The obstacle course: overcoming the barriers to a better later life
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Executive summary

By 2030 there will be double the number of people aged 85 or older compared with 2010. Yet we still have a very long way to go before the oldest in our society are given all the support they need to remain independent and live healthy, enjoyable lives.

Faced with an ageing population, the time has come for policymakers to take firm action and help the UK to get ready for rapid demographic change.

Independent Age’s 2030 Vision is that the UK should become the best country to grow older in.

Unfortunately, life at present is not as universally positive or rewarding for older people as some commentators would have us believe. Too many older people have to fight to be heard and have their needs recognised. They can struggle to get the most basic support and can often feel like they are battling a system that is set up to complicate things and present barriers to getting help.

Many older people and their carers tell us they don’t want to feel dependent, but more support is needed to help them prepare for and manage the setbacks and challenges old age can bring.

Through our Helpline and other services, we have learnt:

- **Accessing healthcare and getting support following a stay in hospital can be fraught** and frustrating as people battle to receive basic after-care.

- **Where people have more serious care needs, the system is characterised by complex rules** which can present barriers to receiving help and support.

- **Managing finances in later life can be complicated** with many pensioners unaware of the extra support they could receive to help avoid poverty.

- **Feeling in control can be a real challenge with tough advance decisions to make** about housing, finances, and health and care treatment.

By 2030, it is estimated there will be 15.7 million people in the UK aged 65 and over. The government has already indicated there will be an increase of 2 million over-75s in Britain in just the next decade.

Evidence from our own services, together with other findings, highlight where major gaps still need to be plugged so that the country can respond to millions more of us living into old age.
In **chapter 1** we focus on the difficulties older people tell us they experience securing basic support following a stay in hospital or when their health needs become more severe.

In **chapter 2** we focus on the adult social care system in England. Older people and their families tell us they face multiple barriers finding out about support and then accessing it when they need personal care and practical help.

In **chapter 3** we focus on the benefits system for pensioners. Low awareness of many sources of income support are leaving growing numbers of pensioners struggling to get by on a low income.

In **chapter 4** we focus on some of the major life changes older people can experience, especially relating to their finances and housing.

And in each section, we conclude that things could vastly improve.

- **1.2 million older people in England don’t receive all the social care support they need**.
- **Just under 2 million pensioners across the UK are now living in poverty**.
- **£3.5 billion worth of benefits go unclaimed by older people each year**.

In 2016, Independent Age responded to the needs of the older population with over 1 million people accessing support from us.

More recently, focusing on the period between May 2016 and April 2017, the top 10 issues we were contacted about on our Helpline were:

1. Means-tested benefits
2. Disability benefits
3. Paying for care
4. Care needs assessments
5. Support for carers
6. Aids and adaptations
7. NHS Continuing Healthcare
8. Managing affairs (eg, Lasting Power of Attorney)
9. Hospital discharge
10. Housing options
Despite some progress in recent years, major reforms are still needed across health, social care and the benefits system.

- Older people need more help with being discharged from hospital, obtaining aids and adaptations to move back home and to manage continuing healthcare needs.

- Older people and carers need more support with paying for and getting assessments for care. They also require their needs to be met when providing unpaid care.

- Older people need more support with finding out about benefits such as Pension Credit, which 1.4 million pensioners are entitled to, but don’t currently receive today.

- Older people need help with managing their affairs, including their finances, and choosing where to live in later life.

We also know that over 1 million older people say they always or often feel lonely and that loneliness is a growing problem as our population ages. There are many explanations for this and it can be harmful to both older people’s mental and physical health.

Clearly, older people can face many barriers in later life in terms of their health, finances and staying socially connected.

In this report we share some of our own evidence, including stories older people and their family members have shared with us. We specifically focus on the obstacles that need removing so older people and their carers can access the most basic services and support. Their testimonies reveal what a difference early intervention can make, as well as where things are going wrong.

The inescapable conclusion is that we are still not responding well enough, as a country, for a rapidly ageing population and remain underprepared.

Now it is the job of policymakers to act.
The extraordinary increases in life expectancy that were achieved in the 20th century have changed what it means to be an older person in the 21st century. The needs of an older person today are often very different from what they once were.

Independent Age’s 2030 Vision is that the UK should be the best country to grow older in. Whether we can achieve this vision depends on how successful we are in responding to the complex and changing needs of older people.

Our 2030 Vision for older people

Independent Age has some simple aspirations so the UK can become the best country to grow older in.

In just over a decade’s time, we want to see the UK become a country where:

- older people can live healthily and get the health and care services they need
- older people can live comfortably with the money they need
- older people can live free from discrimination and make an active contribution in later life
- older people can stay connected to their families and the world around them.

By 2030 there will be double the number of people aged 85 or older compared with 2010. Yet, as this report suggests, we still have a very long way to go before the oldest in our society are given all the support they need to remain independent and live healthy, enjoyable lives.

Previously we have argued there can be no excuses for inaction and that the UK needs to act now to get ready for rapid population ageing. Governments have been warned that the UK is “woefully underprepared” for the demographic changes the coming decades will bring.

In this new parliament, the government has a responsibility to confront and respond to the realities of demographic change.

Policymakers need to both acknowledge the challenges ahead, but also seize the opportunity of building a country that works for the millions more now living into old age.
The struggle still ahead

This report reminds us that life in the UK is not as universally positive or rewarding for older people as some commentators would have us believe. We know many older people have to fight to be heard and have their needs recognised. They can struggle to get the most basic support and can often feel like they are battling a system that is set up to complicate things and present barriers to getting help.

Many older people and their carers tell us they don’t want to feel dependent, but more support is needed to help them manage the setbacks and challenges old age can bring.

Unfortunately, there is much more to be done to remove unnecessary bureaucracy and barriers as we look to build a society that is fully inclusive of older people.

The pensioner population today

In our report, we offer some recommendations for how things could be improved for older people. We need to be clear that as our older population grows, it will also become increasingly diverse. Not all older people will qualify for, need or even want help from charities or state support. However, many will.

Many of the older people who need support live alone, or far from family, and some live in a home or community that they don’t always feel meets their needs.

Others will now be in their 80s and 90s. With increasing numbers living alone, many will need additional help with managing their health and accessing care and support services.

And too many pensioners – 1.9 million – still live in poverty, with many more experiencing financial insecurity or worries about making ends meet.

The characteristic image of the wealthy baby boomer has served to obscure political debate about Britain’s growing pensioner population. In fact the majority of pensioners who were born before the Second World War – the so-called ‘Silent Generation’ – are not at all wealthy and many still experience health and other inequalities.

1.9 million pensioners still live in poverty

1 in 6 are living in poverty
A few facts – the reality

• By 2030, it is estimated there will be 15.7 million people in the UK aged 65 and over (the current population is estimated to be approaching 12 million or around 18% of the population. By 2030 this is estimated to rise to 22%)\(^{15}\).

• There are 1.2 million older people in England living with an unmet care need\(^ {16}\).

• Half of all people aged 80 and over will suffer a fall each year. And nearly 1 in 3 people aged 65 and over will suffer a fall each year\(^ {17}\).

• Dementia could affect up to 1 million people by 2025 (currently around 850,000 people are affected)\(^ {18}\).

• 1.9 million pensioners live below the poverty line in the UK. This is 16% of the pensioner population\(^ {19}\).

• £3.5 billion of benefits go unclaimed by older people each year\(^ {20}\).

• Over 1 million older people say they always or often feel lonely\(^ {21}\).

• Almost 1 in 3 people aged 80 and over report feeling lonely in their daily life (29.2%)\(^ {22}\).

• There are around 1.2 million carers aged 65 and over in England, a number that has grown by over a third in just 10 years\(^ {23}\).

• Over 1.5 million older people in England cannot leave their home without help\(^ {24}\).

Our approach

In this report, we take a look at the issues older people and their families specifically contacted us about in 2016.

Having analysed the issues they sought our help with, we focus on the problems older people experience:

• getting the health and care services they need

• getting support to remain independent and live in suitable housing with the money they need.
And based on the enquiries we received in 2016, we have structured the report to address the following four topic areas:

1. **Help with serious health needs**
2. **Understanding social care**
3. **Securing a decent income**
4. **Staying in control**

Overall, we conclude we still have a long way to go before the UK can truly meet our 2030 Vision.

For each topic area, we examine the most common issues older people tell us they’ve faced. In addition, we highlight a number of emerging issues from 2016 which, left unaddressed, may get worse.

The recommendations we set out are no means exhaustive, but offer a starting point for simplifying what is typically a very complicated and impersonal system – across health, care and social security.

They offer important first steps to take to help transform people’s experiences, from navigating a minefield today, to accessing a system that’s more manageable and ‘user friendly’ in the future.

What’s often missing from analyses of policies affecting older people is how the initiatives and the services aimed at assisting them are experienced by the users themselves – including how easy they are to comprehend and access. That’s why we draw on the direct experiences of older people, who feature throughout our report.

We should also not forget how difficult it can be for someone who has looked after themselves their entire adult life to ask for help in the first place. This report acts as a counter argument to the ageing sceptics who characterise our response to the needs of the older population as a social indulgence rather than the social necessity it really is.

In the report we specifically highlight the key issues older people are facing today. This is influenced by the calls our Helpline receives. However, this isn’t the only information we have drawn on.

Throughout the report we also draw on findings from other charities, think tanks and government reports. These sources demonstrate that the barriers facing older people in the UK prevent people from receiving the support they need in a timely manner or, in many cases, at all.

Failure to respond to the needs of the older population is already having an impact on the lives of older people and their families. This isn’t just a problem that needs addressing in the future – it needs addressing now.
How we help

We give free, confidential advice over the telephone for older people, their families and carers on issues such as getting help at home, adaptations and equipment, paying for care, loneliness, healthcare services and welfare benefits. We also produce free public information resources, including guides, factsheets and short information films.

We’re independent, so older people can be. Our information and advice is completely impartial – we don’t sell or recommend products – and our campaigning is independent and based on the needs of older people.

In 2016, Independent Age responded to the needs of the older population with over 1 million people accessing support from us.

In 2016:

- Our online public information was viewed more than 2.3 million times.
- Our guides were ordered over 285,000 times.
- We delivered more friendship calls and visits to older people than ever before.

Independent Age Helpline

We can help in all sorts of ways.

Our Helpline can provide older people with advice or support directly, or point people in the right direction. Our particular areas of knowledge include:

- care and support
- money and benefits
- health and mobility

In 2016 our Helpline received over 30,000 enquiries and we aim to reach 40,000 enquiries in 2017.

Call us for information, to arrange free, impartial advice from an expert adviser, or to order one of our free guides.

Call our freephone Helpline on 0800 319 6789.
The top 10 issues we were contacted about via our Helpline from May 2016 to April 2017

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<td>8</td>
<td>Managing affairs (eg setting up Lasting Power of Attorney)</td>
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<td>9</td>
<td>Hospital discharge</td>
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<td>10</td>
<td>Housing options (eg downsizing, sheltered housing)</td>
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In 1951, average life expectancy in the UK for a man was 66 years old and for a woman, it was 71 years old. By 2011, average life expectancy for a man had increased to 79 years and 81 years old for a woman. Increased life expectancy on this scale is an extraordinary achievement, but it can only ever tell us so much about quality of life and access to healthcare in later life.

Over the past decade public policy and public debate have focused more on ‘healthy life expectancy’ than ever before. Healthy life expectancy measures how many years of life will be spent in good health. This is arguably a much closer measure of what matters to many of us – not simply ‘How many years can I expect to live?’ but ‘How many years can I expect to live in good health?’

The good news for the UK is that healthy life expectancy has tended to increase in line with life expectancy. People aged 65 today can expect to live over half their remaining lives in ‘good’ health. Men aged 65 can expect to have an additional 10.6 years in ‘good’ health, while a woman at 65 can expect another 11.5 years in ‘good’ health.

However, this overall performance hides significant inequalities. Critically, what these headline figures can obscure are the many pressures on healthcare services and the difficulties older people who need healthcare experience.

The focus of this chapter is what happens for people when they have a serious and continuing health need at home or in a care setting.

When an older person leaves hospital, they can have very different needs compared to when they arrived. These needs will vary but can include managing new medication, living with increased frailty or returning to normal life after a major setback to their health.

We know that capacity pressures in hospitals mean that some older people are being asked to leave hospital when it may be unsafe for them to do so. They may no longer need medical care in hospital, but are discharged without an assessment of their needs and may be sent home without any help whatsoever. Some older people may have received an assessment and some care and support at home, but this package of support is inadequate.

Online information and advice

Our online information on health including healthcare rights was viewed over 67,000 times between May 2016 and April 2017.

independenage.org/information

1 Leaving hospital

When an older person leaves hospital, they can have very different needs compared to when they arrived. These needs will vary but can include managing new medication, living with increased frailty or returning to normal life after a major setback to their health.

We know that capacity pressures in hospitals mean that some older people are being asked to leave hospital when it may be unsafe for them to do so. They may no longer need medical care in hospital, but are discharged without an assessment of their needs and may be sent home without any help whatsoever. Some older people may have received an assessment and some care and support at home, but this package of support is inadequate.
In other cases, older people are delayed from leaving hospital because the right care and support package has not been put in place for them\textsuperscript{31}. This can be caused by delays in assessments or the council taking a long time to arrange a care package. Older people can also experience long stays in hospital as they and their family struggle to arrange care at home or find the right care home.

What older people tell us

- Some older people with care needs are not having the assessment they should receive before being discharged. As a result, their ongoing support needs are not recognised and the discharge may be unsafe. In some cases, an older person can end up relying on family and friends or even paying for care they should be receiving for free.

- The older person has an assessment before being discharged from hospital, but their needs are not properly assessed. For example, an older person may be assessed as being able to return home with visits twice a day despite the family believing they need 24/7 care.

- Poor communication between the NHS and the local authority can cause prolonged hospital stays. This could be about arranging the care and support assessment or a post-hospital care package.

- There’s a lack of information and advice for older people (assessed as needing to pay for their own care) and for their families who are trying to arrange their care. This can lead to prolonged hospital stays.

What else do we know about this issue?

In 2016, over 2 million days were lost on account of delayed transfers of care in the NHS in England\textsuperscript{32} – this represents an increase of almost a quarter (23\%) compared with 2015\textsuperscript{33}. 2016 was by far the worst year for delayed transfers of care since records began, with consistently poor performance. All three of the worst ever months for delayed transfers of care since records began in 2010 were recorded in 2016\textsuperscript{34}.

Pressures in social care largely account for this dramatic rise – for example, patients waiting for a suitable home care package to be put in place or for a residential care home place to be found\textsuperscript{35}. Delays on account of problems with social care increased by just under 40\% in 2016 compared with 2015\textsuperscript{36}.

According to a poll by Healthwatch England in 2015\textsuperscript{37}:

- 26\% of people who had been readmitted to hospital within three months felt they had been discharged before they were well enough

- 14\% of people discharged from hospital in the last three years did not know who to contact for further help following treatment

- 18\% of people felt their friend/relative did not know who to contact at the hospital to talk about their condition.
Like everywhere else he went, the staff showed kindness and care but were overstretched and overworked.

After a successful hip operation he was sent to a community hospital for physio and to be assessed. Here, he fell out of bed and chairs five or six times a week. He went to and from A&E each time he fell and then again for treatment and, when they wanted to send him back to the community hospital, I said no because they weren’t able to manage his needs and keep him safe.

Dad’s injury meant he needed combined nursing and dementia care but there is a massive shortage of dual care homes.

In the home he didn’t receive the medication he needed. He fell and broke his hip, went into hospital and the slippery slope downwards began.

This meant he stayed in a side room at the hospital for three months while I searched for a suitable care home for him.

Carol is 53 and lives in the North East.

For three months, my dad was cooped up in a hospital side room with no windows. He suffered multiple urinary, chest and bowel infections. He would refuse to eat and lost lots of weight. I lived with this terrible fear that he would die in a hospital.

Dad was diagnosed with Alzheimer’s in 2015 when he was 88 years old. I gave up work to support and find home care for him. I couldn’t manage his needs on my own and I couldn’t find the specialist dementia care to help me. With great reluctance, I found a care home for him.

In the home he didn’t receive the medication he needed. He fell and broke his hip, went into hospital and the slippery slope downwards began.

Like everywhere else he went, the staff showed kindness and care but were overstretched and overworked.

After a successful hip operation he was sent to a community hospital for physio and to be assessed. Here, he fell out of bed and chairs five or six times a week. He went to and from A&E each time he fell and then again for treatment and, when they wanted to send him back to the community hospital, I said no because they weren’t able to manage his needs and keep him safe.

Dad’s injury meant he needed combined nursing and dementia care but there is a massive shortage of dual care homes.

In the home he didn’t receive the medication he needed. He fell and broke his hip, went into hospital and the slippery slope downwards began.

This meant he stayed in a side room at the hospital for three months while I searched for a suitable care home for him.
During those months of searching I found that some care managers didn’t want their peaceful homes disrupted by people with dementia. Others were more like community centres: no carpets, smelly, and nothing homely about them. People were sitting in corridors, just awful.

When I did find care homes with spaces, the home managers would get mixed messages from the nurses. Some told them Dad’s behaviour was too challenging – they might have witnessed him having one bad night but hadn’t been part of the team who had seen him on a daily basis. Those who really knew him would tell me, “He’s not like that at all.” There should be a named person for care managers to speak to; someone who has the right information.

Dad would get confused and frightened about his surroundings. He had no views or company to lift his spirits. I understood that they were the professionals and making difficult decisions, but my dad was trapped in a vicious circle of indecision and illness.

A care home manager gave me the number for the Independent Age Helpline. I rang and told them, “I’m desperate”. At this point, I needed to find out about funding and it was great to talk to someone who listened and understood.

The lady I spoke to explained my dad’s rights and gave me numbers to ring if I needed help. She was clear that if I was still struggling I could come back to her.

Eventually I found a specialist dementia nursing home with a wonderful manager. She said that she wasn’t surprised his behaviour could be difficult; he was without regular medication, staring at four walls. She asked him, “If you had a magic wand, what would you like?” and he said, “I’d love a bacon sandwich.” She replied, “As soon as you come to me, you will get one.”

The costs of the home are high but Dad’s very settled. I go to see him unannounced and it’s so good to walk in and see that he is loved and well cared for.

We all have to do the best for our parents when they are coming to the end of their lives. The number of care homes – and sometimes the quality of them – is a big problem. There are not enough dementia nursing homes.

I thank everyone involved in my dad’s care during his stay in hospital: for all their hard work, time and also the support they gave me. These people are under enormous stress, working long hours and overstretched. I am not angry with anyone – it’s the system that needs to change.
Once a person is able to leave hospital, the next step should be putting in the support they need to live well at home or in the community and avoid the need for another stay in hospital. Intermediate care and reablement support services often play key roles, as well as aids or adaptations.

**Support after leaving hospital**

**How things work now**

If you’re well enough to leave hospital but you still need some help to live independently, you might be eligible for free, short-term care and support. This is sometimes called intermediate care or a reablement support service.

Intermediate care and reablement services provide a programme of care and support to help a person retain or regain skills to help them live independently at home and in the community. They often aim to help a person stay out of hospital and stay in their own home for longer, rather than move into residential care.

What services are available depends on the local area, but could include care in a community hospital, care home or in your own home.

Intermediate care and reablement services are time-limited. If you are assessed as needing this support, it must be provided free of charge for up to six weeks.

In addition to these services, aids and adaptations can be offered by councils or the NHS. They can include things like the installation of a handrail in the bathroom or a small ramp at the front of someone’s house. If you’re assessed as needing them, all aids and minor adaptations should be provided free of charge up to the cost of £1,000.
**What we know can go wrong for older people**

- Intermediate care and reablement is not offered when it should be, sometimes leading to older people paying for short-term care and support after hospital.

- An older person is told they are not eligible for intermediate care or reablement when they could be.

- Delays arranging intermediate care and reablement services at home can cause prolonged hospital stays.

- Some delays for these services can be so long that an older person even declines them in order to leave hospital.

- Older people are not made aware of aids and adaptations that could help them or people are being asked to pay for aids or adaptations they should receive for free.

**What else do we know about this issue?**

In November 2015, The National Audit of Intermediate Care published their annual report looking at access and the quality of intermediate care. The report estimated that investment in intermediate care, which includes services to support hospital discharge, was at about half the level required to meet demand.

The report also showed an increase in waiting times for intermediate care between 2013 and 2015. The average waiting time for reablement services in 2015 was 8.7 days. This timeframe is particularly problematic when one considers that older people can lose 5% of muscle strength per day in a hospital bed.

**Richard’s experience**

Richard, 68, was admitted to hospital after a number of health problems meant he needed to have a foot amputated. While in hospital, he had a fall which damaged his hip and further delayed his recovery.

After a month in hospital, Richard was declared medically fit for discharge. He was told he would benefit from a temporary stay in a community hospital for further rehabilitation but, due to a lack of space, the hospital could only offer a ‘reablement service’ of four care visits a day for about a month. However, Richard lived in a different local council area to the one the hospital was based in, and unfortunately no care needs assessment was carried out by his local social services team. In addition, no referral was made to an occupational therapist or community physiotherapy service.

As a result, no home adaptations, wheelchair, longer-term care or ongoing physiotherapy were in place by the time Richard was to be discharged. Richard has no downstairs bathroom (only a commode was offered for the toilet). This left him with no option but to wash in the kitchen.

All that was offered to him were short-term measures and no formal assessment had been carried out. We advised Richard’s family about how a hospital discharge should work in order to be safe, and how to raise concerns with the hospital. We also advised on how to get the assessments and referrals he needed in order to get ongoing support at home.
NHS Continuing Healthcare (NHS CHC)

If a person has complex health and care needs, they may be eligible for NHS Continuing Healthcare (NHS CHC). This is a package of care that is arranged and fully funded by the NHS. It is not means-tested and if someone is eligible, they do not need to contribute towards their care costs. A Clinical Commissioning Group (CCG) must take reasonable steps to carry out an NHS CHC assessment if it appears that a person may have a need for such care.

To qualify, a person must be assessed as having a ‘primary health need’. This means that a person’s nursing and care needs are beyond what a local council could be expected to provide. The assessment will consider the nature, intensity, complexity and unpredictability of a person’s needs.

A person usually has to go through a two-stage assessment in order to determine if they are eligible for NHS Continuing Healthcare.

The first stage is a Checklist Tool assessment. This is a screening process which looks at whether or not a person is likely to qualify for NHS Continuing Healthcare and if they need a full assessment.

The second stage is a multi-disciplinary team assessment using the Decision Support Tool (DST). This is the full assessment to determine if someone is eligible. The multi-disciplinary team must be formed of two or more people: either two health professionals or one health professional and one social care professional.

If a person has a rapidly deteriorating terminal condition, they may be assessed using the Fast Track Pathway Tool (FTPT). This needs to be completed by an ‘appropriate clinician’, which is defined as those who are responsible for an individual’s diagnosis, treatment or care and are registered medical practitioners (such as consultants, registrars, GPs or registered nurses). If a person is found eligible after a fast track assessment, the care package should be in place within 48 hours following the decision.

We know that NHS Continuing Healthcare is one of the most difficult aspects of the health and care system to understand and access.

What older people tell us

- Health and care staff don’t always identify an older person who may need an NHS Continuing Healthcare assessment.
- A lack of awareness of NHS Continuing Healthcare funding among older people means they simply don’t ask about an assessment. When they do happen, family members are not always involved and are not given the time or the information they need to prepare.
- Some people have been told they will not be eligible for NHS Continuing Healthcare without even a Checklist Tool screening assessment being carried out.
- If this screening is done, some older people do not then receive the full Decision Support Tool assessment within 28 days, contrary to guidelines.
• Evidence is not properly collected or interpreted during the assessment meaning some people are wrongly found ineligible and have to work to overturn the decision on appeal. People can also face significant delays with the appeals process, such as CCGs taking longer than three months to conduct an internal review of a decision.

• NHS Continuing Healthcare funding is withdrawn despite an older person having the same or increasing health and care needs.

**What else do we know about this issue?**

In a report from the Continuing Healthcare Alliance in November 2016\(^42\), it was reported that 80% of healthcare professionals thought the Decision Support Tool for NHS Continuing Healthcare was ‘not fit for purpose or there was room for improvement in some areas’\(^43\). The report also found that despite national guidance saying assessment should take place within 28 days, of the 100 CCGs who replied only 14 said they usually achieved this timeframe\(^44\).

As at December 2016, 58,723 patients were eligible for NHS CHC in England, representing a 3.2% decrease when compared to the same quarter in 2015-16\(^45\).

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**Shalman’s experience**

Shalman phoned us about his grandmother’s difficulty in accessing NHS Continuing Healthcare (NHS CHC). His grandmother is 92, blind, has hearing loss, limited mobility and mild memory loss. She was admitted to hospital after having a fall and assessed using the Checklist Tool, which found her eligible for a full multi-disciplinary team assessment using the Decision Support Tool.

However, rather than moving forward with the full assessment, she was reassessed using the Checklist Tool just two weeks later. This time she was found not to qualify for the full assessment. It was only after he questioned the second assessment that yet another one was carried out and his grandmother was found to qualify for a full assessment.

His grandmother was found ineligible for NHS CHC after the full assessment but Shalman’s family are questioning this decision and feel that the assessors were trying to downplay her needs. This has been an extremely upsetting period for Shalman and his family and has caused delays to a permanent care package being put in place for his grandmother.
NHS-funded nursing care (NHS FNC)

If a person living in a nursing home is found ineligible for NHS Continuing Healthcare, the assessors can consider if they are eligible for NHS-funded nursing care (NHS FNC). NHS-funded nursing care is a flat rate payment paid by the NHS towards the care provided to that person by, or under the supervision of, a registered nurse in the nursing home. A person should be assessed for NHS Continuing Healthcare before they are considered for NHS-funded nursing care.

In July 2016, the NHS-funded nursing care rate was increased from £112 to £156.25 per week and the increase was backdated to 1 April 2016, meaning some older people were entitled to a refund. On 1 April 2017, the rate was decreased slightly to £155.05 per week.

What older people tell us

- There is often a lack of clarity about whether NHS-funded nursing care is being deducted from the overall fees for older people who pay for their own care, or added on top of their payment.

- Some nursing homes have claimed NHS-funded nursing care on behalf of an older person and not informed the resident or their family.

- Older people who pay for their own care are not being given the rebate for April - July 2016 after the rate was increased and backdated.

- Older people are being assessed for NHS-funded nursing care without receiving the full NHS Continuing Healthcare assessment first.

What else do we know about this issue?

Following an independent review, the government announced that it would increase the NHS Funded Nursing Care payment for nursing home residents by 40%. LaingBuisson estimates that the increase of £44.25 per week is being paid for about 110,000 privately-paying and council-supported residents of nursing care, adding approximately £250 million to nursing homes’ annual income.

Meanwhile, we are hearing about the difficulties nursing homes are having recruiting nurses and the shortage of nursing home beds in some areas.

David’s experience

One caller to our Helpline, David, said that his mother has been living in a nursing home in West Yorkshire since 2014. David phoned us at the end of 2016. He had been told that NHS-funded nursing care would be deducted directly from his mother’s care fees as set out in her contract. When he read his mother’s invoices though, he saw that her nursing home had continued to deduct only £112 per week off her fees after April 2016 rather than applying the new rate of £156.25. If David hadn’t spotted this and questioned the nursing home, it is possible it would not have been corrected and his mother would have continued to pay more than she should have.
Recommendations to help older people access healthcare

Independent Age’s recommendations include:

• Action needs to be taken to improve delayed transfers of care and tackle unsafe hospital discharges. While best practice models for discharging patients from hospital are well understood in some areas, elsewhere hospital trusts and other partners in health and care are still performing too poorly. NHS England and NHS Improvement should report on what steps have been taken for all areas to adopt best practice and the impact on patient outcomes.

• NHS Continuing Healthcare (NHS CHC) needs to be delivered much more smoothly, recognising the older people trying to access the system are often very sick or frail. A mandatory programme of training for professionals who organise and assess people for NHS CHC should be designed and implemented to ensure that they comprehend rules on eligibility and how to use the decision tools. The checklist and Decision Support Tool used to make decisions should also be examined to ensure that they effectively measure someone’s health needs against the care a local authority can provide.

And something more fundamental that could take place:

• The government needs to ensure that our NHS services have the necessary funding to meet the increased demands presented by an ageing population. This should be based on new service models to provide genuinely integrated health and care services.
2

Understanding social care

Understanding and navigating social care can quickly become one of the most stressful and challenging of tasks.

Even the term ‘social care’ can be unfamiliar and little understood by many people, let alone terms such as ‘deprivation of assets’ or ‘deferred payment agreements’. Yet in the end, these are processes many of us will have to get to grips with and confront. There may be times when we have to find our way through an incredibly complex system with scarce information to help guide us, during a time of crisis.

Social care refers to practical and personal support that assists someone to live as independently as possible. It covers a range of support from assistance within one’s own home, like help with bathing and dressing, through to help in care homes.

In 2016, Independent Age found that 70% of local authorities could not demonstrate they were providing online information in all the areas required of them as part of the Care Act. More recently Better Connected investigated the level of online information available to assist people to find local care support for an older person. Their survey found that only half of councils provide ‘good’ or ‘very good’ levels of online information and advice on care.

What’s key to making sure that older people can get the right help at the right time, is the availability of accurate, independent and accessible information and advice. We know from our Helpline that many problems faced by older people and their families could have been avoided if they had known what was expected of them and what was available to them sooner.

The Care Act 2014

The Care Act came into force in April 2015. It applies to England only and sets out the rules local authorities need to follow when arranging care for their residents. These include the implementation of national eligibility criteria for social care, a social care system centred on personal needs and wellbeing, the right for all carers to receive a formal assessment where they have a support need and a greater focus on prevention services.

In July 2015, the government postponed the ‘care cap’ and associated measures due to come into place in April 2016. However, the 2017 General Election campaign saw the government again commit to a lifetime limit on care costs.
Financial assessments for social care

For an older person to receive state-funded care and support they have to go through two assessments. The first assessment focuses on the care and support needs of the person. If someone is assessed as needing care and support, the local authority then assesses their income, capital and savings. This is to decide what contribution the older person may have to make to the cost of their care in what, after all, is a heavily-rationed and means-tested system.

As well as paying towards their care from their income, an older person may have to make a contribution based on their savings and capital.

How it works now

- If an older person has savings and capital of less than £14,250, they will not need to use any of their savings to pay for their care.
- If an older person has savings and capital between £14,250 and £23,250, they will need to pay £1 per week towards their care for every £250 in savings they have over £14,250.
- If an older person has savings and capital of more than £23,250, they have to pay for all their care.

What older people tell us

- Poor communication between a local authority’s finance team and social services, and between a local authority and the older person about what financial information is needed can lead to a number of problems for older people. It can lead to delays in completing the financial assessment and to long delays between the care needs assessment and financial assessment (see page 29). Sometimes people start receiving care, but don’t receive any bills for months making it difficult to budget.
- Even when an assessment has taken place, older people don’t always receive a written record of the local authority’s final decision. This means that they don’t know who is expected to pay for their care, if they are found ineligible for state-funded care and they may not know how to question the decision.
Iris’s experience

Iris, 79, was being cared for by her daughter before a fall led to a social worker recommending the need for nursing home care. It took more than a month for a care needs assessment to be carried out and Iris and her family were not provided with a record of this nor were they given any information about capital thresholds. Many months passed and Iris’s savings were at £24,000. A financial assessment had still not been conducted to establish who was paying for the care and what her contribution would be.

Importantly, a portion of Iris’s savings was a war compensation payment and should have been excluded from any means-testing for her care. A year later, the family’s lawyer (who was now involved) asked for a copy of the care assessment which they finally received. It was entirely hand written and largely inaccurate. By this stage Iris had run out of money and the care home was threatening her with eviction.

Because it took so long for a financial assessment to be completed, Iris has spent her war compensation payment as well as all her savings. Some of this money should have been disregarded from any local authority decision on what capital Iris had to pay for her care. Iris is facing considerable uncertainty and the prospect of eviction while these errors are being investigated.

What else do we know about this issue?

Independent Age’s Care Act Watch Survey (September 2015 – March 2016) found that too often older people and their families are having to fight to have their needs recognised and receive timely financial assessments.

The findings of that survey support reports from our Helpline that older people and their families are not always receiving a written statement following the local authority’s assessment.

• Sometimes people are not given a care assessment at all because they are prejudged on their likely financial situation (and whether they are likely to qualify for means-tested social care). This is unlawful, but does happen.
Managing a property and accessing social care

For home owners, managing their housing wealth and accessing social care can be one of the hardest challenges they face. When the local authority carry out a financial assessment for someone needing residential care, the value of their property is included, except in certain special circumstances, for example, when their spouse continues to live at the property.

What older people tell us

- Low awareness of property disregards can mean that older people rarely request one. For example, a property disregard can be awarded if a person gave up their home to live with and care for an older person.

How it works now

Managing a move into a care home and selling your house is a lot for anyone to deal with. For someone moving into residential care, with savings below £23,250, the local authority must disregard the value of a person’s main or only home for the first 12 weeks of their time in residential care. This is known as ‘the 12 week property disregard’ and is meant to give older people the time to make the best decisions in their long-term interests.

An older person is not allowed to deliberately pass on their wealth, be it housing wealth or other forms of investments and savings, in order to reduce how much they pay towards their future care costs. To do so is known as ‘deprivation of assets’. This could happen if an older person transfers large amounts of money to family members immediately before needing care. If the local authority decides this has taken place they can treat the person as if they still have the asset and include this in their financial assessment as notional capital or income. Alternatively, they could recover some of the charges from the person who received the assets or they can take legal action to recover the debt. Cases such as this can leave older people and their relatives feeling like they are battling a system that feels unknown and impersonal, particularly if transfers were made without this intention of depriving themselves of assets. Older people may have gifted money, as an early inheritance for example, and not anticipated needing care.
• Low awareness of deferred payment agreements means they are not asked for and not offered when they could be. When they are offered, older people are not being given enough information about the advantages and disadvantages, nor their responsibilities.

For example, it is not always made clear that a deferred payment is a loan and there are administrative and interest charges. Interest can continue to be charged after a person has died and only ends when the deferred payment is paid off.

• People are not aware of the rules about deprivation of assets – this can mean that older people do things with the best intentions but suffer for it. For example, an older person may downsize and give money to their family. At the time they moved an older person may have moderate care needs but then quickly need to enter a care home.

There may be grounds for the local authority to argue that the older person deliberately deprived themselves of assets to avoid or reduce paying care home fees because they knew that they may need more care in the future. There is no time limit to how far back a local authority can investigate potential deprivation of assets.

What else do we know about this issue?

Prior to the Care Act being introduced, local authorities were not obliged to offer deferred payment agreements and as a result, the use of them was sporadic. Since the Care Act 2014, local authorities in England have been required to offer deferred payment agreements to self-funders assessed as needing residential care with less than £23,250 in non-housing assets. Yet requiring them to be available in every council has not resulted in the take-up levels originally envisaged. The Department of Health estimated that the number of deferred payment agreements would rise from 4,000 in 2012 to between 8,600 and 12,300 by 2015-16.51

NHS Digital collected information on deferred payment agreements for the first time in 2015-16. There were only 2,895 reported across England, though it’s important to note that this reporting was on a voluntary basis (in the future such reporting will be mandatory). In fact, of the 55 local authorities who reported numbers in 2015-16, the first year they were required to be offered, just 1,300 deferred payment agreements were written.
Making the assumption that this sample is representative, this suggests that only 3,600 deferred payment agreements in total were issued in 2015-16, less than a third of the original estimate and lower than those in force in 2012.

Rose’s experience

Rose lives in a residential care home. While she is now settled in the care home and pleased with the support she receives there, getting to this point was far from easy.

Rose was assessed as no longer being able to live in her own home and moved into a care home. The social worker who assessed her told her son, Edward, that she would be a self-funder as she owned her own home. However, Rose only had savings of £10,000.

Edward got in touch with Independent Age after a few months as his mother’s savings were running low and he was struggling to sell her home. He was worried about what would happen if she couldn’t continue to pay her fees.

We advised Edward that for the first 12 weeks Rose spent in her care home the value of her property should not have been counted in the financial assessment because her savings were under £23,250. We advised him to ask the council to apply the 12-week property disregard from the date that Rose became a permanent resident and to consider a deferred payment agreement after that.

3 Getting help if you’re a carer

The Care Act marked an important change when it introduced strengthened legal rights for carers. This includes the right to receive a carer’s assessment from the local authority where there is a support need. The Care Act was meant to show that carers can receive an assessment of their own support needs, regardless of the amount, and type of care they provide.

A local authority is also meant to provide information and advice on how carers can prevent their needs from increasing, regardless of whether they are found eligible for support after a carer’s assessment.

What older people and their carers tell us

• Despite the introduction of the Care Act in April 2015, friends and family of older people, as well as older people who are providing care themselves, remain unaware of their rights. We hear from carers who are struggling to help their loved ones and are completely unaware of there being any help available to them from the local authority.

• We know of cases where medical staff and social services have put pressure on people to continue or take on caring responsibilities.
During a care needs assessment, the support someone receives from carers should not be considered. Support from friends and family should only be taken into account at the stage of care and support planning. Social workers can confuse these stages meaning a carer carries on providing the same level of care even when it isn’t the right thing for them. Carers can be placed in the position of having to demonstrate that they are unable to carry on caring before they receive any support from the local authority.

What else do we know about this issue?

The number of older carers is rising rapidly. Between 2005 and 2015, the number of carers aged 65 and over increased by 25%\(^54\). There are almost 90,000 (87,346) carers aged over 85 in England – over half of these carers provide over 50 hours of care each week\(^55\).

Almost half (45%) of respondents to our Care Act Watch Survey (September 2015 – March 2016) were either a carer aged 65 and over or a carer for someone aged 65 and over. When we asked if they had received a carer’s assessment since April 2015, 66% (93 out of 141) said they had not. This suggested low awareness of carers’ assessments among the general public and professionals\(^56\).

In May 2016, a survey of more than 6,000 carers carried out by Carers UK revealed nearly a third (29%) of all carers who’d been offered a carer’s assessment, or requested one, waited at least six months to be seen\(^57\).

Mrs Khanna’s experience

Mrs Khanna, 81, cares for her 89-year-old husband with dementia. Mrs Khanna is not in good health herself and the decline in her husband’s health has taken its toll.

She finds herself very tired, very stressed and is struggling to cope. She is no longer able to leave Mr Khanna alone and has become isolated, so running errands has become increasingly difficult.

Their council conducted a needs assessment and Mr Khanna now receives two hours of care each morning, which is not enough, and there was no mention of a carer’s assessment for Mrs Khanna.

Mrs Khanna called Independent Age feeling quite overwhelmed and not knowing where to turn. After having her rights explained to her, she felt much better placed to assert her own needs, which she had overlooked since her husband’s diagnosis.
Care needs assessments under the Care Act

The first step to getting help at home is normally organising a care needs assessment from the local authority. Although we have already highlighted where financial assessments can prove problematic, we are increasingly now learning about the basic difficulties older people are experiencing to even receive a care assessment in the first place. Anyone who appears to need support should be assessed, in a reasonable time, taking into account the urgency of the situation, and an assessment should be carried out regardless of their personal finances.

What older people tell us

- After requesting a care needs assessment, it is not unusual for a person to wait two months until it takes place, and then even longer for the care arrangements to be put in place. In the meantime, an older person may be living without the support they need and their health and wellbeing can deteriorate.

- Sometimes, after an initial request, the local authority may then phone to check that an older person still requires a care needs assessment and what type of assessment they need. While this could demonstrate that they are using resources wisely, it may well add delays in the system and is frustrating for older people and their families who believe they are already confirmed and waiting for an assessment to take place.

- Some older people may have a care needs assessment and then have to wait again for an assessment from an occupational therapist, causing further delays in receiving care.

What else do we know about this issue?

Research published by Independent Age in January 2016 found that almost a quarter (35 of 152) of local authorities were failing to provide present and up-to-date online information regarding assessments and eligibility. More recently, Better Connected conducted a survey that found that only 50% of councils are providing a ‘good’ or ‘very good’ online service on social care.

In 2015-16, the Local Government and Social Care Ombudsman received 600 complaints about assessment and care planning – the most complained about area of social care. Common complaints in this area have been about delays to care assessments and reviews, or concerns that the views of older people or their families were not taken into account.
Jenny’s experience

Jenny is 76 and lives in the South East

I was sitting at home with my head in my hands thinking, “I’m not coping.” I didn’t know which way to turn.

I typed a few words into my computer and a message appeared from Independent Age that said, ‘Don’t know which way to turn? Do you need help?’ It was like a miracle! I wrote the Helpline number down quickly and rang the next morning.

One of my problems is that I can only stand for a couple of minutes. If I walk it’s as if my legs aren’t holding up my body.

I was having to crawl up the stairs because I couldn’t climb them.

There was no way I could get into the bath. I would hold on to the side and try to put in one leg and then the other but it frightened me. I was so scared of slipping. Instead I would have to sit on the toilet and wash myself bit by bit.

My big fear was that I was going to have to move out of the home I have lived in for 40 years, away from my community and my terrific neighbours and into sheltered housing. I phoned up Independent Age the following morning and told them about my situation.
I was sent all the information I needed in big print so I could read it. I contacted you just in time.

I was told who to ring at the council. Before this I had problems finding the right person. No one I spoke to wanted to know. Because of my eyesight I couldn’t go through the phone book.

I called and someone from the council came round within a week and told me how they were going to help me and when they were going to do the work to adapt my home. I knew then that I wouldn’t need to move out and that I would be safe here. I cried with relief.

Within a week they had come round and put wall rails next to the stairs to help me for the time being. They also suggested I should have a bar to help me get in and out of bed. I didn’t think I needed it but I use it all the time now.

They sent me some addresses for stair lifts and they helped me pay for one. I asked if I could have a shower fitted instead of a bath but they said they would help me install a whole wet room instead.

I have to be so careful. I have arthritis in the tops of my legs. If the arthritis was in my hips I could have hip replacements but, because it’s in my legs, nothing can be done to help me. I still feel vulnerable and I can’t go out on my own.

It’s amazing to think that just two years ago I was really active. My hobby was belly dancing and I would entertain the elderly in homes in my finery. Now I have trouble putting my clothes on in the morning, but I can cope. I sit on the bed and dress myself a bit at a time.

The changes to my home have changed my life. I’m now looking forward to the summer. I know I’ll be able to go up to the bathroom and have a shower when I’m hot, just like anyone else. A lot of my anxiety has gone.

I’d say to anyone reach out while you can do it. Don’t leave it too late. I had no idea of the help that was available. My sister said to me recently, “I don’t know what to do. My husband can’t get up the stairs,” and I passed on the advice from Independent Age. Now they have a bannister. Then my neighbour asked me what she should do, so there’s a chain reaction. Ringing your Helpline has changed my life – and other people’s lives too.
Recommendations to help older people, their families and carers better understand social care

Independent Age’s recommendations include:

• Local authorities need to fulfil their Care Act duties to provide information and advice on care. Local residents should be provided with accurate and easily accessible information on receiving assessments, paying for care and understanding carers’ rights.

• Care needs and financial assessments need to be carried out in a timely way, with clear communication to older people and their families about what the process entails and what their rights and obligations are. Local authorities should have clear timescales for completing these, which should be publicly available and reported on.

• Local authorities need to ensure that all people who undergo a care needs assessment or carer’s assessment receive a written record of it, to ensure compliance with the Care Act 2014.

And something more fundamental that could take place:

• Local authorities should be adequately funded to meet all their responsibilities to deliver care and support older people and their families with the costs of care. To achieve this, the government needs to ensure that the promised Green Paper on adult social care needs sets out the long-term reforms the system needs to remain fair and sustainable. The reforms need to provide much greater clarity on the state’s role and individuals’ own contributions towards care costs.
Securing a decent income

The stress and anxiety of not having enough money is a major worry for anyone, regardless of their age, but can be especially serious for an older person living on a low fixed income. While help is available, we know that far too few older people are receiving it. For example, Pension Credit is a welfare benefit designed to boost the incomes of some of the poorest pensioners. However, take-up of Pension Credit has remained low with current estimates suggesting over a third of people, who are eligible for Pension Credit, do not claim it.

In 2016, Independent Age reported that the biggest financial worry for almost a quarter (23%) of people aged 65 and over is that their savings will run out. In addition, an estimated 3.5 million older people (31%) have run out of money before the end of the month.

When asked about welfare benefits, it is common for older people to explain that benefits ‘aren’t for people like me’ and that they are ‘for people who have less money than I do’. However, these same people may go on to tell us that they have had to cut down on heating their home or are eating less in order to save money. Stories like this show us that many older people are stoical about financial matters, but miss out on assistance they’re entitled to and struggle to afford essential goods and services.

Online information and advice

Our online information about benefits was accessed over 2 million times between May 2016 and April 2017.

independentage.org/information

1 Awareness of welfare and disability benefits

Low awareness of the financial help available to older people continues to be a problem. This can be related to income from pensions or the help that is available for the extra cost of having care and support needs.
Pension Credit

What is it?

Pension credit is a financial benefit to increase the incomes of some of the poorest older people. There are two parts to Pension Credit: Guarantee Pension Credit and Pension Savings Credit.

To qualify for Guarantee Pension Credit an older person needs:

- to have reached the State Pension age for women which is currently 63 and rising, depending on when they were born*.
- to have a weekly income below £159.35 for a single person or £243.25 for a couple*. The payment will top people's incomes up to these levels.

To qualify for Pension Savings Credit, an older person needs:

- to have reached State Pension age before 6 April 2016 and now be aged 65 or over, if single.
- to have reached State Pension age before 6 April 2016, together with their partner if they are in a couple, with the oldest partner aged 65 or over.
- to have a qualifying income of at least £137.35 a week for a single person or £218.42 a week for a couple.

It is worth noting that most people who reach State Pension age on or after 6 April 2016 won’t be eligible for Pension Savings Credit.

*Amounts as at April 2017

Attendance Allowance

What is it?

Attendance Allowance is a benefit for older people who have personal care needs. To qualify for Attendance Allowance an older person needs:

- to be aged 65 or over
- to have a long-term physical disability or mental illness
- to have needed help with personal care or continual supervision from someone else for at least six months (It can be awarded regardless of whether or not an older person receives help.)
- to not already be receiving Disability Living Allowance or Personal Independence Payment.

Crucially, Attendance Allowance is not means-tested so any older person who meets the criteria can claim it, regardless of their income and wealth. There are two different rates for Attendance Allowance:

- Lower rate – £55.65 per week if you need care or supervision during the day or night.
- Higher rate – £83.10 per week if you need care or supervision during the day and night.

Being awarded Pension Credit or Attendance Allowance can mean an older person may become eligible for, or entitled to an increased amount of, additional financial support through Housing Benefit and/or Council Tax Support.
What older people tell us

• Low awareness of Pension Credit and Attendance Allowance means that older people are not claiming the benefits they’re entitled to.

• Men may not know they have reached the age where they could claim Pension Credit because the qualifying age is lower than the State Pension age for men.

• Older people may be aware of Attendance Allowance but have no understanding of the eligibility criteria.

• Some older people struggle to complete the form for Attendance Allowance or find help with filling in the form. For example, the form requires an older person to give detailed descriptions about the difficulties they have with their personal care as a result of their medical conditions or disabilities.

What else do we know about this issue?

• £3.5 billion worth of benefits go unclaimed by older people each year\textsuperscript{65}.

• An Independent Age survey in 2016 found that an estimated 4.4 million people over the age of 65 (39\%) have never checked to see if they are eligible for benefits such as Pension Credit or Council Tax Reduction\textsuperscript{66} and almost half (48\%) didn’t know they could get a 25\% discount on Council Tax if they live alone\textsuperscript{67}.

• Over a third of pensioners who are entitled to Pension Credit, or up to 1.4 million people, are not claiming it\textsuperscript{68}.

• While it is hard to identify the eligible population correctly, it has been estimated that as many as 30\% or more of the eligible population for Attendance Allowance are not claiming it\textsuperscript{69}.
Veronica’s experience

Veronica is 78 and lives in the South East

Seeking help doesn’t come naturally to many in my generation and I have always been an independent spirit, but it is so important for people to know how the system works.

I’m on Pension Credit now, which is an essential top-up, and for people like me without property or savings, even more so. Before I spoke to the Helpline at Independent Age, I didn’t know this existed. You don’t know who to ask for help. I believe the current pension is not enough for anyone to live on.

Over the years I have broken both hips, my kneecaps, one of my arms and fractured my spine, all through osteoporosis. I receive Attendance Allowance because of how these trauma injuries and my ailments have affected me. This helps me to be able to look after myself and to maintain my independence.

I have primary Sjögren’s Syndrome, a rheumatic, autoimmune disease. During bad flare ups I can hardly move my joints and struggle with getting about. Yesterday morning I thought, “I don’t want to live with these pains,” but you have to lift your own spirits and find out what’s around the corner.

We all get unexpected expenses. These are very stressful and that’s when it helps to ask for advice. To me Independent Age is such a tonic, better than any medicine.

I know that there is someone I can ring and say, “I don’t quite know what to do about this.”

I have found that having a smart meter really helps as I can tell how much money my power is costing each day. I have little tricks including heating my coffee in the microwave rather than boiling a kettle, and restricting when I use my oven. Electricity bills have risen so much. I live in a bedsit with a high ceiling and the central heating is turned off in the building after the winter. As it’s extremely expensive to use extra heaters, unless it’s really cold I pile on the sweaters if I’m chilly.

I used to work in the fashion business where I developed an eye for good fabric and I buy my clothes in charity shops. I bought a pair of beautiful spectacles in a lovely case in one for £2 and had my prescription lenses put in them. The frames would have cost me 50 times as much at an optician. I’m a ‘Second Hand Rose’ as the song says. You can still enjoy life while you conserve money.

It’s so important to wake up and think, “I’m going to do this or that today.” My hobbies are all free or don’t cost me much. I get so excited when I discover a new writer I like. I use the library, where they often have additional interesting sessions. So much more can be done by organisations locally to help isolated people.
It is so important to stimulate the intellect and join societies if that is what interests you. I volunteer at a museum. I am an armchair traveller, sitting at home looking at pictures and TV programmes. I do crosswords. My grandchildren call me ‘Nana Cake’ because I love making cakes.

When I was younger it was jolly hard work to bring up two children on my own, working six days a week running two shops, and looking after elderly relatives.

Now I feel a lot of my generation is in a poverty trap. The situation with the care home system and the NHS is quite frightening. People are dropping out of care working.

I think, “Supposing I can’t get around anymore, what am I going to do?” I’ve learnt that the moment you start finding things difficult and feel as if you are ‘in the trap’, it’s so important to seek help.

The Helpline has helped me understand about the money available to me. They also give the moral support you need when you’re living on your own – someone to talk things through with you and be a helping hand. I don’t know what I would do without this support.
Life on a low income

Over the past 15 years we have seen a great drop in the number of older people living in poverty. While this is a major success, there are still almost 2 million pensioners living in poverty and over 1 million pensioners living in severe poverty.

Life on a low income doesn’t only negatively affect an older person’s physical health, but it can also have significant consequences for their mental health. This can result from the constant worry about running out of money or ending up in debt, or the indirect effects of cutting down on socialising to save money, leading to feelings of loneliness.

What older people tell us

- Some older people could have been receiving more financial support at an earlier stage meaning they have made unnecessary sacrifices or foregone certain expenses, such as going to bed early to save on heating, cutting down on food expenses or cutting down on social activities.

- Some older people tell us that fuel expenses can be a particular cause for concern and that assistance with meeting energy costs can be a great relief.

- Older people and their families sometimes don’t know who to turn to for debt advice or emergency financial support.
What else do we know about this issue?

In 2015/16, around 1 in 6 (16%) of pensioners were in relative low income After Housing Costs (AHC) and using the same measure after housing costs, roughly 1 in 7 (14%) were on an absolute low income. A total of 8% of older people were in material deprivation. The overlap between these two measures is small, meaning that at least a fifth of pensioners live on a low income or in material deprivation.

The oldest pensioners are more likely to live on a low income: 16% of pensioners aged 75 and over are on relative low incomes compared to 12% of pensioners under 75.

Over 50s who are finding it difficult to manage financially are almost eight times more likely to experience poor mental wellbeing compared with those who say they are living comfortably.

Noleen’s experience

After a divorce later in life, 79-year-old Noleen, was left living alone for the first time in 50 years. Noleen lives on the basic State Pension which is topped up by Pension Credit. She says having the Pension Credit is crucial.

“After the divorce I was just living on my pension so money was pretty tight,” she said. Noleen shops sensibly, as she has always done, and will have baked beans on toast as a meal when she knows some others might want something more. She doesn’t go out much, or to the cinema anymore, as it is too expensive.

Noleen lives in a rented one bedroom flat, on the south coast, in a block with other older people. She intends to manage without carers for as long as she can, but couldn’t afford her rent without the housing benefit. “When you don’t have any savings to speak of and you then have to fork out [for unexpected essentials] it can be a real worry,” she said.
Moving from Disability Living Allowance (DLA) to Personal Independent Payment (PIP)

A person’s age can affect what benefits they’re entitled to. Making the move between two different systems of entitlement as a person ages can be very confusing, and people worry about their incomes being reduced.

Disability Living Allowance (DLA) is a disability benefit for people who have mobility difficulties and/or need help with personal care. DLA no longer exists for new claims. For some people already in receipt of DLA, it is gradually being replaced by a new benefit called Personal Independence Payment (PIP).

People who were 65 and over on 8 April 2013 will continue to receive DLA as long as they remain eligible, but those who were under 65 on this date will eventually be invited to claim PIP. Crucially, this is the case even for people who are already over 65 and receiving DLA.

All people who were under 65 on 8 April 2013 and claiming DLA will receive a letter from the Department for Work and Pensions by October 2017 inviting them to claim PIP. It may not be appropriate to make a claim for PIP before they receive this letter because they may be unsuccessful in their claim for PIP and will lose DLA at the same time. People who qualify for DLA may not be awarded PIP because there are different qualifying criteria. And if PIP is not claimed when the older person is invited, the DLA payments will still stop.
What older people tell us

- Older people are not aware that even if they are over the age of 65 already and in receipt of DLA, they will have to make a claim for PIP if they were younger than 65 on 8 April 2013.

- Older people phone us confused about what they should be doing, for example asking if they should be actively changing from DLA to PIP.

- PIP and DLA have very different qualifying criteria meaning someone who qualifies for DLA may not get the equivalent amount of disability benefits on PIP.

What else do we know about this issue?

The change to PIP was always intended as a savings measure77. The government has said that it is too early to say how many DLA claimants, currently receiving the higher rate mobility component, will fail to qualify for the enhanced rate PIP mobility component.

Yet caseload estimates, published by the DWP in December 2012, suggested that once PIP was fully introduced, 428,000 fewer people would qualify for the enhanced rate mobility component compared with the higher rate DLA mobility component78.

Under PIP, individuals who do not need a wheelchair only qualify for the enhanced rate mobility component if they can only move distances of no more than 20 metres.

Bill’s experience

Bill receives Disability Living Allowance and called Independent Age after hearing from a friend that there could be changes to his payment. Bill was 63 on 8 April 2013 and is therefore subject to claiming the Personal Independence Payment when he’s invited to do so, or if his circumstances have changed. Bill is yet to be invited to claim, however his care needs resulting from osteoporosis have increased and this will have potential implications for his payment. He receives Disability Living Allowance at the higher rate for mobility but the lowest rate for care.

Bill faces a situation where if he is not awarded the Enhanced Rate Mobility Component of Personal Independence Payment, he risks losing his Motability car. The Independent Age adviser Bill spoke to advised him to seek face-to-face advice to go through the PIP qualifying criteria and points system to see if he may qualify for Enhanced Rate Mobility and, if he was in doubt, to wait until he is invited to claim.

Bill, and others in his position, remain uncertain about whether they will receive like-for-like support under PIP, if indeed they are able to successfully claim, creating doubt about what levels of support they can expect in the future. This is a stressful position to be in and one which Bill continues to worry about.
Recommendations to help older people get a secure income

Independent Age’s recommendations include:

- Older people need to be better informed about what benefits are available, what they may be eligible for and how to apply. Awareness campaigns, particularly around Pension Credit as a source of vital extra income, would go a long way to ensuring that those who are eligible are aware of it.

- The move from Disability Living Allowance (DLA) to Personal Independence Payment (PIP) needs to be well communicated and fair, so that existing recipients of DLA, who are now over the age of 65, are not disadvantaged by the phasing out of one benefit and the introduction of another.

And more fundamental steps that could take place:

- The Triple Lock, which sees the Basic State Pension increase each year by the highest of price inflation, earnings growth or 2.5%, should not be removed until a proper review of the impact on older people on the lowest incomes has taken place, and appropriate protections have been put in place to prevent these pensioners from falling further into poverty.

- Specifically, we believe it would be premature to remove the Triple Lock before uptake of Pension Credit has significantly increased among those pensioners who are eligible and who are most dependent on the State Pension to maintain a decent standard of living.
Older people tell us that they want to live life on their own terms as they age. While people are living longer – and living well for longer – later life can still bring situations where an older person needs assistance from the people around them.

If this happens, an older person may wish to ask someone they trust to help manage their finances or give permission so someone close can make key decisions for them should they no longer be able to do so for themselves. These are often not things that people necessarily want to speak about before they need to, but that can often mean they wait for a crisis before they seek the necessary help. Similarly, while many older people and their families may have thought about these scenarios, they might not always know what they need to do to prepare for a big change in life circumstances.

In 2016, Independent Age looked into the issue further and found that there are around 7 million people aged 65 and over who have never had a conversation with family about any of the following topics: where they would live if they could no longer live at home, who will care for them when they are older if they need it and preferences for end of life care.

When an older person is no longer able to make their own decisions, their families can find it difficult to arrange the legal authority to be allowed to make decisions on their relative’s behalf. This can lead to distress within families and confusion about who is responsible for organising and delivering the care and support an older person needs.

A feeling of loss of control over important parts of an older person’s life won’t always be the result of a decline in their physical or mental health. Changes in personal finances and housing can both lead to a sense of insecurity. For example, we know that the decision to move in later life can be very hard for an older person. However, even when they have decided they would like to move, or in fact they need to move as their current housing is no longer suitable, limited housing supply often means that they are unable to do so.
Managing your affairs if you become ill

There may come a time when a person needs someone else to make decisions on their behalf – perhaps because of ill health. Many older people speak to Independent Age about the different ways they can prepare for the future and ensure that someone they trust can make decisions about their finances, care and welfare if they are no longer able to do so themselves.

An increasing number of people choose to set up a Lasting Power of Attorney: a legal document that lets a person they trust make decisions for them. There are two types: Lasting Power of Attorney for Property and Affairs allows the appointed attorney to make decisions about financial matters such as bank accounts and selling property. This can be used straight away (with the person’s consent) or can come into effect when the person loses mental capacity. Lasting Power of Attorney for Health and Welfare covers decisions about care and treatment – potentially including life-sustaining treatments. It can only be used after the person who set it up loses mental capacity.

If someone loses mental capacity before they set up a Lasting Power of Attorney, a person can apply to the Court of Protection to be appointed their deputy and given the authority to make certain decisions on their behalf.

Any decision made on behalf of a person who lacks mental capacity must be made in that person’s best interests.
When a power of attorney is set up, the attorney must also make all decisions in accordance with the Mental Capacity Act 2005. In order to do this an attorney should, among other things, do everything they can to involve the person in the decision, try to identify the things the person would have taken into account and, if appropriate, consult friends and family.

Another way people can prepare for potential ill health is by setting up Advance Decisions to Refuse Treatment. Previously known as a living will, this is a legal document that people can use to refuse specific types of treatment at some stage in the future. It lets health practitioners and family members know one’s wishes if they are no longer able to communicate them.

What older people tell us

- There is low awareness of what is needed to make a decision for someone who has lost mental capacity – many people wrongly assume their ‘next of kin’ or friends and family will automatically be able to act on their behalf. Similarly friends and family may have been managing personal finances or making decisions for an older person but do not realise they need legal permission to continue to do so.

- Some people don’t set up a Lasting Power of Attorney because of the costs involved and are not aware that there are discounts or exemptions available for people on low incomes.

- It is not always clear if a person has lost mental capacity, or if it is fluctuating. This can make it difficult to know when to make decisions on their behalf, or when to support them to make the decision themselves.

- People are unwilling to think about their future health and care and put off the decision until there is a crisis or even when it is too late.

- Sometimes there is a dispute between family members and the local council or NHS about what care is in the best interests of a person who has lost mental capacity.

What else do we know about this issue?

There is a considerable north-south divide in the use of Lasting Power of Attorney. For example, the take-up rate of Lasting Power of Attorney in parts of Southern England is more than double the rate in parts of the North East of England. Use of Lasting Power of Attorney is associated with higher income groups and people with high property values.

In 2014, a national survey found that 45% of people aged 45 and over had never heard of Lasting Power of Attorney.
Carol’s experience

Carol is 63 and lives in the South East

When she was well, my mother wouldn’t discuss setting up a power of attorney. If she had, my brother and I could have made decisions on her behalf more easily than when she was no longer able. She didn’t think that this time would ever come.

She died in hospital last October. One of the reasons for this was that we were not able to persuade the hospital to do what we knew was best for her. No one would listen to us.

I had taken my mother, who was 85, to A&E after she had cut her leg on her bedside table. They didn’t stitch up her leg but instead they used Steri-Strips and these didn’t work. In the end, she lost so much blood that her blood pressure fell too low. They admitted her to hospital to deal with this but, once there, she picked up infections including C. difficile.

She was placed in an isolation room and didn’t receive physiotherapy for six weeks. Because of this she became unable to walk. Her false teeth were lost and she was no longer able to eat properly. She lost three stone in six weeks. Then she had a bad fall. All of these things took their toll.

When it was time for her to leave, if we had had power of attorney we may have been able to say that we wanted her to be in a care home and that my brother and I would pay. She would have been looked after.

Instead there was wrangling between social services and the NHS. A team of people from occupational therapy, physiotherapy, other departments and social services met and said they wanted her to go back to her own home. In their paperwork they were cherry-picking the information that went into their report to make it look like she was fine to go home with family support, when to us it was so clear she wasn’t. We had to argue for what we knew was best for our mother.

The downstairs rooms at her home were too small to have a hoist to lift her so this would mean she would have to stay in her bedroom, living in her bed, with carers coming every four hours. She would be made incontinent, as she was now immobile, and would have been there in muck and mire until the carers arrived. I said this was inhumane but the professionals seemed to believe that as long as older people are in hospital beds with the sides up so they can’t fall out, it didn’t matter.

My brother and I argued that this would mean she would be a prisoner in her bedroom. She wouldn’t even have been able to see out of her window.
I was desperate to get help and contacted the Independent Age Helpline. This reinforced for me that there are people fighting for the benefit of older people. There is someone to support you in the minefield.

We presented our case at a meeting but the hospital said she didn’t need the help we knew she would need. It had been against my mother’s wishes to be in a care home, but she no longer had the capacity to understand why it was the best thing for her. She would never have understood why she was being kept prisoner in her bedroom. She would be captive there. She would have been crying her eyes out and what quality of life would that give her? At a care home she could have been wheeled around for a change of scene and met other people.

The idea of sending people back to their own home sounds fantastic, but the facilities and services are not there to make this work. The assumption was that my brother and I could go on giving our support, but she was past the stage where we could physically help. This lack of resources needs to be addressed urgently.

A lot of elderly people don’t want to face the future. This was a complete horror story for our family. You never envisage these complications until they happen.
Moving home in later life

The decision of whether to move or not in later life can be a very challenging one. And the choices open to older people can be far more limited than they expected. For example, in some areas the demand for sheltered housing means that some older people who are keen to move cannot find alternative accommodation and are continuing to live in properties that are unsuitable for them. Older people who would like to downsize can find it difficult to find the right type of property to move into, or simply cannot afford the cost of moving.

What older people tell us

- Older people are trying to get sheltered accommodation but are being told there is no immediate availability in their area.

- Older people want to continue living in their current area – particularly if they are near friends and family – but struggle to find a suitable sized or priced home to rent or buy. Some older people find the financial cost of moving home too great a barrier.

- In some schemes, older people are being presented with unexplained, and even unaffordable, service charges in sheltered housing and extra care housing.

- Owner occupiers can be asset rich but cash poor and struggle to maintain and repair their property.
What else do we know about this issue?

More than half (58%) of people over 60 are interested in moving and more than half (57%) of those interested in moving would like to downsize by at least one bedroom, rising to 76% among older people currently occupying three-, four- and five-bedroom homes.

In some areas, 40-50% of older people are priced out of the retirement housing market and almost 30% of purchasers of specialist housing have less housing equity than the value of their new home. The costs of moving and Stamp Duty have also been identified as barriers to older people who want to move home.

More recently, Independent Age polling among UK adults aged 65 and over has shown that a deterioration in health and mobility are cited as the most common factor that would cause older people (over 2 in 5) to consider moving home.

However, this same polling also suggests that not many older people are immediately planning to, or prepared, to move home. More than 4 in 5 say they have not planned or prepared.

Brenda’s experience

Brenda’s mother had thought about looking at housing options and moving somewhere more manageable and with more support. She had a brief look into it some years ago but found the process complicated and that there was no guarantee that she would get a place.

“My mother always said she would like sheltered accommodation, but then left it too late till illness and frailty ruled it out,” Brenda told us.

“She was supported at home with carers and a close friend but sadly things deteriorated suddenly and she had to move to a residential home during a crisis period. It was possible but difficult. If we had been able to do a planned move, it would have been less stressful for both of us.”

More than 4 in 5 older people are not planning or prepared to move home.

The obstacle course: overcoming the barriers to a better later life
Recommendations to help older people manage their affairs

Independent Age’s recommendations include:

- The ideas on building housing, set out in the government’s recent Housing White Paper, now need to be translated into action. Planning authorities need to set clear policies to provide an adequate supply of accessible housing and stimulate the supply of new homes for older people.

And something more fundamental that could take place:

- People need to be better informed about the importance of planning for later life, including options around how their finances and health decisions will be managed should they no longer be able to independently make these life decisions for themselves.
Managing changes in later life – loneliness

Loneliness can affect all of us from time to time especially in later life, with over a million older people saying they are lonely often, or always.

Most of us will feel lonely at some point in our lives but there are some experiences common in older age that can make it more likely.

Recent evidence from Independent Age shows that more than 1 in 3 (35%) of those aged 75 and over in Great Britain say that feelings of loneliness are out of their control, equivalent to more than 1.8 million people. And almost 1 in 4 (23%) worry about how often they feel lonely, an estimated 1.2 million people.

We offer a range of services and support, from providing regular phone calls to visits from a friendly, dedicated volunteer. We also provide advice through printed guides and online information.

Our If you’re feeling lonely guide provides tips on staying socially connected in older age and suggests things older people could do to try and reduce feelings of loneliness.

For more information on this wide range of support please visit independentage.org/information/personal-life/loneliness.

Or call our freephone Helpline on 0800 319 6789.
Conclusion

All too often, Independent Age hears from older people and family members who are struggling to access services, or navigate what can feel like labyrinthine processes to gain support.

And all too often, new evidence is published showing, despite incremental progress, too many older people are still living in poverty, without all the care they need, or feel lonely and socially isolated.

This report provides just the briefest of overviews looking at where things are currently going wrong.

We have shown how older people sometimes only receive support when they reach a crisis, despite needing assistance much earlier on.

We have highlighted how the people who contact us, including relatives, experience great anxiety due to hospital delays and a lack of coordination between support services or after care.

And we have revealed where people remain bewildered and confused by the complex benefits and social care systems, often left hopelessly frustrated when trying to exercise their rights to access vital services.

Independent Age will continue to campaign so we no longer allow systems of support that contribute to unmet need and undermine older people to go unreported and unaddressed.

The challenges to making the UK the best country to grow older in by 2030 are already considerable.

We must see policymakers taking firm action – now.
Fundamental steps for the new government:

1. Ensure the funding provided to NHS services adequately reflects the increased demands presented by an ageing population.

2. Build on new service models to provide genuinely integrated health and care services.

3. Ensure that the promised Green Paper on adult social care needs sets out the long-term reforms the system needs to remain fair and sustainable so local authorities are adequately funded to meet all their responsibilities to deliver care.

4. The Triple Lock should not be removed until a proper review of the impact on older people on the lowest incomes has taken place, and appropriate protections have been put in place to prevent these pensioners from falling further into poverty.

5. Uptake of Pension Credit must significantly increase among those pensioners who are eligible and who are most dependent on the State Pension to maintain a decent standard of living.

6. Take action to help inform people about the importance of planning for later life, including options around planning future finances, housing and health needs.
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Whatever happens as we get older, we all want to remain independent and live life on our own terms. That’s why, as well as offering regular friendly contact and a strong campaigning voice, Independent Age can provide you and your family with clear, free and impartial advice on the issues that matter: care and support, money and benefits, health and mobility. A charity founded over 150 years ago, we’re independent so you can be.

For more information, visit our website at www.independentage.org

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