

Report

THE INCAPACITY CRISIS - A NATION UNPREPARED

As Lifetime Lawyers report reveals, people rarely think about possible future mental incapacity even though we are worried about it. As a nation, we are failing to talk about what our wishes would be for our later life, should we lose the ability to make our own decisions.

This report was created under our previous branding as SFE.



The logo for Solicitors for the Elderly (SFE) features the letters 'SFE' in a bold, yellow, sans-serif font, set against a blue rectangular background.

SOLICITORS FOR THE ELDERLY

SFE report

The incapacity crisis - a nation unprepared

Make sure your wishes are heard

Glossary of terms

We have attempted to avoid legal jargon throughout this report, although the topic requires some legal terminology. To help define some common words and phrases, we have summarised below.

- **Attorney** – a person appointed to act on behalf of another individual
- **Best interest decision** – a decision that is made by another party for someone who is unable to make the decision for themselves. Must follow the best interest principles under the Mental Capacity Act 2005 and consider wishes, feelings and beliefs of the person for whom the decision is being made
- **Court appointed deputy** – a person appointed by the Court of Protection who makes specific or on-going decisions for someone who lacks mental capacity
- **Court of Protection (CoP)** – a distinct superior court of record created by The Mental Capacity Act 2005, which makes decisions, declarations or appointments of deputies on financial and/or health and welfare matters for people who are unable to make decisions at that time for themselves
- **Deputy or deputies** – a person(s) appointed by the Court of Protection to make decisions on someone's behalf if they lack mental capacity to make decisions for themselves
- **Donor** – the person who appoints someone else (an attorney) to act on their behalf
- **Lasting power of attorney (LPA)** – a legal document created by the donor which appoints one or more people (known as 'attorneys') to act on their behalf by way of best interest decision making. In the case of a health and welfare lasting power of attorney, this gives the donor the ability to give instructions and preferences as to how they should be treated in the event of an accident or illness, if they do not have mental capacity to take a specific decision. See below for further details
- **Lawyer** – a professional who practices in law (such as an advocate, attorney, barrister, chartered legal executive, counsel, or solicitor)
- **Mental capacity** – the ability to make a certain decision; a person who can make their own decisions has capacity
- **Mental incapacity** – the inability to make a decision; a person with incapacity can no longer make certain decisions of their own, often because of illness or disability such as dementia, a stroke, brain injury or a learning disability. They cannot do one or more of the following:
 - Understand information given to them about a particular decision
 - Retain that information long enough to be able to make the decision
 - Weigh up the information available to make the decision
 - Communicate their decision
- **Mental Capacity Act 2005 (MCA)** – a law that protects you if you are not able to make decisions for yourself. It says:
 - There is a presumption a person has the capacity to make a decision themselves, unless it's proved otherwise
 - Wherever possible, a person must be helped to make their own decisions
 - A person is not treated as lacking capacity to make a decision just because they make an unwise decision
 - If you make a decision for someone who doesn't have capacity, it must be in their best interests
 - Before any decision is made, regard must be given to achieve the least restrictions of the person's basic rights and freedoms
- **Ministry of Justice (MoJ)** – a ministerial department of the British Government at the heart of the justice system, with the aim to protect and advance the principles of justice
- **Office of the Public Guardian (OPG)** – an executive agency created by the Mental Capacity Act 2005 which is part of the Ministry of Justice. Its principal role is for registering LPAs and dealing with the supervision of court appointed deputies. It has a safeguarding function to ensure that an attorney or deputy is complying with their duties under the MCA and acting in the donor's best interests
- **Practising Solicitor** – a qualified legal professional, regulated by the Solicitors Regulation Authority
- **SFE (Solicitors for the Elderly)** – a membership organisation for solicitors, barristers and chartered legal executives who are specialists in advising older people and those considering plans for later life



Foreword

Lakshmi Turner, CEO of Solicitors for the Elderly (SFE)

In my role, I see first-hand the vital importance of thinking about what we want for ourselves as we get older. Most of us don't like thinking about, let alone talking about death, disability or disease, despite the fact that it surrounds us daily and touches our lives. So, I'm here to encourage more people to do just that – talk about it and take action. It's vital that we consider what we want should the worst happen. And on the flip side, if you had to take care of a loved one yourself, you would want to know what they want.

As a nation we are living longer, which is a testament to healthier lives, including better health and social care. On the other hand, more of us face conditions that limit and ultimately halt our ability to make our own decisions, which is known as a loss of mental capacity. At this point, most of us expect trusted family or friends to step in and make decisions for us – to ensure our wishes are carried out. However, this often isn't possible unless we've planned ahead.

More and more of us are getting wills in place to set out our wishes after death. Some of us are putting plans in place for our finances and assets should we face a loss of capacity. However, far too few of us are planning ahead to set out our wishes for our health and social care should we lose capacity.

In instances where we haven't thought ahead (and that's the case for most of us), we are leaving important and highly personal decisions in the hands of strangers – things like where we are cared for (which may not be near family and friends), whether we are resuscitated when we would not have wanted to be, whether our organs are donated (even when we're on the donor register), who cares for us, and even what we wear.

I've seen for myself the distress caused when family members have not spoken to each other about their wishes. At a time of crisis, families have to make huge decisions about a loved one quickly, whilst under a massive amount of stress, without knowing their loved one's wishes. Having had the terrifying experience of sitting in an Intensive Care Unit with a loved one, it is certainly not the place for making such significant decisions - consultants need fast decisions to respond quickly.

Worse still, without appropriate plans in place, decisions may be taken out of family members' hands altogether and someone else, whose reasoning is entirely objective, may make decisions about something that is personal and highly subjective.

This report has found that more of us than ever are at risk of incapacity and reveals the myths and misconceptions surrounding what we think will happen. It's time to set the record straight, highlight the risks and how to avoid them.

Don't leave life-changing, highly personal decisions in the hands of strangers.

#choicenotchance



Preface

Professor Ilora Finlay, the Baroness Finlay of Llandaff

With decades of experience working and campaigning around palliative medicine, the low numbers of health and welfare lasting power of attorneys is of concern.

It's likely that many of us will face conditions that limit, or even halt, our ability to make decisions in the future. When a person loses capacity to take decisions, it is sad to see families and professionals struggling to try to determine what a person would have wanted. Delays and distress can be avoided by appointing someone to speak for you when you can no longer speak up for yourself.

As SFE's report reveals, people rarely think about possible mental incapacity and the options involved, even though they are worried about it. Discussing medical and care wishes ahead of time ensures that care can respect an individual's wishes, with the respect they deserve. Talking about all those "what if" situations that might happen also enables loved ones to act with best interests, giving them assurance that they are making the right decisions – even when it comes to fulfilling wishes after death, such as organ donation.

Counter to common assumptions, a next of kin means nothing in cases of mental incapacity. The term simply gives professionals a contact in case of death. These misconceptions, as shown in SFE's report, present significant problems as often people do not think they need a lasting power of attorney in place.

It's important to have an open discussion about future illnesses and possible incapacity. I urge the millions of people who haven't given loved ones the opportunity to listen, to act now.

Baroness Finlay of Llandaff is an internationally renowned expert in palliative medicine and a crossbench peer in the House of Lords. She is also Vice President of Hospice UK and Chair of Living and Dying Well. She was the first consultant in Palliative Medicine in Wales in 1987.

Baroness Finlay was previously President of the British Medical Association (2014-15) and the Royal Society of Medicine (2006-8). She also long campaigned to change the current organ donation from 'opt in' to 'opt out', which has now been implemented in Wales.



Executive summary

Dementia has overtaken heart disease as the nation's leading cause of death.

SFE (Solicitors for the Elderly) has worked closely with leading think tank Centre for Future Studies (CFS) to understand the impact of this, and how prepared the country is to face the rising levels of incapacity.

Based on forecasting analysis of the evidence, this report suggests the UK is now facing an incapacity crisis. This is caused by the gap between the rising number of us facing incapacity (due to people living longer and the prevalence of conditions like dementia), compared with too few Britons planning ahead for a loss of capacity.ⁱ

This paints a worrying picture of a nation leaving our fate in the hands of strangers. Whilst more of us are making provisions for our personal assets and finances, we are still leaving our wishes around our health and care to chance and the choices of others.

As a nation, we are failing to talk about how we can retain control and dignity should we lose the ability to make our own decisions. Our research found that over three quarters of us have not spoken about, or even considered, our personal medical and care wishes in the event that we lose capacity.

The primary factors preventing us from confronting the possibility of mental incapacity are; feeling uncomfortable, not knowing how to start the conversation, or where to go for advice. Other reasons include that loved ones do not want to engage with the topic as they do not wish to think about such difficult subjects.

This report sets out the scale of the 'incapacity crisis' and how we can address it before it's too late. The cost of doing nothing will impact individuals and families across the country, whilst putting further strain on health professionals and services.

Incapacity on the rise

Dementia is now the primary cause when it comes to loss of mental capacity, which is why we have focused on the condition in our analysis. Strokes and conditions like diabetes that can lead to increased risk of dementia have also been considered and built into the analysis.



There are more than **100,000 strokes in the UK each year – that's roughly one stroke every five minutes**

Our findings do not take in to account all causes of mental incapacity, such as severe learning disabilities, long-term alcohol and substance abuse, brain injuries following major trauma, motor neurone disease, as well as some rare mental health conditions. These constitute a very small number of cases that would fall under the Mental Capacity Act 2005, therefore have not been included in our future predictions of the incapacity crisis.

Whilst conditions like dementia are often associated with older people, it's worth noting this is not always the case. Dementia, and other causes that limit mental capacity, affects people of all ages – incapacity is not just a later life issue.

People living with dementia should be supported to live well for longer and to make informed personal choices around care and wellbeing for as long as they are able to. When they are no longer able to, it's important that their wishes, feelings and beliefs are specified so they can be adhered to.

The study shows that the number of people diagnosed with dementia in the UK has increased by 53.4% in just over 10 years (from 2005/6 to 2016/17). This doesn't include those who are undiagnosed or do not currently have a diagnosis.ⁱⁱ

Our research shows that there are currently 539,062 people in the UK diagnosed with dementia, but including those that are undiagnosed, the number is estimated to be closer to 850,000.



Research shows that **dementia is the biggest cause of death in England and Wales accounting for 12% of all deaths in 2016, up from 11.6% in 2015**



In 2014, the annual cost of dementia in the UK to the NHS, local authorities and families was estimated to be **£26.2 billion**^{viii}

The number of people with dementia is expected to rapidly increase over the next decade, mainly due to increases in life expectancy and population. In 2025, there will be one million people in the UK diagnosed with dementia. It's predicted that, including those that are undiagnosed, there will be 1.3 million people living with dementia.

By 2050, it is forecast that there will be a total of 2.7 million people in the UK living with dementia.ⁱⁱⁱ

In addition to this, the number of strokes across the UK is likely to rise by almost half (44%) in the next 20 years. Around a third of stroke survivors experience aphasia, a complex disorder of language and communication caused by damage to the brain. Vascular dementia is also common following a stroke.

It's clear that the upward trend of dementia and incapacity is spiralling, with the associated costs and care requirements increasing at the same time.

And the risks increase with age - 1 in 14 people are predicted to develop dementia at age 65 rising to 1 in 6 at age 80 and above. There are currently 12.8 million people over the age of 65 in the UK. By 2025, it is forecast that the number of people aged over 65 years will have increased by 20.3% to 15.4 million.^v

The upward trend of dementia, that will eventually lead to incapacity, is spiralling. With associated costs and care requirements increasing, it's vital that we consider the extent of current and future incapacity across the UK and take immediate action.



Every three minutes **someone in the UK develops dementia**^{vi}



A nation unprepared

We commissioned independent research from Centre for Future Studies (CFS), a specialist think tank, to forecast the disparity between the number of people who risk developing dementia or other forms of mental incapacity, and the number of people planning ahead for this eventuality by getting a H&W LPA in place.

CFS' research shows that there are currently 12.8 million people over the age of 65 who run the risk of developing dementia, yet there are only 928,000 H&W LPAs currently registered with the Office of the Public Guardian (OPG) across England and Wales. This suggests that almost 12 million of those people that are at high risk of future incapacity haven't planned ahead to ensure their wishes are followed.

Looking ahead at the forecasts which are based on current trends, by 2025 there will be some 13.2 million people unprepared for the increased risk of incapacity, with only 2.2 million H&W LPAs estimated to be in place.

It's clear that, as a nation, we are facing an incapacity crisis; one that we are unaware of and unprepared for.

Our research also found that 73% of the population are worried about becoming mentally incapacitated and losing the ability to make decisions for themselves – that's almost 49 million people in the UK.

It's not just our health and welfare that we are leaving in the hands of strangers or to chance, our research reveals that many of us aren't planning ahead at all. Over one third (36%) of people admit to not having made any provisions for later life including contributing to a pension, writing a will, saving for retirement, saving for a funeral or creating an LPA.

The reasons people aren't taking action to plan ahead and protect themselves are varied and include a number of misconceptions when it comes to decision making in case of mental incapacity.

Over half (58%) of adults across the UK incorrectly believe that the NHS organ donor register carries all the information needed to ensure organs are donated following death. However, it's crucial to discuss your wishes to be a donor with your loved ones, as agreement from them is usually sought following death.

What is a Lasting Power of Attorney (LPA)?

An LPA is a powerful legal document, which allows a person (or 'donor') to choose one or more individuals (known as attorneys) to handle their affairs in the event that they are no longer able to do so themselves, for example if they lose mental capacity. Attorneys are usually trusted family members or friends, but people can also select a legal professional as their attorney.

An LPA must be put in place while a person has the mental capacity to do so. It's important to plan ahead and get your wishes down on paper as early as possible to ensure that whoever you choose to manage your affairs can retain control, should you lose capacity.

There are two types of LPA: a health and welfare LPA (H&W LPA), and a property and financial affairs LPA (P&F LPA). The former covers things like choices around care plans, medical treatment and end of life wishes. The latter deals with the management of property, other assets, bank accounts and bill payments. Details on creating an LPA are included in section nine.

The UK Transplant Activity Report 2016/7 shows a record breaking number of people on the NHS Organ Donor Register (23.6 million) with 36% of the UK's population opting to donate. However, if we don't discuss end of life decisions with loved ones, our organs may never make it to the recipient, despite our registration as a donor.

In addition to this, a staggering 63% of people incorrectly believe that their spouse can make medical and care decisions on their behalf and 65% think a next of kin has the power to do so, should they no longer be able to. In fact, this is only the case if a registered H&W LPA is in place. Some 70% of the public specify that they'd like a family member to make medical and care decisions on their behalf, and only 1% would want a deputy appointed by the Court of Protection. However, the current and forecasted low number of H&W LPAs in place demonstrates a huge disparity between our wishes and what will happen in reality.

It's clear that an overwhelming number of people have not specified their medical and care wishes, in case they can no longer make those decisions for themselves – an incapacity crisis is on its way, and as a nation it seems we are sleepwalking into it.

Based on the collation of data and future forecasting, CFS predicts a looming incapacity crisis in the UK. This is caused by the gap between the rising numbers of us facing mental incapacity (due to an ageing population and the prevalence of conditions like dementia), combined with not enough of us planning ahead should we face a loss of mental incapacity in the future.

The solution:

What you can do to keep being you for as long as possible

The forecasted rise in the levels of incapacity makes it more important than ever for each of us to think about what we want, should we no longer be able to make our own decisions.

There are a number of ways of doing this and simply beginning to think about your wishes is a good place to start. Talking to family members and trusted friends is also very important, but nothing offers more protection and control than putting a H&W LPA in place.

Understanding a health and welfare LPA

To ensure your wishes around your medical treatments, end-of-life wishes, care and living arrangements are adhered to, should you lose capacity, a H&W LPA is vital.

As it is a powerful legal document, getting your LPA right requires experience and care – particularly when thinking through scenarios that are unfamiliar to you and you hope will never happen.

There are many issues and decisions to consider and the government body that registers all LPAs, the Office of the Public Guardian (OPG) for England and Wales, receives over 1,000 calls to its contact centre every day with people asking questions and asking for support. Age UK and Alzheimer's Society both report that queries on LPAs are common on their helpline services – such as the National Dementia Helpline - with the topic being one of the most talked about subjects.

Putting an LPA in place

An LPA is created with both the donor and their attorney(s) completing and submitting a form which, once registered, creates a legally-binding document.

It's important to note that a H&W LPA cannot be used unless the donor has lost capacity. This contrasts with the property and finance LPA which can be used when a person has capacity as well as when they have lost it.

Not having a H&W LPA in place, if you later lose mental capacity, leaves your loved ones navigating complex best interest decisions at an emotionally difficult time. It also forces them to watch decisions made on your behalf without the legal power to regain control and act on your wishes. Instead, the most personal decisions will be made purely objectively by medical and social care professionals who may never have met you.

The consequences of not having a H&W LPA in place

Family members wishing to apply for the right to make best interest decisions on your behalf when no LPA is in place must apply for a Court of Protection order. This type of order can take a minimum of 4-6 months to complete and securing one can be a complicated process.

Health and welfare orders appointing a deputy are very rarely granted and it is estimated that at least 90% are not approved. This is because the scope of health and welfare decisions are much wider than for property and finance. More often, the court will assign power over only one specific issue rather than an overall health and welfare power.

The only exception to this is for young adults who have very high dependency needs requiring regular hospital visits for their condition, either an on-going basis, or over a long period of time. In such cases, a deputy needs to be in place on a more permanent basis to make those ongoing decisions. The Office of the Public Guardian supervises the appointed deputy and there is an administration charge for doing so. The annual fee for general supervision is currently £320 or minimal supervision is currently £35. The level will be determined by them on the initial assessment, which is around £100.

Did you know?



SFE polled the nation and found that two in five would want their life support machine switched off if they were in a minimally conscious state, knowing that they had little or no chance of a full recovery.

65% of people believe their next of kin can make their medical and care decisions for them, should they not be able to. This is a myth – only doctors acting in your best interest have the authority to make the final medical and care decisions for you, with or without the consent of your spouse/relatives, should you not be able to make them yourself. Any disputes will be referred to the Court of Protection.



Assuming the growing trend, and that 2.2 million H&W LPAs are in force in 2025, the specific health and welfare requirements of **13.2 million people** won't be taken in to account.^x



Social services can choose a care home that is **not in your preferred location** (and may be a significant distance from your home or friends/relatives), if you do not have a H&W LPA in place.

Only 3% of those polled have a health and welfare lasting power of attorney in place.



70% of Brits would want their family to make their medical and care decisions on their behalf if they were unable to make them themselves, and 79% of Brits haven't discussed their medical or care wishes or later life with their loved ones.



58% of Britons believe that by being on the NHS organ donor register ensures that organs are donated. This is a myth; it's important to speak to family and friends about organ donation preferences - if they do not know you have opted to donate, it may not happen. Embedding your decision in a H&W LPA confirms your wishes in writing.

A staggering 47% of people believe that a Do Not Resuscitate (DNR) order is issued by your doctor and is placed on your medical records for every future decision. This is a myth. A DNR order does not travel with you. Each time you move locations (ie. to a different hospital or to a care home), a new DNR order needs to be created. However, if you embed a DNR request in a H&W LPA, it makes your wishes known wherever you are as your attorney can show the document to all the professionals involved in your care.

By 2025, the number of **people aged over 65 will increase to 15.4 million**, one million of those will be diagnosed with dementia.^{viii}

By 2050, it's forecasted that there will be **2.7 million people in the UK living with dementia**.^{ix}

73% of the population worry about becoming mentally incapacitated and losing the ability to make decisions for themselves – that's **over 48.5 million people** in the UK.



Debbie, 56, Peterborough.

Debbie is both a property and financial affairs and health and welfare attorney for her father - she was also a health and welfare attorney for her mother.

Debbie was advised to become an attorney by a solicitor as both her parents had serious health issues. Debbie's parents discussed their wishes with her, so she knew what they'd want should they become incapacitated. This included types of treatment, organ donation, and a Do Not Resuscitate (DNR) order amongst other decisions.

Debbie didn't find it difficult to have this kind of conversation with her parents because they wanted security in knowing that their decisions were in the hands of someone they trust, should they lose capacity. Debbie says that she would struggle to act on her parent's behalf if they hadn't previously all had the conversation about their end of life wishes.

Helen, 51, Cheshire.

Helen's father was diagnosed with dementia and had not completed or registered a health and welfare LPA.

Helen spent more than two years fighting for her father's medical and care wishes once he became incapacitated.

Because her father did not have the document in place, Helen was unable to choose the location of the care home, or how her father was cared for. As a result, he was based in a care home over 200 miles away, leaving Helen frustrated as she was unable to visit him very often. As a result, it added complications to Helen's father's care and she was not kept up-to-date with his everyday medical or care decisions – they were not legally obliged to do so.

Trevor, 39, and June, 77, Peterborough

June looked into DIY kits, but didn't feel confident submitting the online forms without consulting someone first. June and Trevor met with a solicitor to discuss the decisions that were right for her, leaving them confident he will carry out June's wishes.

Meeting with a solicitor helped June not only to realise the importance of this legal document, but also to consider a huge range of options, such as end of life care and decisions in a medical emergency, as well as the possibility of setting up a do not resuscitate order, that were previously unknown to her. With the benefit of expert advice, the conversations around her end of life care and medical decisions that she had previously found difficult were more structured, making her feel more at ease.

Trevor is now confident that he understands what his mother wants should the situation arise, has it documented, and feels reassured that he is acting in his mother's best interests. The conversations that June had with her solicitor, and the subsequent conversations that June had with her loved ones, really put June at the centre of these medical decisions, rather than making them about what it is her family and loved ones would want for her, should the situation arise that she loses mental capacity.





Advice on creating your health and welfare LPA

Karon Walton, Chief Legal Officer at SFE (Solicitors for the Elderly), has been helping people put LPAs in place for many years. She shares her advice.

There are many things that need to be considered and decided on by others if you lose mental capacity, such as the many types of medical and care treatments you could receive. This includes whether you want life sustaining treatment in all scenarios, life support decisions, where you live, your daily routine, organ donation and even what you wear and eat.

Anyone that makes decisions about you must act in your best interests. If you state your wishes, values and feelings, it then makes it easier for this to happen and for the right choices to be made. Some decisions may also require more than just a simple yes or no answer. Consider your wishes in detail and think about every aspect of your care.

Have the conversation

It's really important to consider and talk to the person or people, such as a family member or close friend, who you want to make decisions on your behalf should you lose capacity. You need to let them know you'd like to leave your wellbeing in their hands and what you'd like to happen when it comes to key decisions.

Some people may find this kind of conversation very difficult, it may bring up topics that we naturally shy away from. However, having a conversation about your medical and care instructions and preferences early will ensure that your wishes will be followed.

It's worth considering who the right person is to act in your best interests – someone who knows you well and feels confident making decisions on your behalf. It's never too soon to have these conversations with them, but it can be too late. If they are to carry out your wishes and retain control, they need to know what you want.

Write your wishes down

Conversations are important, but it's also necessary to set out what you want in writing. Even creating an email trail with key decisions will help, but the best way to do this is to formalise your wishes in a H&W LPA. This eliminates doubt and gives legal validity to your choices.



Think about
your wishes



Have the
conversation



Formalise it
with an expert

Speak to a specialist and get it finalised

It is possible to create your own DIY LPA online and register the document with the Office of the Public Guardian. This is the cheapest way of getting an LPA in place. National charities such as, Age UK and Alzheimer's Society has volunteers than can help with the process, although they are not legal professionals.

Seeking specialist advice means you avoid the risk of a weak or flawed document, which is sometimes the case with a DIY LPA. A self-made LPA may not consider all possible outcomes and be legally inaccurate, causing significant emotional and financial strain when you come to use it.

A lot of thought may go into getting your wishes down on paper and not all choices will be straightforward. An expert with experience of creating robust LPAs will be able to help you set out exactly what you want using the right terminology, and prompt you to consider things you may never have thought of.

The charity Action on Elder Abuse also advises seeking specialist support to ensure safeguards are in place for older or vulnerable people.

Accredited SFE lawyers have a great deal of experience in creating LPAs. Knowing your document is correct offers peace of mind and means that, when the document is needed, your loved ones will not have the burden of worry.

To find out more about LPAs, or to find an SFE-accredited lawyer, visit www.sfe.legal



Conclusion

We're all living longer, which is good news for most people. However, it means the prevalence of conditions like dementia are on the rise. The uncertainty and grey areas that surround mental incapacity are extremely unsettling, which is all the more reason to take immediate action and consider your health and welfare wishes.

By 2025, the population aged over 65 will have increased by 20%. The number of us facing high risk of conditions that cause incapacity is rising. Over the next decade, around 13 million people will be at risk of losing capacity with no provision in place to ensure their wishes are taken into account – which is a scary thought. We are leaving some of the most important and personal decisions to chance, in the hands of strangers, by assuming we, or our family are in control..

As a nation we understand personal health and wellbeing is important, through healthy lifestyles, food choices and exercise, so why are we limiting our end of life options without specifying what we want? Our research shows that for most of us it's simply because we're unaware of the risks. More than 70% of us believe that our loved ones will step in and make decisions on our behalf should we no longer be able to. Without a H&W LPA in place, we know this is not the case. The current picture is worrying and this needs to change.

It's important not to risk leaving your health, care and welfare choices to people who don't know you. It is likely to result in objective decision making for something that is very subjective and personal. It's important to act now, have the discussion with loved ones and get your wishes on paper.

If we fail to specify what we want in these circumstances, it will be difficult for others to make the right decisions on our behalf. It also puts a huge strain on our loved ones who are unsure what we want, and they may struggle to reclaim control in an already distressing situation.

Most of us are failing to put our wishes down on paper and even to talk about them to our loved ones – the very people we hope will make best interest decisions for us. The taboo around medical decisions and end of life care needs to be broken and H&W LPAs should be a topic of discussion around any dinner table. Planning ahead gives us peace of mind for the future and prevents further strain to health and care services across the UK.

The evidence in this report highlights that the problem is only going to get worse if current predicted trends continue. We need an immediate mindset change to tackle the imminent incapacity crisis.

We urge people across the country to start thinking about their wishes should they face incapacity. Challenge yourself to have a conversation about your end of life wishes with family and friends today. If it helps, set out your options on paper before talking about it and formalise these in a H&W LPA.

Partners



Jeremy Hughes CBE, Chief Executive of Alzheimer's Society

“We welcome this initiative. Lasting powers of attorney for health and welfare too often get overlooked. But planning ahead for future care and treatment can be just as important as financial planning, and for some people more so.

“People with dementia have the right to make choices about their care, just like anyone else. Making someone they trust their attorney for health and welfare is one of the ways people can do this. A health and welfare LPA provides reassurance to them and the act of creating one can start useful conversations about the future with family and friends.”

Gary Rycroft, Chair of the Dying Matters Forum

“We have long been advocates of the health and welfare lasting powers of attorney. End of life treatments can be uncomfortable and upsetting – for both the person in question and their loved ones.

However, death and dying needn't be a taboo topic. There is dignity to be found in dying, and one of the best ways of ensuring this is by specifying your wishes around how you would like to be cared for.

“Without a health and welfare lasting power of attorney, you risk having very personal choices being made on your behalf by people who do not know you – such a medical or legal professional. We support SFE's campaign to raise awareness of the importance of these documents.”

Tish Hanifan, Founder & Joint Chair of Society of Later Life Advisers (SOLLA)

“End of life health and medical treatments are very personal, and often complex decisions to make. For this reason, it is important that people discuss their wishes to avoid being caught out – or worse still, causing your family unnecessary strain.

“However, the most important thing is to formalise these in a health and welfare lasting power of attorney. Leave nothing to chance. By writing down your wishes, you know that you will be looked after the way you would want, despite being incapacitated.

“SOLLA fully supports SFE's campaign and urges people to start thinking, vocalising, and finally writing down their wishes and needs for later life.”

Jane Ashcroft, CBE, Chief Executive of Anchor

“At Anchor, we believe that planning ahead is key to ensure you live your life to the fullest. By preparing for every eventuality in your later years, you will avoid unnecessary distress – whether this concerns your living situation, your health or your finances.

“A lasting power of attorney is an essential tool for many of our customers and their families. Creating an LPA is one of the only ways to ensure your end of life medical and care wishes are carried out as you would wish.”





Gary Fitzgerald, Chief Executive of Action on Elder Abuse

“A key way that older people can ensure their wishes will be respected in later life – whether that is about what sort of care they want, or about future health care support – is to talk about those wishes with family or friends and ensure everyone understands what they want.

And formalising these expectations in a health and welfare lasting power of attorney can then ensure they are also understood by others too. This can give everyone confidence, including family members, that the right decisions will be taken in the unfortunate case that the older person can no longer make their wishes known.”

“Powers of Attorney need to be drawn up safely and properly, so we would always recommend seeking considered and professional advice – assuring that both the donor and attorney fully understand the decisions that are being made.”



Office of the
Public Guardian

Alan Eccles, Public Guardian, England and Wales

“As Public Guardian, I whole-heartedly support action that encourages people to plan ahead. Individuals often take care of their financial affairs, but neglect important choices about their future health and wellbeing. Both are equally important if we are to have peace of mind.

“OPG’s own insight shows that we especially need to reach out to those on lower incomes. They need a voice when it comes to their future care and to know that LPAs are within their reach.”

Caroline Abrahams, Charity Director at Age UK

“A health and welfare lasting power of attorney (LPA) lets you stay in control by saying who you want to make decisions, on your behalf, about how you are cared for - even if you lose mental capacity. The best advice is to get an LPA set up well in advance, when you have time to reflect on what you want as it doesn't have to take effect immediately. You can specify what decisions you are happy for them to make on your behalf and you can also choose more than one attorney who could be a family member, a friend, spouse, partner or civil partner, or a professional, such as a solicitor.”



About the authors

Solicitors for the Elderly

Solicitors for the Elderly (SFE) is an independent, national organisation of over 1,600 solicitors, barristers, and chartered legal executives, committed to providing the highest quality of legal advice for older and vulnerable people, their families and carers. The extensive experience and qualifications required of SFE-accredited lawyers make them the gold standard for solicitors, barristers and chartered legal executives advising on Lasting Powers of Attorney (LPAs) and other legal services for older and vulnerable people.

Centre for Future Studies

Centre for Future Studies (CFS) is a strategic futures consultancy enabling organisations to anticipate and manage change in their external environments. Its foresight work involves research and analysis across the spectrum of political, economic, social and technological themes.

CFS is affiliated with Kent University and has access to multi-disciplinary specialists throughout the UK academic and business communities. They work across a wide range of industry sectors bringing specific commercial knowledge to particular projects.

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