6] and in Northern Ireland 74.4%.[7] These demographic shifts bring new challenges to health and social care systems, globally and across the whole of the UK.

It is estimated that 40% of people over 65 years old and over two thirds (69%) of over 85 year olds have a long term illness.[4] Sixteen million adults were admitted to hospital in England in 2014-2015, and, of these, almost half (47%) were aged over 65.[8] Up to 60% of older people in hospital have existing mental health problems or develop them during their admission.[9] Of people aged over 70 admitted as emergencies to an acute hospital, 50% have cognitive impairment, 27% have delirium, and 8-32% have depression.[10]

Social isolation and loneliness are major factors affecting the quality of life and mental health of older adults. Age Concern England published two reports on mental health and well-being in 2006[11] and 2007[12] and made a number of recommendations based on the evidence considered at that time: areas highlighted included active ageing, health promotion for older adults, and measures to reduce social isolation. A more recent report using data from the from the English Longitudinal Study of Ageing found that loss of independence underpins social exclusion and that increasing social exclusion links with lower quality of life and deteriorating health status: deteriorating self-rated health was associated with becoming excluded from local amenities; taking less exercise was associated with becoming excluded from social relationships; and becoming depressed was associated with becoming more excluded overall and becoming excluded from cultural activities.[13] Other important factors include ageism,[14] and the complex inter-relationship between physical and mental health.[15]

Increasing awareness of the latter together with the prioritisation of physical healthcare above mental healthcare has led to the inclusion of parity of esteem in terms of physical and mental healthcare in policy documents.[16]

Currently both the King's Fund[17] and the Royal College of Physicians[18] acknowledge that the NHS (National Health Service) is not meeting the needs of older adults, who are likely to develop complex co-morbidities, disability and frailty as they age. Hospitals are "on the edge" and care is "fractured".[18] A radical rethink is needed for the health and social care system to rise to this challenge.

The evidence

Organisation of care

The interfaces between health and social care, and between primary and secondary have become more fluid, with initiatives that bring secondary care into the community and primary care into hospitals. Purdy's review of the evidence in terms of avoiding hospital admissions[19] supports possible roles for hospital at home schemes; integration between primary and social care; and closer integration between primary and secondary care such as schemes involving specialist outreach as part of multifaceted interventions. 62% of hospital bed days in 2014-2015 were occupied by people aged 65 and over.[20] Of people aged over 65 admitted to a general hospital, 60% have or will develop a mental disorder during the admission: approximately 40% have dementia, 53% depression and 60% delirium.[21] Since older people with mental health problems are major users of secondary care services these initiatives are likely to bring major benefits for them.

Specialist older people's mental health services have been criticized in the past as ageist but one of ten key messages for those commissioning services for older people with mental health problems[22] is that older people's mental health services should not be subsumed into a broader 'adult mental health' or 'ageless' services,[23,24] and that the needs of older people with both functional and organic mental illness may be distinct from the needs of younger adults. Needs based criteria for specialist services have been developed by the Royal College of Psychiatrists.[22] The criteria are threefold: people of any age with a primary dementia; people with mental disorder and significant physical illness or frailty which contributes to, or complicates their management; and people with psychological or social difficulties related to the ageing process or end of life. Traditionally older people's mental health services provided home assessments in community clinics,[25] and the principle of community assessment brought practical advantages.

The challenge of dementia

By 2015, 850,000 people were estimated to be living with dementia in the UK, with the number expected to rise to over 1 million by 2025.[26] There is evidence of a decrease in the prevalence of dementia in England between 1991 and 2011 of around 20% for reasons which are as yet not understood:[27,28] this challenges population projections for numbers of people living with dementia. The emphasis in dementia services recently has been to increase the early identification and diagnosis of dementia. This has led to burgeoning memory assessment services,[29] although there are a range of models in operation, including primary care memory clinics.[30,31] For example, the Gnosall model[a] has been shown to provide a better quality service at lower cost and with less use of hospital beds but is only one type of localised specialist model and has not yet been exported to a larger population. Criticisms of some models include failing to keep pace with referral numbers, and lack of post-diagnostic support services. People with dementia have worse outcomes when they become acutely unwell and are admitted to hospital: they are more likely to die,[32] at risk of longer hospital stays,[17] and likely to decline functionally during their stay resulting in a greater risk of moving into a care setting.[33]

a   The Gnosall model of primary care memory clinic involves an old age psychiatrist working in the clinic in the Health Centre in partnership with a member of practice staff (the Eldercare Facilitator) who carries out initial assessments, maintains ongoing contact with patients and families after diagnosis, and liaises with primary care staff.

Dementia may be recognised for the first time during an acute admission, since it is commonly a co-morbid condition when people are admitted for other reasons. Purdy's King's Fund report highlighted two important factors in avoiding hospital admissions: continuity of care from the GP and integration of care, both health and social care and primary and secondary care.[19]

Alongside this, the population of older adults living in care homes in England and Wales has remained almost stable since 2001: in 2011, 291,000 people aged over 65 lived in care homes, and this represents only a small proportion (3.2%) of the total population in that age range.[34] Based on a range of studies the estimated prevalence of people with dementia in care homes in 2014 was 69%.[26]

The National Dementia Strategy was called Living well with dementia[35] and started a drive towards early diagnosis and increased education/awareness about dementia. For most people living with dementia means living in their own home, not in a care home, but they should have access to good quality, timely and appropriate health and social care services wherever they live. NICE later published a Quality Standard which set out 10 quality statements.[36]

ARBD (Alcohol related brain damage) may account for 10% of the dementia population, and a greater proportion of those with dementia under age 65.[37,38] The prevalence of ARBD is increasing[38] and very few services are available to support this group of people.

Mental health problems in later life

Depression is regarded as the most common mental health problem in later life and a systematic review found a prevalence rate for major depression ranging from around 4% to 9%, and for depressive disorders ranging from around 4% to just over 37%.[39] The prevalence of depression is reported to be even higher in nursing home residents: figures of between 29 and up to 40% have been reported across nine European countries.[40] Depression is also associated with worse general health. Only a small proportion of older people with depression seek treatment. A Centre for Policy on Ageing review found widespread evidence of under-recognition and late diagnosis of depression in older adults: although 20-40% of older people in the community show signs of depression meriting treatment, only 4-8% consult a GP.[41] It was suggested that depression is often seen simply as a part of ageing.

Data from the Office for National Statistics show that in 2013 the highest UK suicide rate by broad age group was amongst men aged 45 to 59, but it is of note that the rate for 60 to 74 year old men had risen significantly from its 2012 level, to 14.5 per 100,000 in 2013.[42] It is a matter of concern that older adults have a higher completion rate (ie fewer attempts in relation to completed suicides) than adults in younger age bands.[43]

Older people may grow old with an established psychotic illness or develop a psychotic illness anew in late life, and the classification of late onset psychosis lacks clarity.[44] The prevalence of psychosis in older adults is estimated to be less than 3%,[45] and has been reported to be linked with hearing impairment, social isolation, and soft neurological signs.[46] There is a lack of research on treatment and service options for this group. Psychotic symptoms are, however, much more common, and occur in the context of delirium, dementia, and depression.[47]

Substance misuse in older people is an overlooked area and there is a significant increase in rates of licit and illicit drug use and misuse, together with rises in alcohol- related hospital admissions and mortality, amongst older people.[48] Only 6–7% of high-risk people with substance misuse problems over 60 years of age receive the treatment that they require.[49] Older people are more likely to have mild dependence and be motivated to abstain, but are less likely to complain of a substance problem. Individuals from some BME backgrounds have higher levels of alcohol misuse and resulting health problems than the general population, in particular older Irish and south Asian (Sikh) male migrants to the UK.[50] Both alcohol misuse and ethnicity are linked with social disadvantage.

Discussion

Improving older people's mental health and well-being will need fundamental changes to how the health and social care system operates.

1. **How might services achieve real practical parity of esteem?** Older people's mental and physical health should be core business for the NHS. How much teaching do medical students receive on the assessment and treatment of older adults and in assessing both mental and physical health routinely as a matter of good practice? Is the quantity and depth of teaching sufficient to meet current population needs, when the oldest old are the fastest growing sector of the population; when comorbidity is known to increase with age;[51] when policy is to facilitate early diagnosis of dementia; and when the aim is parity between mental and physical health, countering ageism in health care?[14] Undergraduate and postgraduate medical teaching should embody parity of esteem in the quantity, quality, and depth of teaching delivered on geriatric medicine and older adult mental health.

2. **How might the boundary between primary and secondary care become more flexible?** Integration of primary and secondary care is suggested[19] but there are also ways of bringing secondary care into the community.[52,53] The NHS Five Year Forward View[16 54] makes the case in England for what has been called triple integration; integration of health and social care, primary and specialist care, and physical and mental health care. Triple integration is equally applicable across the whole of the UK.

3. **How might services be taken to people who need them rather than people taken to the services?** In the community hospital-at-home initiatives offer ways of treating older people at home without hospital admission[19] and avoid some of the adverse consequences of hospital admission. This approach could be applied to people living in care homes and those needing end of life care (particularly those with dementia).[55] In hospital this would mean taking care to the person rather than moving them between wards.

4. **Health promotion initiatives also need to be integrated into the system:** for example there is evidence that preventative exercise programmes are a cost-effective way of reducing the risk of mental illness in older people and the Centre for Policy on Ageing argues that the absence of such programmes may be an example of indirect age discrimination.[41]

5. **How might services involve older people and their families fully in assessment and ongoing treatment?** Services aim to be person-centred but should be equally relationship centred, which means involving their families and ensuring continuity of care in professional relationships (a concept also explored in the briefing in this series on *Living with long term conditions*).

The role of medical professionals

Doctors need to recognise their responsibility as leaders to improve care through innovation and change. The General Medical Council states that "in their day-to-day role doctors can provide leadership to their colleagues and vision for the organisations in which they work and for the profession as a whole".[56] In mental health "new ways of working"[57] has eroded the leadership role of the consultant psychiatrist to the detriment of holistic care of their patients[58,59] and, in dementia care, there is a financial imperative to shift care to the cheapest possible provider with consequential loss of continuity of care and also de-professionalisation of dementia care.[60] Doctors have unique expertise which enables them to assess, diagnose and manage complex co-morbidities, with support from their multi-disciplinary colleagues. They need to continue confidently to lead in all areas providing health care for older people with mental health problems and resist further erosion of their role.

Alongside this, doctors have a responsibility to "keep the sick from harm and injustice",[61] to safeguard adults from abuse and neglect,[62] and to implement legal frameworks including the Mental Capacity Act.

GPs have a unique role in coordinating the care of older adults with physical and mental health problems: continuity of care[19] and advance care planning[63] are two areas that are key to providing better care. Resources and investment will need to reflect the key roles of general practice, the need for rapid supported discharge from hospital, and for responsive integrated community services.

Hospital doctors need to recognise that mental healthcare is an important part of the physical healthcare of older people using their services and that, in the vast majority of cases, older people should not leave hospitals having lost the functional abilities they had when they were admitted.[33] Rapid supported discharge back to the place from which the person was admitted should be the aim: Purdy found evidence to support a role for structured discharge planning in avoiding hospital admissions.[19]

It is ageist not to make available the specialist services that benefit older people with complex comorbidities and support them in their own homes. Early referral to specialist old age psychiatrists who operate as community psychiatrists and work both with and within primary care will enable integrated care plans across primary and secondary care, aiming to treat people in their own homes as far as possible.

Recruitment to general practice, geriatric medicine and old age psychiatry needs to be prioritised if older adults are to receive appropriate services to maintain their health and independence.

Conclusion
The principles of care of older people with mental health problems apply across health and social care: they are
1. parity of esteem between physical and mental health;
2. flexible triply integrated services to provide seamless care;
3. taking services to the person, to promote independence whilst safeguarding the vulnerable;
4. health promotion despite disability;
5. person and relationship centred care at the core of flexible and appropriate services.

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4 **Briefing paper**

Living with long term conditions

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Briefing paper (4): Living with long term conditions

**Authors: Dr Jim George – North Cumbria University Hospital Trust;
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Key messages:
— Demographic changes have resulted in greater number of older people living longer with more disability and often with two or more long term conditions.
— The training and education of all clinicians should acknowledge future demographics, and include sufficient focus on the key principles of geriatric medicine to ensure all doctors are aware of the specific needs of older patients.
— There is a good case for regarding frailty as a long term condition. Comprehensive geriatric assessment (CGA) — a multidisciplinary, diagnostic process to describe the medical, psychological and functional capabilities of a frail older person — should be used to design a coordinated, integrated plan for long term treatment and follow up.

Introduction and overview

This paper primarily focuses on living with long term conditions in England but includes references to the devolved nations where the situation is similar. A long term condition is any medical condition that cannot currently be cured but can be managed with the use of medication and/or other therapies. This is in contrast to acute conditions which typically have a finite duration such as a respiratory infection or inguinal hernia or a mild episode of depression.[1] Common LTCs (long term conditions) include diabetes, chronic obstructive pulmonary disease, chronic heart failure, osteoporosis and dementia. Currently approximately 70% of the health spend in England is on 30% of the population who have LTCs. It is estimated that over 15 million children, adults and older people in England live with at least one LTC. This figure is set to increase to around 18 million by 2025. People with LTCs are high users of the health services as they account for 55% of all GP appointments, 68% of all hospital and A&E appointments and 77% of all inpatient bed days.[2] Most LTCs are more prevalent in older age groups — for example the prevalence of diabetes rises steadily with age in men and women peaking at 22% for men and 17% for women in their eighties. Similarly the prevalence of dementia is very low for men and women aged 60-64 at 0.3% but rises to nearly 20% for men and women in their eighties. The majority of people over 75 live with two or more LTCs. There is also a strong link between LTCs and social inequalities — compared to the highest social class, people in the lowest social class have a 60% higher prevalence of LTCs and 30% higher severity of conditions.[3] The annual health and social care cost per person per year for a person without a LTC is £1,000, this rises to £3,000 for those with one LTC and £8000 for those with three.[4]

The population is ageing. Between 2005/6 and 2014/15 the number of people aged 65 or over in England increased by almost a fifth and the number aged 85 rose by a third. This increase in the older population is projected to accelerate over the next 20 years. Unfortunately disability free life expectancy is rising more slowly than total life expectancy which means that people are living for more years with disabilities.[1] In the cognitive functional ageing study in three geographically defined centres in England (Cambridgeshire, Newcastle and Nottingham), it was found that between 1991 and 2011 there was a mixed picture in changes in cognitive impairment and disability — there was a reduction in cognitive impairment, an actual improvement in self-perceived health but an increase in less severe disability but not severe disability.[5] Disability, frailty and multi-morbidity are linked with the presence of LTCs. This is a UK issue. For example, a large scale Scottish study reported that 82% of those aged 85 years or older had two or more LTCs.[6] In contrast a study in Newcastle showed a higher chronic disease count (a median of five in women and four in men).[7] People with dementia have on average 4.6 additional chronic illnesses and only 5.3% of people with a diagnosis of dementia have no other long term disorder.[8] The relationship between mental and physical problems appears to be bidirectional — patients with severe mental health problems such as chronic depression and dementia are at a high risk of

developing long term physical problems and the risk of mental health problems increases in those with physical problems. Patients with multi-morbidity have a high treatment burden in terms of understanding and self-managing their conditions, attending multiple outpatient appointments and managing complex drug regimes.[9] There is evidence that older people receive poorer levels of care than younger people with the same condition.[10] For example older people are less likely to receive psychological therapies for mental illness. General medical conditions are treated more effectively than geriatric conditions such as incontinence and less than one in four people over 75 self-report receiving any support or advice in falls prevention or managing their own diabetes.[11] In addition there are around 6 million people in the UK as a whole, who are unpaid carers for older people and many of these are elderly themselves and have their own health and financial problems.[12] The challenges commonly experienced by older patients with multiple long term conditions are summarised in Table 1.

> ### Table 1: Problems commonly experienced by older patients with multiple long term conditions[9]
>
> — Polypharmacy.
> — High treatment burden.
> — Mental health problems;
>   — anxiety
>   — depression
>   — dementia;
> — Functional difficulties eg falls, incontinence, immobility.
> — Reduced quality of life.
> — Increased healthcare utilisation with poor coordination of care.

The financial background is bleak as the NHS in England has a projected shortfall of £30billion by 2020 and budget cuts of 12% in social services in the last four years.[13] We need to examine potential service changes so that an imminent health, social and financial crises in the needs of older people with long term conditions can be avoided or at least ameliorated. Several strategies have been suggested including person-centred care, care pathways and guidelines, case management, integrated care, acute hospital initiatives, and frailty strategies using comprehensive geriatric assessment. These potential solutions are not mutually exclusive and are described next.

Person-centred care

Person-centred care is fundamental to the NHS and has been defined as treating patients as individuals and enabling them to make choices.[14] The aim of person-centred care is to provide a system of care that facilitates an understanding of the person's health and wellbeing and uses co-production of solutions that includes or goes beyond medical interventions. In surveys patients with LTCs say that they want to be supported to engage in their care and contribute to decisions about it. They also want a proactive and seamless service in which the NHS acts as a team and they are treated as a whole person.[15] Unfortunately feedback from patients often falls short of this ideal. Also there are practical problems in older people as person-centred care runs the risk of over emphasising independence and stigmatising dependence and interdependence.[16] Dementia for example may present as failure of self-care and patients with dementia may be heavily dependent on family carers who are also elderly and have social and medical needs. Although person-centred care is the ideal, sometimes relationship centred care is more realistic. Relationship centred care puts the focus on the interaction between patient, family, carers and health and social care staff (a concept also explored in the briefing in this series on *Older peoples' mental health and wellbeing*).[17] These interactions are essential in supporting many older patients with multiple long term conditions in the community.

Care pathways and guidelines

Evidence based guidelines are generally developed for people with single diseases. They can naturally lead on to care pathways to streamline and improve care and make it more efficient. However simple disease guidelines may be inappropriate for people with multiple LTCs. They may result in over-treatment and over-complex regimes of assessment and surveillance.[18] Alternatively guidelines may result in under-treatment as well in patients with multiple co-morbidities, for example a new condition may actually increase the risk of a complication from an old condition and then the argument may be for more treatment, not less. On the other hand when life expectancy is poor from one condition then the potential benefit of treatment of another may be considerably lessened. These clinical decisions require individual clinical judgement in collaboration with the patient weighing up the benefits and risks for treatment for that individual, rather than slavishly following strict single disease guidelines. Similarly care pathways are more difficult in older people with multiple interacting conditions and social and functional constraints. The main aim of care pathways to optimise outcomes and reduce variation is more easily achievable in single disease conditions. NICE (The National Institute for Health and Care Excellence) have recently produced guidelines on care planning in older people with social care needs and multiple long term conditions.[19] The guidelines emphasise identifying and assessing social care needs and working collaboratively and supporting carers. There are new NICE guidelines on managing multiple comorbidities due for publication in September 2016.

Case Management

The concept of case management incorporates case funding, assessment, care planning and care co-ordination. The evidence for the effectiveness of case management is mixed.[20] To be successful case management needs to be properly targeted and there needs to be continuity of care with professionals working in multi-disciplinary team. If it works well case management can potentially reduce expensive emergency hospital utilisation by reducing admissions, improve care outcomes and enhance patient experience. Where it has been less successful it has been poorly targeted and although it has been popular with patients and possibly reduced unmet need, it has failed to improve measurable outcomes or reduce hospital admissions. An example of a case management project is the Evercare model of case management. People over the age of 65 years, at risk of unplanned hospital admission were targeted. Evaluations showed that patients valued the improved access to health care, the increased psychosocial support and improved communication with health professionals but hospital admissions were not significantly reduced.[21]

Integrated Care

Improving integration is a common UK theme and being approached differently in the devolved nations. There are many different definitions of integrated care. National Voices, an organisation that represents patients, service users, carers and families defines integrated care from a patient's point of view - 'my care is planned with people who work together to understand me and my carers, put me in control, and deliver services to achieve my best outcomes'.[22] Integrated care represents care that is coordinated between all those involved in the delivery of an individual person's care thereby reducing duplication, fragmentation and lack of ownership. The expectation is that integrated care schemes will serve a defined patient group (eg older people), coordinate care delivery, share outcomes, share budgets and share IT systems. The hope is that this will improve efficiency and reduce costs, but there is little evidence of this. Because of the many different definitions of integrated care and the practical difficulties of designing a controlled trial, there are no high quality systematic reviews to guide us. However few would disagree that well coordinated care that is person-centred is better than ad hoc poorly coordinated care. An example of an integrated care system in the UK is the Torbay Care Trust, targeted at older people and is quoted as reducing emergency hospital admissions and admissions to care homes.[23] Unfortunately this improvement in Torbay was not maintained and the Trust has been taken over as part of a reorganisation. Overall evidence from integrated care schemes is mixed in terms of definite outcomes. An evaluation of 16 integrated pilot sites in the UK found no evidence that integrated care reduced the level of emergency hospital attendances.[11] There are concerns that the budget cuts in social care will impact against NHS care. Pooling budgets may not be in the interests of the NHS.

Acute Hospital Care Initiatives

Acute emergency admissions to hospital particularly for older people, are increasing year on year. Hospitals frequently have bed crises and emergency departments become overcrowded with older patients with acute illnesses in combination with multiple LTCs waiting to be admitted. The UK has around 2.8 hospital beds per 1,000 population which is considerably lower than most developed countries. Bed occupancies in hospital continually run at over 85%. The Nuffield Trust predicts that at current trends we will need 6.2 million more bed days per year by 2022.[24]

Hospitals are the only places where 'the lights are always on' when there is a medical crisis. National policy is to try and reduce this dependency on hospitals by increasing community services. It is unlikely this will have much of an effect at least in the short term - this is because new schemes tend to reveal unmet need initially and take at least five years to become established. In the meantime we will increasingly rely on improved hospital measures to assess frail older people at the front door to avoid admission or reduce length of stay (Table 2). We will also need improved measures to avoid delayed discharges with improved collaboration with rehabilitation and social care services. The Future Hospital Commission report recommends that hospitals should increase their emphasis on ambulatory (day care) emergency care, enhanced recovery and early supported discharge.[25] There is a potential to develop new systems and ways of working that deliver more specialist medical care outside the hospital setting to enable hospitals to become the hub of clinical expertise for the local population.[25] At the moment there is an approximate 50% shortfall of home based reablement and bed based intermediate care outside hospitals to facilitate early discharge.[26]

Table 2: Improving acute hospital efficiency for older people[12]

- Use of comprehensive geriatric assessment for all frail older people.
- Specialised elderly care units and wards.
- Older people's liaison teams for discharge.
- Old age psychiatric liaison teams for management of mental health illness in old age.
- Frailty assessment units in Emergency Departments.
- Front door assessment by a geriatrician.
- Ambulatory care suitable for older people.
- Surgical and orthopaedic geriatric liaison units and teams.

Frailty and comprehensive geriatric assessment

Frailty is a distinctive health state related to the ageing process in which multiple body systems gradually lose their built in reserves.[27] There are two broad models of frailty. The first is the phenotype model which describes a group of patient characteristics (weight loss, reduced muscle strength, reduced gait speed and self-reported exhaustion). The second is the cumulative deficit model which assumes an accumulation of deficits (eg loss of hearing, low mood, cognitive impairment) which occur with ageing and can be combined to measure a 'frailty index'.[27] The second model is more in keeping with clinical practice and more easily measurable in primary care. A person with frailty is more vulnerable to illness and typically presents with a geriatric syndrome such as falls, immobility, confusion and incontinence. Frailty, disability and multi-morbidity are distinct but overlapping concepts. Frailty is common (7-16% in people over 65) and predicts disability, falls, admission to hospital and care homes, and death.[28] Nearly 400,000 older people in the UK live in care homes and nearly all of these are frail and have high rates of hospital admission.[27] A person with frailty is more vulnerable to acute illness which will be more treatable if detected early. An evidence based approach to frailty is CGA (comprehensive geriatric assessment) which is a multidisciplinary, diagnostic process to describe the medical, psychological and functional capabilities of a frail older person in order to design a co-ordinated, integrated plan for long term treatment and follow up.[29] CGA has been shown to improve quality of life, reduce mortality and reduce admissions to care homes.[29] Identifying frailty can be difficult but one recently established reliable method is to use the eFI (electronic Frailty Index) which uses existing data held in the primary care patient record.[30] The eFI is being used to identify

and code for mild, moderate and severe frailty and then combined with interventions, for example health promotion and exercise for mild frailty, case management for moderate and CGA for severe frailty. The eFI is currently in use in over 40 Clinical Commissioning Groups in England. There is a good case for regarding frailty as a LTC,[31] and this opens up frailty to the application of chronic care models described previously such as person-centred care. Importantly frailty can considerably pre date disability and may be potentially reversible and hence offers greater opportunities for effective interventions eg exercise.

Implications for doctors, nurses and therapists

If we are to attempt to move care of LTCs more into the community away from hospital – then this has huge implications for clinical staff. Moving care into the community does not equate to moving the skill set into primary care. Undergraduate training in geriatric medicine is presently inadequate for modern day needs.[32] Few GPs have developed a specialist interest in elderly care. GP trainees should be encouraged to train in geriatrics and complete the Diploma in Geriatric Medicine qualification. The Diploma in Geriatric Medicine is a postgraduate qualification designed to give recognition of competence in the provision of care of older people to general practitioner vocational trainees. The evidence for the required multidisciplinary approach including CGA is greater in the hospital environment and rehabilitation is more time consuming (taking into account travel time) and less cost effective in patients' homes.[33] On the other hand the ideal of the Future Hospital Commission of training more generalists and encouraging more specialists to outreach in the community may not be feasible with the lack of training numbers. Many consultant geriatrician posts at present for example are unfilled with lack of suitably trained applicants. There needs to be a change in the training of all doctors, nurses and therapists which acknowledges future demographics. The development of specialist nurses who can take on specialist assessment of older people is a welcome development. Apart from obstetrics and paediatrics – all specialities will need expertise in managing older frail people and training and education will need to reflect this. Some practical tips for doctors and nurses working in primary care are given in Table 3. It is recognised that to achieve these aims, general practice requires sufficient investment and resources.[27,34]

Table 3: Practical tips for dealing with the challenges in caring for older patients with multiple long term conditions and/or frailty in primary care. (Resource and investment dependent)

— Identify complex patients (eg use the electronic frailty index) and ensure continuity of care by assigning a named doctor.
— Use clinical judgement rather than single disease guidelines.
— Arrange regular medicine reviews in conjunction with your pharmacist.
— Promote patient-centred care. What matters most to your patient?
— Encourage participation and support self-care.
— Adopt a policy of arranging extended consultation times for your complex patients.
— Give special attention to older people living in care homes as they are likely to be frail and at high risk of admission to hospital.
— Coordinate multidisciplinary team involvement.
— Get to know and use your local geriatrician.

Conclusion

Demographic changes have resulted in a greater number of older people living longer with more disability and often with two or more LTCs. This has resulted in an imminent crisis of care in the NHS with increasing number of hospital emergency admissions and a considerable strain on community health and social care services. This is likely to get worse with the prospect of reduction in health and social care funding. Proposed solutions include more person-centred care with encouragement of self-care, case management and increased integration of health and social care services at all levels. Evidence for these initiatives is mixed. It is possible that combinations of these strategies will help avert a crisis. A new promising approach is to consider frailty itself as a LTC and develop a 'frailty strategy'. This will include better integration of services with speciality outreach from acute hospitals, frailty units in emergency departments to facilitate discharge and reduce length of stay and a comprehensive frailty identification strategy in primary care allied with case management and comprehensive geriatric assessment. This will need to be backed up with increased training and education in the principles of geriatric medicine for all clinicians. There needs to be a change in attitude and culture in the NHS with an acceptance that both primary and secondary care services need to be redesigned to meet the needs of frail older people who are now our major customers.

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5 Briefing paper
The perception of ageing and age discrimination

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Briefing paper (5): The perception of ageing and age discrimination

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Key messages:
— Perceptions of ageing can subject older people to patronising forms of prejudice, which may be expressed in the language and tone used to communicate with older patients, the settings in which they are placed and the framing of treatment options.
— Health care professionals and organisations should be aware that older individuals are potentially vulnerable to age prejudice and stereotyping processes.
— Healthcare could benefit from much more deliberative questioning of age-based assumptions and of how attitudes interact with policies, structures and practice.

Introduction

Since the term ageism was introduced almost 50 years ago, research has explored the nature and manifestations of age prejudices and its consequences. It has shown that health and social care is a key context that has potential to put older adults at risk of experiencing prejudice and discrimination, and also has potential to perpetuate negative perceptions of ageing. In this brief we outline evidence about perceptions of ageing in the UK and explore their implications for, a) the health and wellbeing of us all as we age, and b) health care professionals and organisations. The brief highlights 'risk factors' at the individual, organisational and societal levels that contribute to ageism in health and social care.

It is nearly 50 years since US gerontologist Robert N Butler, in 1969, introduced the term ageism to describe prejudice and discrimination against people because of their perceived 'old' age. Underlying this prejudice is "a deep seated uneasiness on the part of the young and middle-aged — a personal revulsion to and distaste for growing old, disease, disability, and fear of powerlessness, 'uselessness' and death" (p243). Since then, other definitions have emerged which describe ageism as discriminatory decisions concerning people because of their age, whether young or old,[1] and the experience of unfair treatment, or the stereotyping of or discrimination against a person or group because of their age.[2] These recent two definitions recognise that ageism has the potential to affect anyone at any age, but in this briefing paper we focus on people's perceptions of ageing and growing old. We begin by outlining common negative and positive perceptions of ageing held by people in the UK, we then explore the consequences of these perceptions for decision making, health and well-being in later life, as well as how such perceptions underpin the types of prejudice and discrimination that people face in health and social care settings. We highlight circumstances that perpetuate negative perceptions of ageing, and situations that put individuals at an increased risk of experiencing age discrimination. We conclude by providing practical recommendations for mitigating ageism in health and social care settings and for minimising its impact on employees and users of these services.

Perceptions of ageing in the UK

In order to understand who might be vulnerable to age discrimination, we first have to understand how people define age groups such as 'young' or 'old' and the meaning of these categorisations in the UK. This subjective process of classifying others into age groups is known as 'age categorisation'. Age categorisation is a necessary precursor to people's application of age stereotypes. Therefore, the boundaries people apply to different age categories and common (mis)perceptions associated with the 'old-age' group are an important source of age discrimination.

How old is 'old'?

Age perceptions are partly psychological. In the 2008/9 ESS (European Social Survey) over 50,000 respondents were asked to estimate the age at which people stop being described as 'young' and to estimate the age at which people start being described as 'old'. On average, amongst over 2,000 respondents in the UK, people perceived that youth ended at 35 years and old age begins at 59. This may mean that people below 35 years and over 59 years are more vulnerable to age prejudices and discrimination due to their perceived 'young' or 'old' age respectively. Furthermore across Europe, our research showed that respondent's own age, gender and the country in which they live affected where they placed these age boundaries,[3] such that as people get older their perceptions of the end of youth and onset of old age both increase (**Figure 1**). Further, women perceived the end of youth and onset of old age to be 3 years later than did men, whereas people in Greece perceived that old age starts at 65, those in Turkey perceive that old age starts at 55.[3]

Age categorisations by people in different age ranges
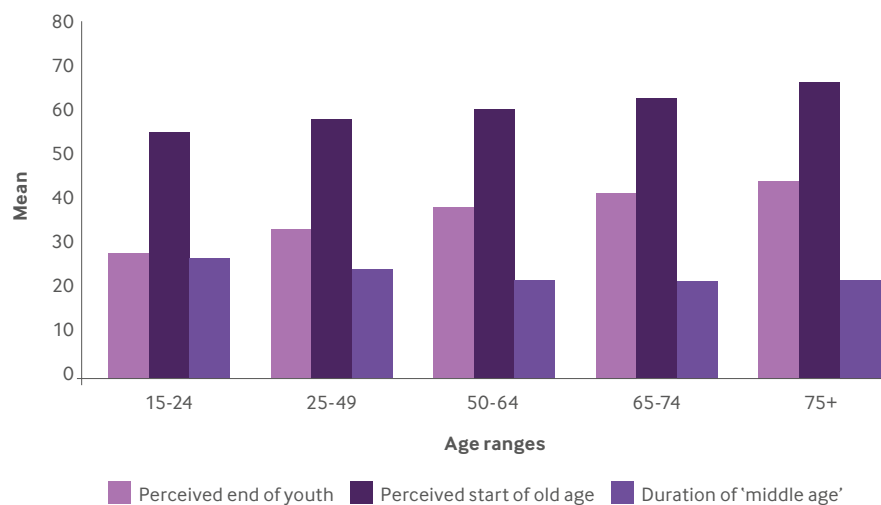
Figure 1 Perceived end of youth, start of old age and duration of middle age (mean estimated age) within the United Kingdom, by people in different age ranges.

People's use of age categorisations may also vary depending on work context and client groups. For example, in a health care setting, O'Donovan, Herlihy and Cunningham (2015) found that undergraduate radiation therapists training in Ireland (mean age of 21 years old) estimated the start of old age to be 65, whereas practicing radiation therapists (age range 26 – 30 years old) perceived old age to start at 70.[4]

Declining health, status and contribution to society

Research from the US, UK and across Europe suggests that compared with younger people, older people are likely to be stereotyped as frail, ill and dependent,[5,6] and to be viewed as having low social status.[3,7] Findings from the ESS revealed that people aged 70 and over are seen as contributing relatively little to the economy and being a 'burden on health services' (**Figure 2**).[3,8] Unfortunately, such views are expressed and perpetuated frequently in the media. We are currently completing an analysis of over 1,500 articles from broadsheet and tabloid newspapers from across the political spectrum, which reveals that older people are most frequently depicted as consumers of finite resources (eg rising cost of pensions, rising cost of care), (**Figure 3**).

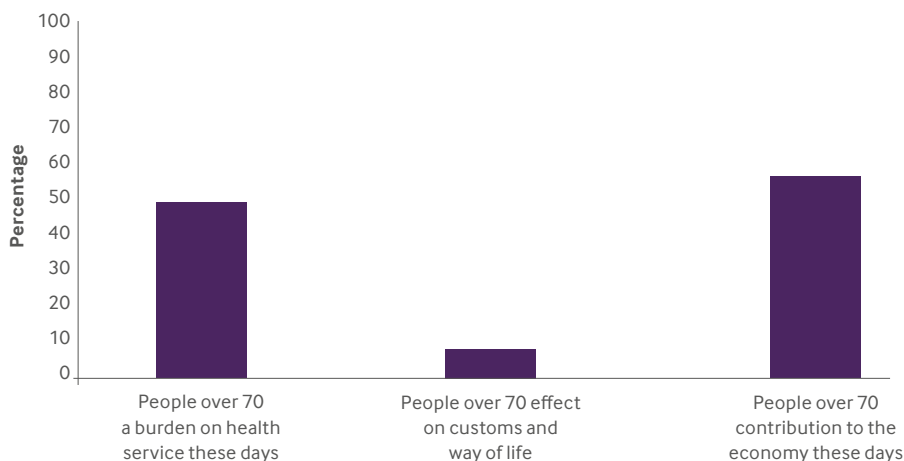**Perceived negative societial impact of people over 70**

Figure 2. Percentage of respondents who perceive people over 70 as having negative impacts on society (From the left, Item 1: includes scores between 6 and 10 on a scale that ranged from 0, no burden to 10, a great burden; Item 2: includes scores between 0 and 4 on a scale that ranged from 0, extremely bad effect to 10, extremely good effect; Item 3: includes scores between 0 and 4 on a scale that ranged from 0, contribute very little economically to 10, contribute a great deal economically)
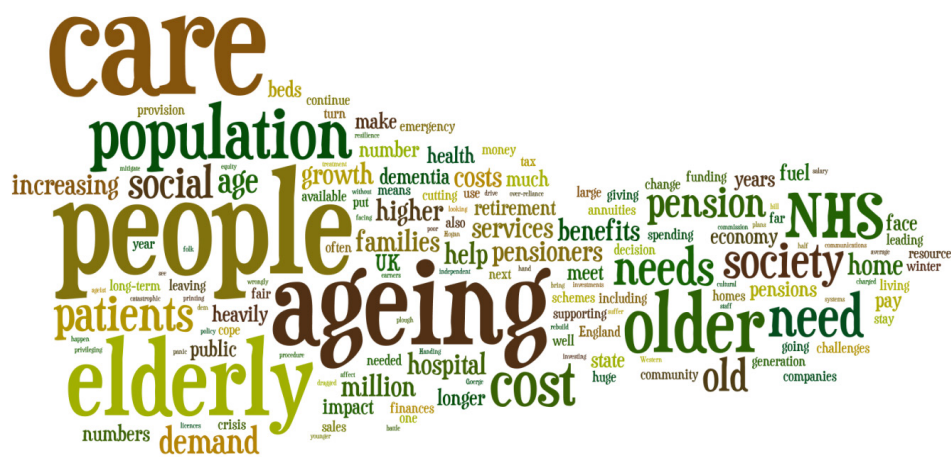
Figure 3. A word cloud displaying representations of older adults in UK newspapers as consumers of finite health-care resources. The cloud gives greater prominence to words that appear more frequently in the media sources.

The perceived 'threat' (negative impact) a group poses to culture or to resources is an important predictor of prejudice against that group.[9] People's perceptions of economic conflicts are a concern because they provide a basis for resentment between particular age groups and are likely to underpin intergenerational conflicts and perceived inequality between generations.[10] The extent to which a group is perceived to be an economic threat are also associated with people's overall concerns about their national economy.[11]

Increasing wisdom, experience and morality

Perceptions of ageing are not all bad. There are positive perceptions of older people as wise, experienced and more moral than younger adults.[3,12,13] Research conducted for Age UK in 2006,[14] showed that people have very clear ideas about the specific competencies of younger and older age groups, some of which favour older people. For instance, compared to a typical 25-year-old, a typical 75-year-old was more likely to be viewed as polite, good at settling arguments, understanding others' view points, and having a healthy diet. Whereas typical 25-year-olds were more likely to be viewed as taking enough exercise.[13]

Mixed perceptions of ageing

Many of these negative and positive representations of ageing can be captured within a psychological model of stereotypes, which has been supported by over 10 years of national and international research. The 'stereotype content model' proposes that stereotypes of younger and older age groups can be described along two basic dimensions of *competence* and *warmth* (otherwise referred to as friendliness).[15,16] Work conducted in the UK has shown repeatedly that mixed stereotyping is applied to older people who are viewed as having high warmth (positive), but low competence (negative).[17,3,18] This mixed 'doddering but dear' representation results in feelings of pity for older people.[16] Thus society appears to hold 'benevolent', but patronising views of older people, which depict them as warm and friendly but as not requiring or deserving of power or voice because of their perceived low status and declining competence.

Consequences of perceptions of ageing

A unique aspect of age-based prejudice compared with prejudices against other groups, is that our own perceptions of other older people ultimately become self-relevant and applied to the self. This 'self-stereotyping' causes people to restrict their horizons if they see themselves as 'too young' or 'too old' to pursue certain activities or roles. There is clear evidence that age stereotypes, whether one's own attitudes to ageing or through discrimination from others, can a) negatively impact on the ageing processes by influencing health and wellbeing, and b) influence decision making processes and performance on cognitive or physical tasks. They also result in discrimination in health and social care settings.

Age-stereotypes influence health and wellbeing

A growing body of longitudinal research conducted in the US (see Table 1 for examples of how perceptions of ageing can be measured) reveals that people with more negative perceptions of ageing tend to engage less in preventative health behaviours such as eating a balanced diet, exercising and abstaining from use of substances such as alcohol and tobacco.[19] They also have worse functional health in later years,[20,21] are slower to recover from myocardial infarction,[22] and ultimately die younger.[23,24] For instance, the Ohio Longitudinal Study of Aging and Retirement which followed 660 adults aged 50 years and over for a 23-year period, revealed that individuals who held more positive perceptions of ageing lived 7.5 years longer on average compared to those who endorsed more negative perceptions.[20] This research controlled for a host of confounding variables known to be associated with health and mortality.

Table 1 – How perceptions of ageing can be measured

Name of the measure	Measure used by	Example items	Response
5-item Attitudes Towards Own Ageing Subscale of the Philadelphia Geriatric Center Morale Scale (Liang & Bollen, 1983; Lawton, 1975)	Levy & Myers (2004); Levy, Slade, & Kasl (2002); Levy, Slade, Kunkel, & Kasl (2002); Maier & Smith (1999); Sargent-Cox, Anstey, & Luszcz (2014).	"things keep getting worse as I get older" "I have as much pep as I had last year"	7-point scale ranging from *strongly disagree* to *strongly agree*
9-item Positive Age Stereotype Subscale of the Image of Aging Scale (Levy, Kasl, & Gill, 2004)	Levy, Slade, May, & Caracciolo (2006)	"When you think of old people in general, how much do the following words match the images or pictures that you have?"	Participants responded by rating the extent to which nine listed positive age stereotypes match their perceptions of older people
17-item short form Aging Perceptions Questionnaire (APQ) (Barker, O'Hanlon, McGee, Hickey & Conroy, 2007)	Robertson, Savva, King-Kallimanis, & Kenny (2015)	"as I get older I continue to grow as a person" "I get depressed when I think about getting older"	5-point scale ranging from *strongly disagree* to *strongly agree*

More recent research has explored the impact of age stereotypes on known biomarkers for Alzheimer's disease. Analysis of the Baltimore Longitudinal Study of Aging revealed that even when controlling for relevant health and demographic variables, those holding more negative age stereotypes earlier in life (over 20 years earlier) had significantly steeper decline of hippocampal-volume and significantly greater accumulation of neurofibrillary tangles and amyloid plaques than those holding more positive age stereotypes, even after adjusting for relevant variables.[25] Collectively, these studies demonstrate the powerful way that our perceptions of ageing, which are learnt through processes of socialization, are cultural-based risk factors for worse health and wellbeing.

A second body of literature has explored the effects of being a target of prejudice, discrimination and exclusion on health and wellbeing. An analysis of 134 studies suggests that experiencing discrimination – based on age, gender, race, sexual orientation or other discrimination – is associated with both worse psychological well-being and physical health.[26] Further research found that perceived everyday discrimination among 6,377 older adults (based on any group membership, not just age) was associated with increased symptoms of depression, worse self-rated health, functional limitations and chronic illness over a period of two years.[27] Given that more people experience ageism than any other form of prejudice,[3] this evidence implicates age discrimination as damaging to wellbeing across the population.

Age-stereotypes influence decisions we make and task performance
There are also more immediate and situated effects of age stereotypes. If older people sense that others are judging them in terms of their perceived *old*-age and the associated age stereotypes, they become at risk of inadvertently acting in line with those stereotypes. A review and meta-analysis of 32 published and unpublished academic papers on older people's cognitive and physical performance revealed that highlighting age or age stereotypes led to lower memory and cognitive test scores.[28] These performance decrements have been attributed to the threat of stereotypes and their influence on the emotions, motivations and behaviours of older adults.[29] These 'stereotype threat' effects have been experimentally demonstrated on both physical (hand grip performance) and cognitive tests similar to those used in medical assessments.[30,31] While it is recognised that these types of tests are rarely used in isolation for diagnosis, bias in the settings and conduct of such tests may contribute towards less accurate assessment of the deficiencies and support needs of older adults.

Age stereotypes can also affect other health related behaviours and motivations. For instance, older people who were made aware of negative stereotypes of ageing reported feeling lonelier and displayed more frequent help-seeking and dependent behaviours.[32] We (and others, eg Levy et al, 1999-2000) have also found that amongst older adults (mean age 70) triggering negative old age stereotypes, even outside of conscious awareness, can be sufficient to reduce their motivation for a longer life, known as 'will-to-live'.[6] Both threats to performance and changes in will-to-live are routes through which age-stereotypes impact negatively on individuals, and have potential to bias medical assessments leading to inappropriate diagnoses and unsuitable levels of support.

Manifestations of ageism in healthcare settings

One in three people in the UK report experiencing age-discrimination.[3] How then does ageism in health and social care settings manifest in relation to the attitudes of health care professionals, and ways in which age discrimination can be directly or indirectly experienced by older people, including the denial of treatment and use of ageist language and patronising communication?

Attitudes of health professionals

Attitudes about and behaviours towards others can be 'implicit', meaning they can operate without conscious awareness or control.[33] Research in the US suggests that 95% of people hold negative implicit ageist attitudes, which is higher than the average proportion of people holding negative implicit attitudes towards others based on gender or race.[34] Research comparing the explicit and implicit ageist attitudes of 17 British geriatric nurses and 32 accident and emergency nurses with those of 34 student nurses revealed that although they did not differ on explicitly held attitudes (which are mostly positive), the practicing nurses, who had greater contact with older patients, held more negative implicit attitudes than the student nurses.[35] This may be due to the more contact practicing nurses' have with unwell older adults. Although several studies support the notion that some nurses and nursing students hold negative attitudes towards older people,[36,37,38,39] one study found that health care professionals (radiologists) did not exhibit ageist attitudes.[4] Differences between attitudes held by different groups of professionals suggests that the type and level of contact with older people influences attitudes to ageing.

A review of research on health and social care professionals' attitudes towards older adults resulting from their contact with older patients, indicated that whilst more contact was linked to more positive attitudes it was also related to benevolent stereotyping.[40] More importantly, a study of 56 care workers in the UK found that the quality of experienced interactions between older adults and social care professionals was linked to other attitudes towards older people.[41] Specifically, care staff who had poor quality (negative) interactions with service users held more negative attitudes towards service users.

A qualitative study of 17 British nurses revealed how they categorised and described older patients recovering from anaesthetic as 'confused' or 'wandering', while a similar younger adult was described as 'disorientated'.[42] Nurses who expressed negative attitudes towards older adults also reported feeling uncomfortable around older adults and found them cantankerous, prone to complain and inflexible.[43,44] Other research from the US revealed that acute care nurses that held more negative attitudes towards older adults were more in favour of using physical restraints (Helmuth, 1995), but this has not been replicated in Australia and, as far we know, is untested in the UK.[45] It has been suggested that nurses' use of negative stereotypes during handovers could perpetuate negative attitudes, especially from senior to more vulnerable junior nurses.[46]

Together these studies suggest that when health professionals make decisions and judgments about older adults, they may not be aware that these are affected by implicit ageism or age biases that devalue older patients, and thus will not notice the harmful consequences that follow.

Dehumanisation

Dehumanisation is defined as "the denial of full humanness to others"[47] and can lead to discriminatory, abusive, demeaning or degrading behaviours. Eldercare settings can be dehumanising if they lack opportunities for personalisation and if people have little control over their own space and support.[48,49] In addition, some healthcare professionals have been accused of using dehumanising language when talking to and about older people, for example referring to older patients as 'crinklies' and 'crumblies' or referring to patients merely by their condition "We have two hips and a knee today" in the surgical ward.[50] Drury et al's (under review) study of care workers in England revealed that carers who perceived the interactions with service users to be more negative, were more likely to hold dehumanising attitudes towards them and other older adults in general.[42]

Denial of treatment

Age discrimination can be experienced directly, where an individual is treated less favourably (eg where an older person is refused access to a particular service because of their age) or indirectly, where an apparent neutral rule or practice that applies to everyone (seeming to be equal), puts a particular group at a disadvantage.[a] There is evidence that older people have experienced both forms of discrimination in health care.

In a randomized control trial, 121 physicians were asked to assess, diagnose and prescribe treatment for two identical patients (via case studies) presenting with depression, who varied only by age (39 or 81). Not only did physicians take longer to reach decisions for the older patients, but both the diagnoses and the treatments advised differed. Younger patients were more likely to be diagnosed with depression and anxiety, whilst the older cases were diagnosed with dementia or a physical illness. The younger patients were then more likely to be prescribed a wide range of relevant therapies including psychotherapy, pharmacotherapy and referral to inpatient or specialist treatment. In contrast, older adults were prescribed supportive counselling. The researchers believe that because the patients were identical other than age, perceptions of ageing must have affected the physicians' decisions leading them to be less likely to diagnose the appropriate disorder and treatment for older patients.[51]

Even among patients with the same diagnosis, differences in treatment based on age are apparent. The Royal College of Surgeons in England (2012) report that "Incidence of breast cancer peaks in the 85+ age group, while the surgery rate peaks for patients in their mid-60s and then declines sharply from approximately the age of 70" (p4). This pattern was repeated for eight different surgical procedures. Further research shows age bias in the treatment of transient ischaemic attacks and minor strokes and the under use of mental health services among older people.[52,53] Differences in the treatment of younger and older individuals with the same condition presents a kind-of indirect ageism, whereby the cost-benefit analysis which justifies the distribution of limited resources disproportionately disadvantages older adults.[54,54] For instance, the use of QALYs (Quality Adjusted Life Years) to assess the relative cost effectiveness of treatments and procedures for Alzheimer's disease, osteoarthritis, osteoporosis or age-related macular degeneration, can be problematic and tend to work against those who are older, with fewer remaining years.[54]

Beyond diagnosis and treatment, a further issue is the exclusion of people over 65 and 70 from participating in clinical trials.[55] Although the situation is improving, this is a clear form of age discrimination outside the NHS which has knock-on effects on treatments available for older patients.[54]

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a   In this case, any policy or practice that treats age groups differently, is unlawful unless it can be objectively justified, see Department of Health's (2012) report on implementing age discrimination legislation for more information.

Language, communications and interaction

A qualitative study exploring ageist practices in clinical settings interviewed 57 health workers, the majority of whom worked in acute or community NHS settings. The study reported that ageism arose in 10 aspects of communication between workers and service users.[56] Broadly, these aspects fell into two groups; either patronising behaviour, with roots in stereotypic perceptions of older adults, or disrespectful behaviour linked to dehumanising attitudes. Patronising and stereotypic communication and behaviour included: not fully informing an older person about their condition, treatment and/or care, assuming they would not understand or want to be bothered about it; labelling older people as 'daft' or 'demented' if they have a problem understanding; talking to, or about, older people in a patronising way – eg treating them like children, and shouting at an older person even if they are not deaf. Disrespectful communication included; not giving enough or appropriate information about medicines, instead instructing older adults to 'just take them'; discussing personal or sensitive issues with an older adult loudly and within earshot of others; and speaking 'on behalf' of an older adult without prior consultation.

A form of patronising communication that some older people have reported experiencing in health care settings is known as 'elderspeak'. Elderspeak is similar to displaced baby talk, denoted by high pitch, slow rate of speaking, reduced complexity (eg reduce sentence length), and simpler utterances.[57] Evidence suggests that people who use this mode of communication may become over-accommodating, and presume the needs and response of the person they are communicating with, rather than letting them communicate their needs and wants themselves.[58]

Ryan, Meredith, MacLean, and Orange (1995) proposed a 'communication enhancement model' for use by care providers to overcome problems of poor communication with older adults in health care settings. The model promotes health in old age by stressing recognition of individualised cues, moderation of communication to suit individual needs and situations, appropriate assessment of health/social problems and empowerment of both older adults and providers.[59]

Implications for health and social care

At the individual level, health care professionals and organisations should be aware that older individuals are potentially vulnerable to age prejudice and stereotyping processes; patients might self-stereotype or be at risk of stereotype threat effects, which have implications for how well they respond to cognitive and physical performance tasks, as well as for their decision making, preventative health behaviours and rehabilitation. It is particularly important, therefore, that health care professions should be careful not to stereotype, use demeaning or patronising language, or use age as a justification for health treatments.

One way to combat ageist attitudes is to learn about both explicit and implicit forms of ageism.[35] It is important to raise awareness that regardless of our explicitly positive views about older adults or our desire to uphold equality issues, we are all susceptible to both patronising 'positive' and unconsciously internalised negative age stereotypes, which can have subtle and negative effects on our thoughts, feelings and behaviour. A recent education-based intervention conducted during a nursing undergraduate module in Spain, focused on the importance of person-centered care and discussion of age-based stereotypes, and successfully reduced negative stereotypes about ageing.[60]

Williams and colleagues developed an intervention that informed care staff of the importance of socialising with older adults.[60,61,62,63] The intervention focused on communication barriers within the care context and the positive and negative aspects of elderspeak. It used simulated and real videotaped staff-resident interactions, from which participants were able to (1) identify aspects of elderspeak in their own interactions and those of others, and (2) reenact the interaction using effective communication strategies. Findings revealed that participants gained knowledge about their own communication patterns, especially their use of elderspeak. They also used fewer psycholinguistic features of elderspeak after training.

At the organisational level, health care settings should be careful not to perpetuate dependency, dehumanization and negative age stereotypes either directly (eg through signage and instructions) or indirectly (eg through age segregation and categorisation). In many health care settings the focus is largely on what can be done for the service user, not how they can co-produce, co-create or support people to keep and maintain a level of independence and control over their lives.

For example, while age-differentiated services that have developed over time in response to a need are not inherently ageist, they have the potential to be discriminatory if older people's services are disproportionately under-resourced in comparison to children's or adult services. Further, the categorisation of hospital wards by age is potentially problematic for patients and staff. For patients, being put on the 'geriatric ward' is an unwelcome categorisation of themselves as 'old', which they may not agree with or wish to be perceived as. For staff, the age categorisation of wards can serve to strengthen age-stereotypes, which can then bias perceptions of new and existing patients, as well as older people in general. To help reduce prejudiced attitudes in health care settings, organisations should identify and reduce circumstances and/or environments creating poor quality interactions between care staff and service users,[42] and where possible patients on age segregated wards should have opportunities to share and join mixed age spaces (eg a garden) and activities.

As a society there is more to be done to promote more positive perceptions of ageing that encourage us to value older people and their contribution to society. This requires a more critical response to the way older adults are represented in the media – challenging the impression that older people are merely consumers of finite resources and focusing on their potential as an asset, providing over £61 billion to the economy through employment, informal caring and volunteering.[64] Are older people bed blockers, or are they trapped in hospital?[b] Changing default perspectives, which are largely based on stereotypical representations of older people, and challenging how older adults are viewed should gradually weaken negative perceptions of ageing that have the potential to negatively affect us all.

b   Grateful to the Age Action Alliance's Attitudes to Age working group for this example

Recommendations

Based on the insights from this review we propose three recommendations for raising awareness and two practical recommendations that can help reduce negative perceptions of ageing and age discrimination in health and social care.

1) Societal narratives that denote older adults as a burden on health care resources and a drain on the economy need to be challenged in recognition of the many ways that older adults contribute to services and the economy throughout their lives to reduce this common (mis)perception of ageing.

2) Health care professionals and organisations should be aware of the different ways ageism can manifest in health and social care settings. For example, age discrimination is not just about fair access to treatment but can also arise in the interactions between health care professionals and patients. Understanding more about the explicit and implicit forms of ageism, how they are manifested, and their consequences, should help to prevent ageism.

3) Health care professions and organisations should be adopting practices and approaches that avoid perpetuating dependency, dehumanisation or negative age stereotypes, such as promotion of co-production, reducing categorisations and promoting use of communal spaces.

4) Those responsible for training health care professionals should be aware of how negative perceptions of age can influence individual's performance, motivations and behaviours. Health care professionals should be cautious not to make a patient's age salient before administering tests that could be vulnerable to age-based stereotype threat effects (eg memory, cognitive performance, physical performance). They should be aware that negative perceptions of ageing and attitudes to age can create psychological barriers to rehabilitation, motivation and response to treatment.

5) As part of their Equality and Diversity policy and culture, health care organisations should identify and address the circumstances or conditions that create poor quality interactions with patients, which have shown to have a negative impact on health care professionals attitudes towards service users and older adults in general.

Conclusions

In this Brief we have shown that perceptions of ageing in the UK include a problematic set of negative (eg incompetent, ill, frail, dependent) and positive (e.g. friendly, moral, wise) elements, that can subject older people to patronising forms of prejudice. These are subtle but powerful and can be expressed in the language and tone used to communicate with older patients, the settings in which they are placed and the framing of treatment options. The Brief highlights that negative perceptions of ageing can impact on individuals as they age. For example they can affect the health care decisions that patients make for themselves (eg will-to-live). Being a target of prejudice and discrimination can also have detrimental effects on health and wellbeing. Ageism is a problem for health and social care professionals and organisations, for example in the decisions that professionals make, which have the potential to lead to misdiagnoses or may deny older people treatment. The categorisation of wards by age, prolonged negative interactions between care workers and service users, and representations of older adults in the media as consumers of finite resources are three risk factors that contribute to the perpetuation of negative perceptions of ageing. We conclude that in order to maximise the prospects for patients and clients' healthy ageing, healthcare could benefit from much more deliberative questioning of age-based assumptions and of how attitudes interact with policies, structures and practice.

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6

Briefing paper
Supporting carers
Author: Emily Holzhausen – Carers UK

Briefing paper (6): Supporting carers
Author: Emily Holzhausen – Carers UK

Key messages:
— 1.4 million people in the UK provide over 50 hours of care per week. Although the vast majority of people caring are of working age, the fastest growing group of carers are those over the age of 65 growing at a rate of 35% in just 10 years.
— Identification of carers by healthcare professionals in all settings and across all disciplines remains a priority so that interventions and better tailored responses can be put in place.
— There should be a focus on developing a 'carer friendly health service', whereby carers are identified, provided with adequate information and advice, and their expertise listened to and respected. Carers should also be supported to look after their own health, as well as that of the person they are caring for.

This briefing intended to explore ways of ensuring carers are properly supported, with a focus on those caring for older people, and older people who have caring responsibilities.

An introduction to the topic and overview of the issue

In the UK today, there are a staggering 6.5 million people providing a level of unpaid care to a relative, close friend or neighbour.[1] The replacement value of carers' support is worth a staggering £132 billion a year, equivalent to a second NHS.[2] Most people will provide care at some point in their lives. 58% of carers are women, 42% men but this relationship is reversed in the over- 85 age cohort, men are more likely than women to be caring (59% to 41%).[3] Women are significantly more likely to provide substantial care ie over 20 hours by the time they are 59, ie in the peak of their careers. Men have the same likelihood by the time they are 74.[4]

Although the largest group of carers are providing just a few hours of care per week, the numbers providing over 50 hours of care per week and more are rising faster than simple population increases. 1.4 million people provide over 50 hours of care per week, a rise of 11% in only 10 years.[5] Although the vast majority of people caring are of working age, the fastest growing group of carers, are the 1.3 million over the age of 65 growing at a rate of 35% in just 10 years[6], outstripping the rate of population growth. It is estimated that by 2030, the number of older carers will rise to 1.8 million.[7]

Caring is as diverse as the UK population. Earlier 2011 Census results showed a relatively younger BAME (Black, Asian and minority ethnic) carers who were slightly less likely to be caring, but population data shows that the 600,000 BAME carers are set to grow in future as longer established BAME populations age.[8] Although more evidence and experience is emerging about LGBT (lesbian, gay, bisexual and transgender) carers, there is less collected evidence and documented experience. Carers UK's best estimates are that there are around 390,000 people who are LGBT carers. [9] One in 20 (5%) of staff in the social care profession have witnessed poorer treatment or discrimination for a patient or service user because they were LGBT.[10]

> "*Having contacts from my community to discuss with people who understand LGBT issues is vital – whether its early onset dementia or mental health/ anxiety. Its so very important to know that other people understand.*"

Importantly for the medical profession, research has shown that every year, roughly one-third of the carers cohort is replaced, meaning that 2.3 million people start caring, and 2.3 million stop caring either because the person they care for has died, or recovered.[11]

The largest cohort of carers, by far, are the 4 million people of working age, around 3 million of whom juggle work and care.[12] Some have younger families as well as caring for parents or partners, sometimes referred to as the "sandwich generation" – 2.4 million people are

currently in this situation. Although the studies show they tend to provide fewer hours of care, the stress and strain on the individual is likely to be higher.

Evidence

42% of carers providing over 50 hours per week said they haven't received any training for their caring role, or information to keep them well.[13]

The amount of care that someone provides varies considerably. From a few hours of care a week from shopping, collecting medication and taking someone to medical appointments to caring around the clock performing nursing care, full time advocate and financial and administrative management. Of the total population of carers, 82% provide practical help such as preparing meals, doing the laundry or shopping, 49% help with financial matters, 47% help deal with care services and 38% help with aspects of personal care.[14]

> In an effort to understand and explain their complex lives, some carers have mapped contact with professionals. One carer said, *"as a management exercise I mapped out every professional that we had contact with in relation to my wife's MS. The result was 32 professionals, some of whom we see regularly. That's a huge amount to keep track of and interact with. What I find difficult is having to repeat information to each professional. I need care to be better co-ordinated so that I can keep working for as long as possible to keep the roof over our head for my wife, my kids and myself. We all need things to work better".*

In terms of health issues, the Census 2011 suggests that those providing over 50 hours of care per week are twice as likely to be in bad health compared with non-carers.[15] The GP Patient Survey showed that whilst 51% of non-carers had a long standing health condition, this rose to 63% of all carers and 70% of those caring for 50 hours or more. The survey also highlighted higher incidences of arthritis, high blood pressure, long term back problems, diabetes, mobility problems, anxiety and depression.[16] Carers' own experiences suggest that long term back problems and mobility problems are caused by long term physical stress, moving and handling without the right equipment or training. Anxiety and depression rates are high, with Carers UK's survey of carers providing significant care – 77% recording anxiety and 83% recording depression since becoming a carer.[17]

For those juggling work and care, carers are more likely to be suffering from ill-health and stress in the workplace. Many experience a dip in income, especially if they have to give up work to care and this results in higher levels of stress and depression associated with money worries alongside caring.

Carers experience of services

Carers have a mixed experience of services and this is common across the UK. We asked carers whether they felt prepared for caring in a survey and most said they were not prepared for caring.

> *"No-one trained to do this role. I never expected to do what I'm doing now, but there is no-one else to help me. I just have to get on with it."*

42% of carers providing over 50 hours per week said they haven't received any training for their caring role, or information to keep them well.[18] In Carers UK's survey, carers' experiences of health services are rated better than care services. 34% reported very positive experiences of hospitals and surgeries, 16% reported negative experiences and 42% said their experiences were mixed.

> *"I have an excellent relationship with all the professionals involved in my husband's care, and the specialist nurse in particular has empowered me to learn about and manage his condition myself, so I rarely resort (touch wood) to any emergency services."*

Those most likely to experience good health services are those caring for a partner or a spouse. Those reporting worst experiences of health services tend to be those caring at a distance.[19] These carers' experiences have a bearing on how carers are identified within the NHS, how knowledge and information is shared and how families and close friends are prepared for caring. It also has a bearing on exploring confidentiality needing more explanation, permissions to be explored and good recording.

Identification of carers

Identifying carers is not always straightforward. Decades of research has shown that people do not identify themselves as carers and many people do not use the term. It does not always translate well into different languages where the word, concept and culture do not read across. People see themselves as mothers, sons, close friends, fathers, nieces and brothers first, and as carers second. Carers tend to put themselves second and often say that they become "invisible" as the person who does the caring, at times not being consulted, involved, or valued. However, when the opposite occurs, which is what they want, carers' lives can be transformed:

> *"My doctor is brilliant. He always takes the time to ask me how I am, how I am coping. And it makes such a difference".*

Discussion of evidence

Caring is something that most people do, but which most people are not prepared or trained for, and which can have a devastating impact on carer's lives in terms of work, health, income, family and other relationships. With the different stages of caring meaning that someone can move from knowing very little about a condition to becoming an expert over time, doctors and medical professionals have to be able to adapt information and knowledge so that it supports carers to do the role they want – supporting and improving outcomes for the patient, too. One woman caring for her husband with dementia said,

> *"It never occurred to me that the way his brain was working with dementia was not just about forgetting things, but it affected the way he thought about things too, meaning he could not do simple tasks like make a cup of tea. Now that I understand that, we both get on better. He is much calmer and doesn't fly into rages and I don't get quite so depressed and tired all the time. All in all, we're much better off. A little bit of knowledge goes a long way."*

Most people who are caring also know the wishes and preferences of those being cared for, which is valuable in delivering more person-centred care for the patient.

The evidence also points to extra challenges for those who have multiple caring roles or conditions that span different areas and disciplines. For example, a parent of a severely disabled child who has learning difficulties, challenging behaviour and physical disabilities has to act as an advocate for her child, the parent also has her own health conditions which are a result of caring, her mental health is poor, she also has an increasingly frail parent. The difficulty of modelling an NHS on a patient by patient basis is that the whole caring situation cannot be examined in the round. This parent often talks about how laws and services are organised around specialisms and segments which complicate her life further. Many carers say that they need their whole needs and lives considered, not just one segment.

One particular area that comes up time and again with carers is the issue of confidentiality and this is particularly key for those caring for people with mental illness. Maintaining confidentiality is key, but good practice has also shown when clear consent and sharing of details can be explored, it can improve health, well-being and outcomes for all – patient and carer.

One particular challenge in measuring the efficacy of different interventions for carers' health and well-being are the inter-dependencies between different services and support mechanisms. Some services, however, have very clear outcomes. Herts Valley CCG has set up a scheme to improve the identification of carers and this is its biggest referral to the local voluntary sector: Carers in Herts. Of those who were registered, 52% of carers took up the

offer of flu jabs and 85% see the benefits of being registered with GPs in terms of their health, well-being and ability to manage. In developing a Carer Friendly Hospital, Lister reduced severe stroke re-admissions due to carer breakdown from 10 to zero, gaining 142 bed days as a result of improving carers' knowledge of stroke, and providing basic support at home. Until this initiative, around one quarter of readmissions were due to the fact that the carer could not cope/carer breakdown.[20]

Suggestions for solutions

— **_Identification of carers still remains a top priority:_** Identifying carers by doctors in all settings and across all disciplines remains a priority so that interventions and better tailored responses can be put in place. The new CCG guidance in England states that carers should be identified and supported. In Scotland, legislation has been in place for over a decade which requires health organisations to have plans in place to identify carers and similar legislation existed in Wales until recently until it was replaced by the new Health and Social Services Act. In Northern Ireland, following Carers Week 2016, there is renewed interest in carers issues around health and well-being from the NI Assembly and Ministers. Patient records have read codes that allow for the identification of carers.

— **_Community based solutions matter:_** As awareness campaigns demonstrate, whole community responses to disability and long term conditions and caring can make a difference, whether it is understanding mental illness better, dementia friendly communities or carer friendly communities. Carers UK's recent research for Carers Week found that when carers found their local communities carer friendly, they were between two and three times more likely to be able to maintain their own health and well-being.[21]

— **_Balancing prevention with alleviating key pressure points:_** The challenge for health services is to get the balance right between these two areas. With prevention, a ground-breaking study by Professor Zarit shows improved cortisol levels for carers of people with dementia when they received a break compared with those who did not get a regular break reducing a number of health risks and ability to manage[22]. Consultations with carers show breaks and support that provides a break are invaluable. Key pressure points for carers are hospital discharge back into the community and responses in an emergency - preventing an A&E admission, or quick admission into residential care that is avoidable.

— **_Supporting carers starts at home:_** One in nine workers juggles work and caring for a relative or close friend, unpaid, and this likelihood rises for women and those aged 45 and over. The NHS 5 Year Forward View rightly suggests that employers within the NHS at all levels need to support workers who are juggling work and care. NHS England is a member of Carers UK's Employers for Carers forum that supports businesses who are supporting their employees who are carers.[23]

— **_Electronic patient records– an opportunity for carers and health professionals alike?_** Electronic patient records offer the opportunity to speed up and integrate. Providing patients with access to their own medical record can allow them to share information with carers as needed, and carers' lives can be made easier by enabling online ordering of repeat prescription and appointment bookings. Patients and carers can be saved from having to repeat the same information many times by enabling systems to share electronic patient records held by the GP with other relevant health and social care professionals. The benefits of information sharing between professionals between primary and secondary care and within specific teams could be beneficial, particularly for complex cases that might involve out of hours services, A&E, or a variety of consultants. The evidence from Carers UK so far shows that carer awareness of their own online patient records remains fairly low, but is increasing. Whilst some remain sceptical about the benefits, others are keenly embracing the technology.[24]

— **_Carers' passports in hospitals_** are schemes being developed in Trusts as a means of identifying carers, as well as improving information and advice to them and additional support to the person cared for. The results show savings on the bottom line for health services. During a pilot at the Central Manchester University Hospitals NHS Foundation Trust, which trialled open visiting as part of a Carer Passport, nearly two-thirds (59%)

of staff felt it had improved communication between staff, patients and their relatives. There was also a change for carers and patients. Prior to the pilot only 23.5% thought staff were available to discuss care and treatment and this rose to 100% at the end of the pilot. The pilot also saw a reduction in the number of falls compared to the same time a year previous which the Ward Manager felt open visiting contributed to.[25]

— **The power of NHS Choices and good Googling:** All advice and information services are seeing a change in the way that people are now consuming information — queries are becoming more tailored and specific. How people consume information about conditions and how to manage them is also changing and an opportunity to increase self-care with managed information and support.

— **Tech-enabled care and tech solutions:** With the rise of apps and online management applications being used increasingly in mental health, tackling other long term conditions, everyday tech monitoring basic health, to specialist telehealthcare, tech is changing the way that we manage care individually and potentially how we organise care. Carers UK has stepped into this sphere with its care-coordination app — *Jointly -* based on carers experiences of having to coordinate many different people in order to deliver care, it creates care circles, assigning tasks and syncs with diaries. With the advent of social prescribing and the new tech tariff in the NHS, a new opportunity to look for different tech solutions for carers is now possible.

— **Boosting and recognising skills:** In some areas, carers are invited to different training programmes, improving health and well-being. Other training and structured learning programmes have been developed, many of which are on-line or with supported discussions. Carers UK, for example, has launched a new e-learning programme aimed at helping carers learn about good nutrition for someone with a long term condition.

— **Understanding caring:** For every doctor from every profession, understanding caring is becoming increasingly important. When medical interventions are shifting to a greater input and element of self-care and self-management, in many instances this will require and will have the input of a carer. Understanding caring also means understanding how caring can impact on a carer's own health and well-being and their ability to manage this. Relevant training needs to remain up to date as well as core training for all junior doctors, mainstreaming caring as an important element.

— **The power of experience:** A mixture of good experiences which are empowering and poor experience which demonstrate the need for change — both have the power to invigorate services and support.

Actions doctors can take:

a) Understanding the caring role, from first diagnosis new to caring through to expert carer.

b) Understanding the two sides to caring: i) the need to be able to manage caring better and get the right support and ii) the ability of a carer to manage their own health and well-being.

c) Giving carers choices about caring ie it's not always possible to care and it's important not to make assumptions about whether someone can care or not.

d) Giving advice/information and training, making sure families and friends care well, safely, etc knowing what is involved.

e) Respecting feedback from carers.

f) Looking at a wide range of support mechanisms eg social prescribing including apps, looking at telecare/telehealth solutions to help support carers.

g) Linking carers into other services – doctors are not experts on the welfare system, but links to organisations and communities who are is invaluable – which is true of both consultants and GPs. This could happen at diagnosis, key treatment times, etc.

h) Looking at staff internally – who are also juggling work and caring. They could be the theatre nurse, the receptionist, the porter, the practice manager, the finance officer, all parts of the team might be experiencing exactly the same issues as any carer of a patient being treated. With trained, skilled and knowledgeable staff at a premium, retention of staff is critical and supporting staff who are juggling work and care becomes a higher priority. Some organisations find it can also transform services, making them more carer friendly.

i) Leadership matters and clinicians leading by example makes a difference to the whole team. Anecdotally, some of the highest performing GP surgeries in terms of carers are those GPs who lead by example.

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