



How to... Manage life with dementia

NO. 5 IN A SERIES OF
GUIDES FROM
WHEN THEY GET OLDER



HELLO FROM US

Thank you for downloading this guide. We hope you find it useful.

This guide highlights important areas you need to know more about if you are worried about someone with a diagnosis of dementia and/or have concerns for a relative. It is written by Sara Wilcox of the charity [Pathways through Dementia](#) in association with When They Get Older.

Sara worked for seven years at the Alzheimer's Society specialising in the legal aspects of the dementia journey. She saw two of her grandparents die with dementia in the 1990s and understands fully the strains that the illness places on families. Her aim is to alleviate some of the stress by providing accessible legal information to people living with dementia.

[When They Get Older](#) is a web service aimed at the children of ageing and elderly parents. Our website is packed full of valuable information, tips and tools to help you help your parents, as well as advice and experience from those who have been this way before. By signing up to become a free member you can download more guides and receive our weekly newsletter, keeping you up-to-date with news and our latest stories.

You can also tell us what you think about this guide, offer feedback on the service, and [get in touch](#) (editor@whentheygetolder.co.uk) with us to tell your own story about caring for the old and elderly.

We look forward to seeing you there.

IN THIS GUIDE

[Introduction](#)

[Managing finances](#)


[Paying for care](#)

[Working in your loved one's best interests](#)

[Day-to-day life with dementia](#)

[Like to know more?](#)

[Our tips for managing life with dementia](#)



CLICK TO JUMP TO
DIFFERENT SECTIONS
OR SCROLL TO READ IN
ORDER.

A guide to managing life with dementia

A diagnosis of dementia affects all aspects of life – emotional and practical. In this guide we aim to give you clear advice about managing legal and financial affairs on behalf of a loved one and how to adjust to living with dementia.

“I have spoken to hundreds of people over the years who are not only struggling to cope with the day-to-day challenges of caring for someone with dementia, but are also grappling with rules, regulations and organisations like the Court of Protection for the very first time. It is handy to know a bit about the legalities which govern our different dementia journeys so that you don’t feel swamped or intimidated by the system.” Sara Wilcox

This guide highlights important areas you need to familiarise yourself with if you are worried about someone with a diagnosis of dementia and/or have concerns for a relative who has memory loss.



Managing finances

It is very likely that at some point you will need to manage the finances of the person you are caring for. Power of Attorney – formally called Lasting Power of Attorney (LPA) for finance and property - is vital.

LPA forms allow a person to nominate one or two (or three or four, even five!) people to manage their money in the event that they become incapable of doing so for themselves.

These forms can be:

- [Downloaded](#) and printed off
- Ordered from the Office of the Public Guardian:
Tel: 0300 456 0300
- Bought from WHSmiths
- Provided by a solicitor if you are using a solicitor to set up the LPA

It is important to note that the person setting up the form and choosing their attorney/s must have “mental capacity” to undertake the task. In other words, they must know what the forms authorise attorneys to do.

You don't have to use a solicitor for this process but it will help if there are different views on whether the person with dementia has or lacks capacity, since the solicitor's job is to evaluate mental capacity.

Tip. At the end of the day, we should all have an LPA form set up. What would happen if you got into a car accident or suffered a stroke or any other life changing illness which affected your ability to manage your own money?

Health and welfare power of attorney

There is also a separate form for managing the Health and Welfare of someone who is unable to make their own decisions and forms can be accessed in the same way as those for the property and financial LPA.



If it's too late for LPAs

If a person has gone past the point where they can understand the meaning of the LPA or they simply refuse to sign one, you will have to apply to become their Deputy through the Court of Protection. This is a longer and more expensive process than applying to become an attorney.

You can:

- [Download these forms](#)
- Order them from the Office of the Public Guardian:
Tel: 0300 456 0300
- Ask your solicitor to provide them if you are using a solicitor

What is the Court of Protection?

The Court appoints attorneys and Deputies but the Office of the Public Guardian does all the paperwork for the Court and is the office you will deal with. People only go to the Court if there are problems with the registration (LPA) or application (Deputyship) where someone has objected to the process.

How much does it cost?

- If you are using a solicitor you will have to check their fees first.
- To register an LPA costs £120.
- To apply to become a Deputy costs considerably more depending on the complexity of the case.
- In either instance the fees can be paid by the person with dementia once you have gained access to their finances.

Safeguarding alerts

If you do not have formal authority in place to manage someone else's financial or legal affairs but take action on their behalf you may trigger a safeguarding alert.

These alerts are intended to protect vulnerable people from abuse, so if you appear to be opening or closing accounts, withdrawing money, becoming a signatory to another's account or doing anything that might seem to be detrimental to that person without an LPA or approval of the Court of Protection, you may find you have to explain your actions at some stage.



Paying for care

When people enter residential care their fees will be paid for in one of the following ways:

- By the resident if they have more than £23,250 in assets and/or savings
- By the local authority if the resident does not have more than £23,250 in assets and/or savings
- By the NHS if the person qualifies for NHS continuing healthcare

If people need some nursing care then this will be paid for by the NHS but they or the Local Authority will still pay their bed and board. As with all government regulations these figures and responsibilities are subject to change.

For many years this has caused consternation for many families who were seeing “inheritance” being handed over to the local authority month in month out, until it was almost entirely run down in some cases. This is why there have been plans to introduce a care cap.

Tip: More information about paying for care can be found in a well laid out, accessible Department of Health document titled, unsurprisingly, [“Charging for Residential Accommodation Guide”](#).

Paying for care at home

In terms of care at home, similar rules apply but the property is not taken into account. So if someone requires homecare and has more than £23,250 in savings they will pay for that care themselves. They may use welfare benefits such as Attendance Allowance or Personal Independence Payment to meet the bills (see below for examples of benefits relevant to people living with dementia).

No free social care for dementia

Many are surprised that people with dementia don’t automatically qualify for free care as those with cancer do.

The law states that people who receive social care can be means tested because social care can be provided by carers who are not medically trained. Most people with dementia can safely have their needs met by a care worker rather than a nurse.



Taking property into account, or not

Sometimes an owned property can be “disregarded” by the Local Authority when it is calculating whether someone has the means to pay their own way if going into care.

A property is completely disregarded when:

- A partner or spouse lives there
- A close relative over the age of 60 lives there
- A close relative under the age of 60 lives there who has a disability

Tip: Don't assume that just because a person other than the owner lives in a property that the value of that property won't be taken into account when assessing ability to pay

Will the Care Cap make a difference?

Aiming to make the system fairer to people with dementia the government had, through the 2014 Care Act, introduced a “Care Cap” so that once people have paid out £72,000 for care their care costs would be met by the state. However, they would still have to pay the fees that cover their bed and board. This Cap has now been deferred until at least 2020.



Welfare benefits

This is a relatively easy area to cover as there aren't many benefits for people with dementia unless they have other issues with their day-to-day living arrangements. People aged 64 or under can apply for Personal Independent Payment which consists of two types and two levels:

Daily Living Component

- Standard level £55.10
- Enhanced level £82.30

Mobility Component

- Standard £21.80
- Enhanced £57.45

People aged 65 or over can apply for Attendance Allowance which also has two components:

- Lower rate: £55.10
- Higher rate: £82.30

Tip: There was a time when being in receipt of any of the above would have secured your relative a further reduction in their council tax bill. Now GPs need to write a letter to confirm that their patient has “severe cognitive impairment” – another hoop to jump through but worth doing.

Carer's Allowance

You can claim Carers Allowance yourself at £62.10 a week as long as:

- You earn £110 or less per week
- You care for someone for 35 or more hours per week
- You are over 16



AN EARLY VISIT TO A GP FOR DIAGNOSIS IS WORTHWHILE.

Working in your loved one's best interests

When you're first worried about their memory

If someone believes that they are fine and do not have any memory loss, the best thing for a family member to do is write to the GP and let them know what is happening at home. A helpful GP could then broach the matter tactfully if the patient attends the surgery on another health related issue.

Additionally it is worth noting that in the case of Alzheimer's disease (the most common form of dementia) taking the anti-dementia drugs as soon as possible can be vital in terms of slowing the progress of the illness down. Pointing this out to someone who may feel afraid of a diagnosis of Alzheimer's disease might encourage them to take action since there is something positive they can do to tackle the problem.

How social services can help

Social services are legally responsible for vulnerable adults and must communicate with families and interested parties when making decisions on behalf of someone else. The Mental Capacity Act outlines how they must also involve the person diagnosed with dementia as far as possible.

Social workers can

- Outline the options for the person with dementia given their present circumstances
- Put together a homecare package
- Arrange for occupational therapists to visit and assess the home environment to see if mobility aids can be introduced to improve the person's quality of life
- Signpost to other organisations such as the local Alzheimer's Society, assistive technology companies, befriending schemes etc
- Provide lists of care homes in the area suitable for people with dementia

Social services are there to help and educate families about the support they can receive and are entitled to.



OCCUPATIONAL
THERAPISTS CAN VISIT
TO SEE IF MOBILITY
AIDS CAN HELP.

Deprivation of Liberty Safeguards

In 2005 a family of foster carers won a court case at the Court of Human Rights in Strasbourg which highlighted the position of people who were living in accommodation against their will but who had no means of challenging their “detention” due to lack of capacity.

This led to the introduction of Deprivation of Liberty Safeguards (DoLS) through the 2005 Mental Capacity Act. If someone is removed from their home and health professionals believe, or suspect, that they are being placed elsewhere against their will, a Best Interests assessment must be carried out to make sure that the decision that has been taken is the least restrictive given their personal circumstances. An Independent Mental Capacity Advocate will also act on behalf of the person who is being moved to make sure that their voice is heard where/if possible.

Over the years the transition to this way of working has been bumpy to say the least and there are many examples of case law where the system failed to apply the principle of DoLS and wrongly detained people, for example the Neary case in Uxbridge (contact Sara for more information, details at the end of this guide).

Making Advance Decisions

The Mental Capacity Act 2005 also introduced Advance Decisions into statute law, which means they have more of the force of the law behind them. Advance Decisions (AD) are documents we can all draw up, a bit like a Will, which state certain medical interventions we would not want at the end of our lives. Research shows that the majority of people who make AD have seen someone they love die in hospital. This is because they have now seen, first hand, the options that are available at the end of life and have thought “That is not for me”. These can include resuscitation, and PEG feed (feed through the stomach).

AD forms should be witnessed and ideally discussed with a health professional such as a GP. They can be very helpful for consultants who are making tough decisions about continuing with healthcare interventions, and families who are traumatised by the fact that their loved one is passing away/at odds with the consultant and/or each other over what the patient would have wanted.



“TELL ME ABOUT YOUR
FAMILY HOME AND
WHERE YOU GREW UP”

Day-to-day life with dementia

Engaging with someone who lives in the past

People with dementia invariably reach a point where they are living more in the past than in the present. The temptation for families is to try to draw them back into reality, especially in the early stages when it can be difficult and upsetting to acknowledge that the person is becoming very confused.

However, this approach will usually be counterproductive and the experts advise that carers engage with how the person with dementia is feeling rather than affirming or denying the time that they believe they are living in.

For example, someone might say “This is not my home, I need to get back to my Mum, she’ll be worried about me” to which a relative or friend could say “I am really sorry you are worrying about your Mum, tell me about your family home and where you grew up”.

People commonly think that they ought to be at work and again we could ask “What did you used to do? Did you enjoy your job?”

Tip: We can always acknowledge feelings and make efforts to soothe distressed people by (where appropriate) giving them a hug, stroking their hand, making a cup of tea etc.

Dealing with challenging behaviour

Similarly, when faced with very challenging behaviour it is important to respect the person with dementia and recognise how frustrated/angry/frightened they are.

There are many ways in which people with memory loss can express how they feel and sometimes the situation can become unmanageable. If health professionals are not already involved, now is the time to involve them.

Social services, [**Admiral Nurses**](#) and dementia support workers are some of the many people who can help families to work with difficult behaviours and carers should feel confident that in reaching out for help, their loved one will be treated with compassion and understanding.



Making the move to a care home

For everyone who has dementia, their decline will affect them in different ways at different times. Legally, vulnerable adults cannot live in an environment where their personal safety is at risk. Many situations can trigger the decision to put them into a home, for example:

- They are leaving the house in the night/in the wrong clothes/in an agitated state
- They are incontinent and need plenty of care and attention to keep them dry, clean and hygienic
- They are not eating/drinking properly
- They are demonstrating dangerous behaviour such as leaving taps running/iron plugged in/ gas on in the kitchen

If social services are aware that a person is at risk and they feel their needs cannot be met by carers visiting, they will start talking about residential care.

Occasionally someone with dementia will want to go into a care home if they are feeling isolated or worried about their ability to cope. Good residential care homes can create a new lease of life for people who are struggling as they offer activities and a community of new friends.

Coping with guilt when someone you love goes into a care home

Carers frequently experience burnout and this is no good for them or the person with dementia. It is best to try to engage with the idea of residential care before you get to this point if possible, for example using a local home for a respite break to ease everyone through the transition as smoothly and painlessly as possible.



The decision to place someone into care is rarely, if ever, taken lightly and can lead to relatives feeling like a failure and/or very guilty. Whilst these are understandable emotions they are not going to change a situation which was never of anyone's choosing and if someone with dementia can no longer be cared for at home it is wise to acknowledge the heartache and start looking for a suitable residential/nursing home that is welcoming and exhibits a good understanding of dementia care.

Tip: For further discussion around these and any other emotional issues, do visit our agony aunt column [Ask Lesley](#). As well as asking Lesley for online responses to your (anonymous) issues you can contact her for one-to-one expert coaching in managing life, work and family.

Choosing a care home

If you know that a family member is living with dementia that does give you time to prepare for a possible short-term or permanent move to a care home. It's well worth taking a look around before the event so that you aren't making a rushed decision in an emergency. Find homes by:

- Asking social services in the area where you are searching, who will have a list of homes to visit – particularly useful if the local authority may be paying for care
- Looking at the growing number of online directories available
- Checking the reports of the Care Quality Commission which is the organisation that officially vets care services

Tip: Take checklists with you when you visit homes so you can assess each one and ask important questions while you're there.

Final thoughts...

Dementia presents us with an infinite number of possibilities and challenges so it is wise to take control where we can by doing things like making a power of attorney and discussing end of life care, even though having these conversations can be difficult.



Like to know more?

Pathways Through Dementia

Pathways Through Dementia (www.pathwaysthroughdementia.org) is the charity set up by the author of this guide, Sara Wilcox, to empower people on the journey through dementia. The charity runs workplace seminars around the topics covered in this guide. If you found the information in this guide helpful you can donate to Pathways Through Dementia on its website. Tel: 07540 982 161.

When They Get Older

When They Get Older is a web service offering advice and tips from experts as well as real-life experiences of families caring for older relatives including:

- Enjoying time outdoors in nature with someone living with dementia
- Why eating well is important in dementia
- Dementia, creativity and napkins

Visit the When They Get Older website via:
www.whentheygetolder.co.uk

Alzheimer's Society

Alzheimer's Society offers information and a forum to share experiences. Helpline: 0300 222 1122

Age UK

Age UK is a charity working for older people.
Tel: 0800 169 6565

Action on Elder Abuse

Action on Elder Abuse is a charity working to prevent the abuse of older people.
Tel: 0808 808 8141

OUR TIPS FOR MANAGING LIFE WITH DEMENTIA

- » **Everyone should set up Lasting Power of Attorney long before they think they might need it**
- » **Consider how to manage investments to best pay for care**
- » **Look at care options in good time so there's no panic if and when they're needed**
- » **Talk to social services about the help they can provide**
- » **Join communities and forums for support from others in the same situation**
- » **Don't take on the burden of guilt. Dementia is not your fault and you can't fix it.**

Did you find the information in this “How to” guide helpful? Perhaps you've got some great tips for managing life with dementia that we haven't included. Have your say and discover more of our free stuff at [When They Get Older](#). Follow us on [Twitter](#), like us on [Facebook](#) or repin us on [Pinterest](#) for updates on news relevant to you and your family.

Our guides are intended to offer food for thought. Please consult professionals for advice on all medical, financial and legal issues.

The information in this guide is correct as at July 2015. Please check for latest regulations before making any decisions.