



Dementia care

A guide to living with Dementia

▶ Understanding the condition
and getting the most out of life

Nash&Co
Solicitors

A guide to living with dementia

Understanding the condition
and getting the most out of life

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Introduction

“The first thing to say is that everyone is an individual and unique human being and their experience of dementia will be unique to them. But there are some common threads that many people experience.”

Here at Nash & Co Solicitors, we will help you support the people around you who really matter; those who you may be looking after. The law can be complicated at the best of times and that is why we are very approachable and understanding. Our aim is simple; to understand your circumstances and to provide the best advice to achieve the best outcome – and we'll do this while supporting you at all times.

If you look after someone who is diagnosed with a dementia and have experienced a time when you wished for someone to be on your side, to explain what is happening and to advocate for your loved one please contact us and we will help.

Talking to lawyers can often be intimidating. That's not what we are about at all. We pride ourselves on being sensitive and understanding, friendly and approachable. We are here to help where we can, and will support your loved one and you as carer, to navigate the challenges that you face and to get the best possible outcome.



Hilary Cragg

Partner, Elderly Law

Background

What is dementia?

Essentially, it's a disease of the brain that causes memory loss, difficulty in thinking, and problem-solving and/or language.

A person with dementia may experience changes in their mood or behaviour. The changes in the brain affect aspects of function, so depending on where the changes in the brain have taken place will depend on what the presentation is.

Since the brain ultimately controls the entire body, including the autonomic functions, if a person lives long enough with dementia, it is likely that these will be affected. Since 65% of people with dementia have another healthcare condition, dementia is not always the cause of their death.

There are many types of dementia and their symptoms vary, as does the progression of the condition.

Its rate of progression and the individual's life expectancy can also vary hugely. Progression is generally divided into three stages:

Mild

Moderate

Severe

In the early stages of a dementia, the symptoms displayed can vary significantly (according to which type of dementia that person has), but as the condition develops the symptoms develop areas of commonality. At the severe stages of different dementias, the individual will require a high level of care to look after them.

The symptoms of the condition vary, depending on the type of dementia and its stage of development. Treatments can also vary, again, depending on symptoms and the type of dementia. The most common type of dementia is Alzheimer's disease (62%)* and the second most common is vascular dementia (17%)*.

*Alzheimer's Society

Research

Currently the clinical causes of Dementia are unknown, although it is believed that lifestyle and genetics can play a part. This is by no means the whole picture. Age is certainly the biggest risk factor for dementia. Because of this lack of knowledge, there is a lot of research taking place globally.

Dementia is the only healthcare condition that has been the subject of a G8 summit (taking place in 2013). One of the outcomes of the summit was co-operation and collaboration in research across the world, in an attempt to improve the understanding of the condition, its causes and its treatment.

In 2017, Bill Gates pledged \$250m to Dementia research. At that time the World Health Organisation claimed that Dementia was the fifth most prevalent cause of death globally. Of the top 5, it was the only one where numbers affected were increasing significantly.

Since currently there is no "cure", the research is split into treatment and research into the benefits of social forms of care that can help people currently living with dementia.

Diagnosis

In order to be able to diagnose dementia, the doctors will initially take blood samples. These are used to rule out other causes, such as depression, etc. Once other causes have been ruled out, the patient is typically sent for a brain scan, allowing the Consultant to interpret the scan and diagnose the specific kind of dementia.

Diagnosis of dementia can be confusing. A lot of information is passed to the patient often leading to feelings of being overwhelmed in coming to terms with the diagnosis. Good practice is for the patient to be referred to a dementia support worker and a social worker to see what help if any, is needed. At this stage, it's also a good idea to undertake a benefits check, to see if there is support that can be claimed, such as council tax reduction / exemption. There are many local charities that can assist with a benefits check - we can help identify some if you are struggling.

The Consultant may also have a connection to various clinical trials that are taking place. The patient may be eligible to take part in these trials, and the Consultant can discuss the pros and cons of taking part.

Mild Cognitive Impairment

Dementia usually starts with Mild Cognitive Impairment (MCI), however there is research that shows that long before any symptoms are seen, the disease has been causing damage in the brain for years. As time progresses, patients can initially experience mild problems, which are not severe enough to be diagnosed as dementia.

Each year about 10-15% of people with MCI will develop dementia*.

The patient with MCI can often confuse their condition with some of the more complex challenges of daily life. Symptoms can include, poor memory, reasoning, planning or conceptualising.

Having been diagnosed with MCI, the patient is likely to still be able to successfully live in the community and manage most of their own affairs. At this stage though, some level of support from either a family member or paid carer might be beneficial to ensure that the person can continue to maintain their skills to live independently in their own home.

*Alzheimer's Society

It may still be possible to keep driving at this stage, but the GP will be able to advise further.



Mild Stage Dementia

In the early stage of Alzheimer's disease, common symptoms include short term memory problems, including confusion around the time of day/date, following a conversation, and difficulties around identifying the correct word.

The dementia support worker can refer the patient to local support groups, clubs, or organisations that they may be interested in joining or taking part in.

At this stage it is helpful for the carers, (whether paid or family) to encourage and support that person to do as much for themselves as they can do, which will become depressed with their difficulties in performing basic tasks and/or become apathetic or anxious about themselves and their future.



Moderate Stage Dementia

As dementia progresses to the moderate stage the patient is more likely to have increased difficulty with memory and planning.

They are likely to experience more confusion generally and may also experience changes to their personality and behaviour.

They are likely to suffer from significantly impaired short-term and long-term memory. One disturbing development is that they may also begin to experience delusions or hallucinations.

It is very likely that they will need some form of care in order to keep them well and safe.

They will need support to safely prepare food and take their prescribed medication.

If they leave the home, it is possible that they might get lost and have difficulty in finding their way back home again safely.



Severe Stage Dementia

At this stage, the person with dementia is likely to be highly dependent and probably living with substantial care.

They are likely to have limited memory and have trouble recognising even very familiar things or people.

If they are not yet confined to bed, then their ability to walk will become poor.

If they use a wheelchair then they are more likely to become increasingly sedentary and confined to bed.

The patient's appetite is likely to be significantly affected and it is common that they lose weight.

They are also likely to become incontinent and lose control of both bladder and eventually bowel.

Their ability to talk will decrease and they may just make noise rather than discernible speech.



Behaviour

As part of their dementia, people can experience significant changes in personality, which can include noticeable changes in their behaviour.

Some people are likely to become very quiet and passive, which together with the loss of personality can be highly distressing for family members.

Sometimes the behaviour changes can lead to aggression and resistance to care interventions, which can be very challenging to handle and cope with.

Behaviour changes can also include:

- **Paranoia**
- **Suspicion**
- **Accusation**

So, carers are constantly being challenged, even though they are trying their very best. Whatever form their behaviour takes, it is very wearing to carers to feel that the person they are trying to help is not appreciative and can even be hostile towards them.

Communication

Since dementia can have a wide variety of changes in the person, the challenges to communication can be varied too.

The person can have word understanding and/or word-finding difficulties, they may be repetitive and could have difficulty concentrating, particularly in a busy environment.

When talking to someone with dementia, the family member or carer should focus on that communication and nothing else, including their name, so that the person with dementia knows they are being talked with. Smile, be empathetic and speak slowly and in short, simple sentences. Maintain eye contact and give the person time to answer.

Avoid questions with open answers, instead, use closed questions that require a simple yes / no response.

Try to respond to the person with dementia in similar terms as their communication, as they could for example have poor memory, be confused, feel unsafe or they could be in pain.

If nothing else, be the kind, smiling person with whom they feel safe!

Medication

65% of people with a dementia have a co-morbidity (another disease or condition - Alzheimer's Society). People with dementia are therefore likely to have medication that relates to their other condition/s.

When people are aware that their condition is starting to deteriorate and that something is wrong, they can become very depressed.



They may be prescribed antidepressants to help. If people are displaying challenging behaviour, it can be because they don't understand their condition and /or their surroundings and become fearful or anxious. There are various

medications that can help to relieve these symptoms - anti-anxiety medication or anti psychotic, both of which can have a sedative effect on the person. There is a balance to strike with this medication in order to relieve the symptoms of challenging behaviour, but not to sedate the person too much that they might become at risk of falls and/or reduced appetite.

Memory-enhancing drugs have also become available. Effectively, the aim here is to ensure that what brain function is working is maximised. However, these medications do not stop the underlying progression of the condition, which will continue to happen regardless.

Please note that all medications should be taken under the advice of a medical professional. Many medications have side effects and the person with dementia should always seek advice from their GP. The effectiveness of medications will always vary from one person to another.

Living with dementia

It is possible to live well with dementia. The dementia friend's social movement is encouraging individuals and businesses to become dementia-friendly. If the person has a dementia worker, then they should be able to let them know of any events or activities that they may like to join in. There will also be information from the local Age UK or Alzheimer's Society branch on things that they can enjoy.

There is also a lot of technology designed to assist people both in and outside of their homes.

The person should be allocated a social worker and the social worker should also be able to advise on local events and groups. The person can have an assessment by an occupational therapist to see what they can do and what they might need to support them.

The person can still travel and if they declare a disability to the train company or airline, then they have an obligation to make "reasonable adjustments" to

support the person's travel, this usually takes the form of escorting them onto the train, possibly with baggage and a vehicle to drive them long distances through the station or airport. There are also quiet spaces to wait in some stations and airports.



Legal Affairs

Getting your affairs in order

As soon as the person gets a diagnosis, they should make sure that they get their affairs in order. If they have not already done so, they should create Lasting Powers of Attorney, both for financial affairs and health and welfare decisions. The person should also make a Will, to deal with their estate after they pass away. It is helpful if they organize their paperwork so that it is easier for someone else to take over the management of their affairs in due course and ultimately deal with the administration of their estate.

It is highly recommended that the dementia patient and their family discuss what they want to happen in the future, including issues such as future care and what their priority for their future is. This enables carers and clinicians to organize care with these expressed wishes in mind. If you need advice or assistance, please contact Hilary Cragg at Nash & Co Solicitors.



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Lasting Powers of Attorney

There are two kinds of Lasting Power of Attorney, one covering financial matters and the other dealing with health and welfare issues.

The person can appoint attorneys and replacement attorneys to act on their behalf if they are unable to manage their own affairs.

Both types of Lasting Powers of Attorney must be registered at the Office of the Public Guardian before they can be used. The financial LPA can be used if the person still retains their mental capacity but might have become physically frail. The LPA for health and welfare can only be used if the person has lost their

mental capacity to make those decisions themselves.

Lasting Powers of Attorney are only valid if the person is alive, the power ceases as soon as they have died.

It is important that Lasting Powers of Attorney are created sooner rather than later, but they do not necessarily have to be used immediately and can be kept in safekeeping until they are required.

Nash & Co can also act as a professional Attorney if the person with dementia has no one else to act for them. For more information, please contact Nash & Co.



Wills

A Will deals with the person's estate after they have passed away. The basics here include who the person wishes to act as Executor (the person dealing with the paperwork), and who will be the beneficiaries (the person/s receiving the gifts from the estate). A funeral clause can also be added to their Will, covering any specific wishes for their funeral.

Additionally, they can include a clause regarding guardians for their children if relevant.

If the person has pets, they can include a clause regarding their pets and should consider who will look after them after the person has died.

Wills can be complicated and involve tax planning and/or trusts. If you need advice or more information, then please contact Hilary Cragg at Nash & Co Solicitors.



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Deputyship

If the person with dementia has lost their mental capacity and they need help to manage their affairs, then an application must be submitted to the Court of Protection for a Deputyship order. This works like a Power of Attorney for finance, however depending on the size of the estate, there can be ongoing annual costs of supervision and insurance of the value of the estate, that is required by the Court.

The costs involved in applying for a Deputyship order are usually significantly more than those associated with the creation of Lasting Powers of Attorney.

Nash & Co Solicitors can act professionally as Deputy. For more information on how this would work and any relevant advice, please contact Hilary Cragg at Nash & Co.



Caring for someone with Dementia

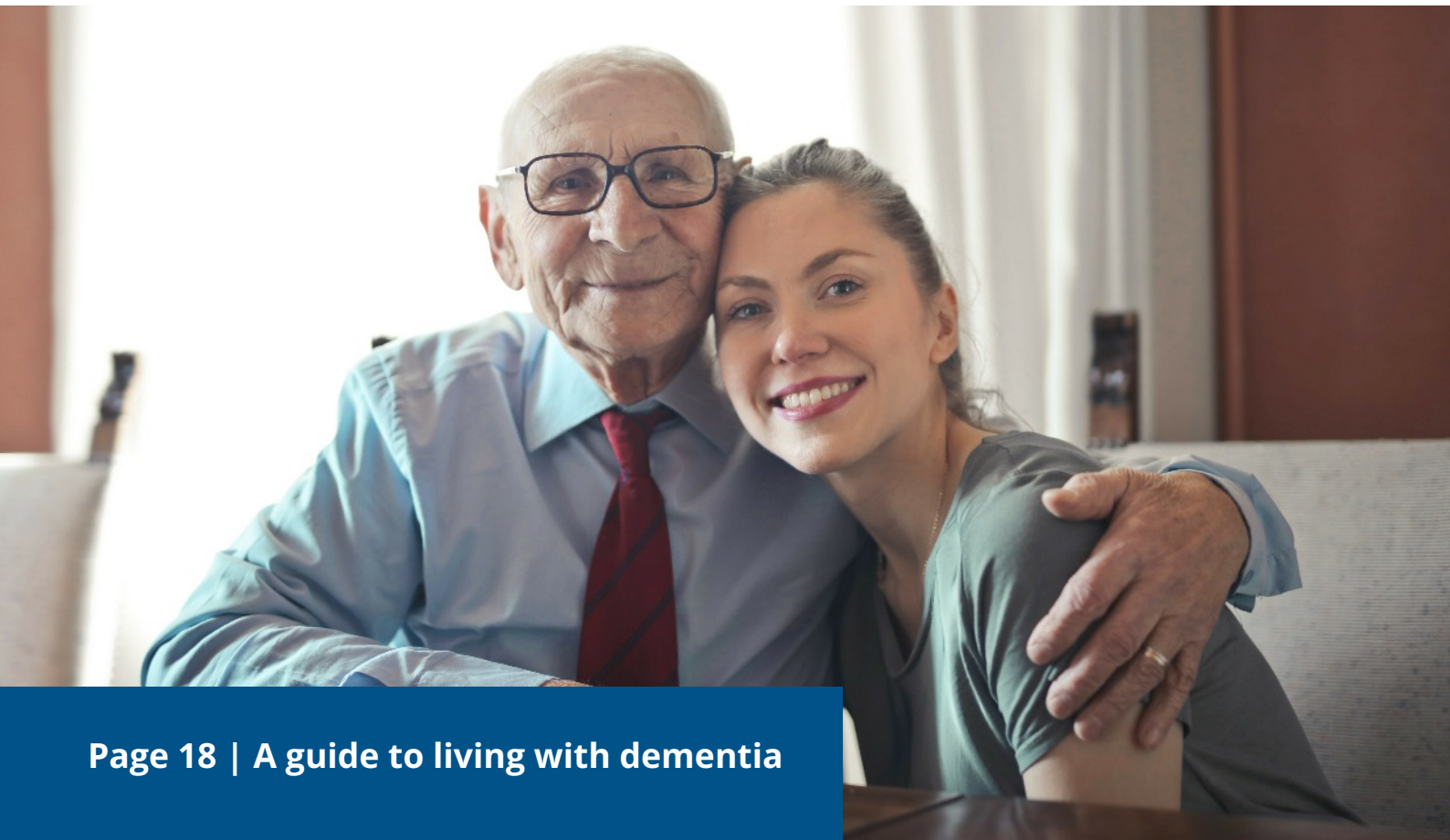
Family Carers

Caring for a loved one with dementia can sometimes be a very challenging and thankless role.

Family members want to do the best that they can, but it can often feel like a losing battle. It is important to focus on the quality of life that is achieved, rather than preventing the condition from deteriorating. It is worthwhile seeing what activities and support groups there are local - the dementia support worker or social services should be able to advise on this.

To be able to continue to care, it is important that the carer takes time to look after and care for themselves. It is often the case that other family members do not always appreciate the work, and emotional stress involved in caring for someone with dementia.

The diagnosis itself can be hugely distressing and upsetting, and take a huge toll on everyone involved. It's vital that families understand the need for caring for one another as well as the dementia patient themselves.



Domiciliary Care

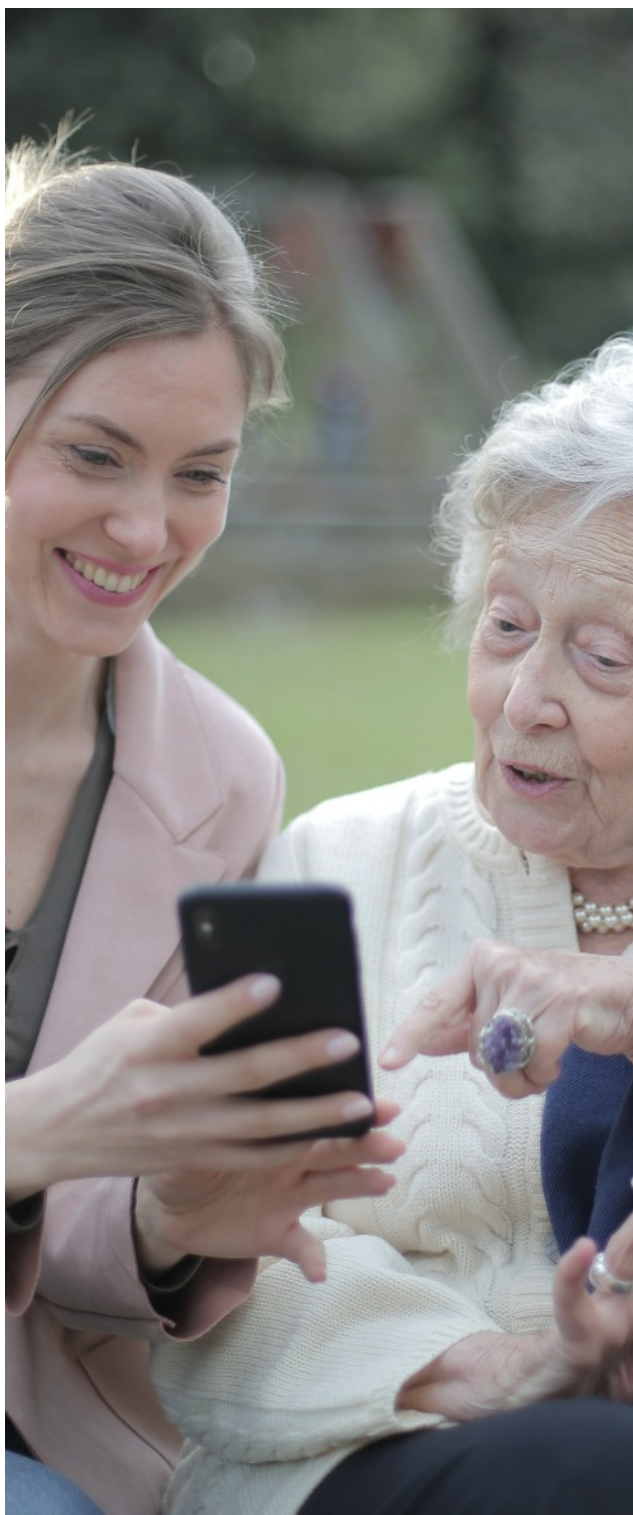
In the early stages of dementia, dementia patients might need some support, but largely are capable of living in their own home without a problem. Care can be arranged via Social Services, who have a statutory obligation to "promote an individual's wellbeing" and "must provide or arrange services.... to prevent or delay the need of care and support" (Care Act 2014).

This means that Social Services are required to assist, to arrange appropriate care, and possibly organise adaptations to the home to allow that person to continue to live in their own home for as long as is practicably possible. Support from Social Services is means-tested, so depending on the person's financial means, they may also be required to pay for the care.

Care visits to the home can be arranged depending on the needs of the person. In general, Social Services would arrange visits up to 4 times a day, and they could last anywhere between 20 minutes and a couple of hours.



Live-in Care



When domiciliary care is not enough, it can be possible to arrange for a live-in carer to provide care and there are care agencies that will take care of this for you. They will need their own bedroom to live in and usually get around 2 hours a day off, sleeping at night, but on call, if there is a problem. If the person needs help with moving, this will usually require 2 carers. This can either be arranged by periodic visits from a domiciliary carer, or a second live-in carer, in which case another bedroom would be required.

If live-in care is appropriate, then an assessment of needs will be required, along with a discussion with one or more care agencies to discuss the needs, costs, and provision of that care.

Live-in care is generally something that Social Services would not provide as it is usually more expensive than residential care.

Residential Care

When domiciliary care is no longer sufficient to keep that person cared for, and live-in care is either not appropriate or affordable, then the person with dementia will need to move into residential accommodation. At the time of admission into care, there should be an assessment of needs to find which is the most appropriate kind of home. Social Services should also have a list of homes with vacancies, which is updated daily.

Often, the admission into care is a managed process, so that the person and their family can choose the home that they want to go to and wait until a vacancy arises. However, the admission

into care often follows an acute admission into hospital (e.g. because of a fall) after which it is no longer possible to stay at home. This means that it may not be possible to go to the home that was originally considered, as they don't have a vacancy. Once that person is then settled into a home, it is often better for them to stay there, than to risk upset by moving them to a new home.

When and if the home they are currently living in is no longer able to meet their needs, then it will be necessary for them to move and the advice and assessment by Social Services might be necessary to find a suitable alternative.



Care in general

The first thing to understand about care is that most of the hands-on care is provided by people with some, but limited training. The level of training carers have will depend on the care home and the level of training required to work there to care for those residents.

In nursing homes, there are far fewer registered nurses on duty than there are care staff, who will undertake the basic care tasks.

They will always do something "wrong" in the eyes of the family, it might be as small as making their tea too strong or too weak or it could be more. In this circumstance, there needs to be a level of tolerance, however, the family should

liaise with the staff to ensure that care is provided in a way that the person with dementia would like or as close as can be achieved.

There is no excuse for bad or negligent care, and this might need to be reported to the governing body (CQC), Social Services, or possibly even the Police, if a crime is involved.

Care is almost always a distressed purchase, almost no one when they are younger wishes to become ill and be admitted into care. People wish to be fit, well and active right up until they pass away. All parties should have an appreciation of the stress that this will inevitably cause.



Care funding

Funding for care via social services is generally means tested. If the person has limited financial resources, then social services will fund their care, subject to an income contribution.

If the person has their own money and are subject to a social services means tested financial assessment, then they will need to meet the cost of their care themselves. The legislation for charging is within the Care Act 2014, which can be quite complicated.

If the person's needs are sufficiently great to be considered a "primary healthcare need", as opposed to a primary social care need, then the NHS will meet the

cost of the assessed needs, following a successful assessment for [**NHS Continuing Care funding**](#).

NHS Continuing Care funding can be applied for in order to cover future care. However, it can also be claimed retrospectively if the NHS should have paid for care, but didn't (this is only possible if all of the person's physical and mental health needs meet the eligibility criteria for NHS Continuing Care funding).

If the person or their family needs advice regarding care funding, please contact Hilary Cragg at Nash & Co Solicitors.



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Driving

It may still be possible to drive having had a diagnosis of dementia, however, the person should talk to their GP about this. Dementia can affect the person's reaction time, route planning, visuospatial ability and problem solving, all of which could affect their ability to drive.

It is a legal requirement to report a diagnosis of dementia to both the insurance company and to the DVLA. If they do not report it to the insurance company, then it will likely invalidate their policy.

If the person wants to continue to drive, then they must report this to their GP. The DVLA will send them a form that includes a request for details of their GP. The DVLA will then ask for their medical report from the GP or their Consultant. If the report is favourable and the DVLA decides that the person is still safe to drive, then they will renew their driving licence, probably just for 1 year. The person will then have to return to their GP for assessment each year and to see if they are still safe to drive.

Should it still be unclear to the DVLA whether or not it is safe for the person to

drive, the DVLA can send them to an official Test Centre. If the person is then found to be unsafe to drive, their licence will be immediately revoked and they will not be allowed to drive again, including driving their car home.

People with dementia will often voluntarily surrender their driving licence or they can be encouraged to do so by their families. In these circumstances, it is common that the family will take the car away, so it is not a constant reminder or temptation.

If the GP decides that it is unsafe for the person to drive, but the person doesn't agree and does not want to give up driving, then the GP will most likely report their concerns to the DVLA, who will then revoke their driving licence. There is nothing that the person can do to legally prevent the GP from reporting their concerns.

Working

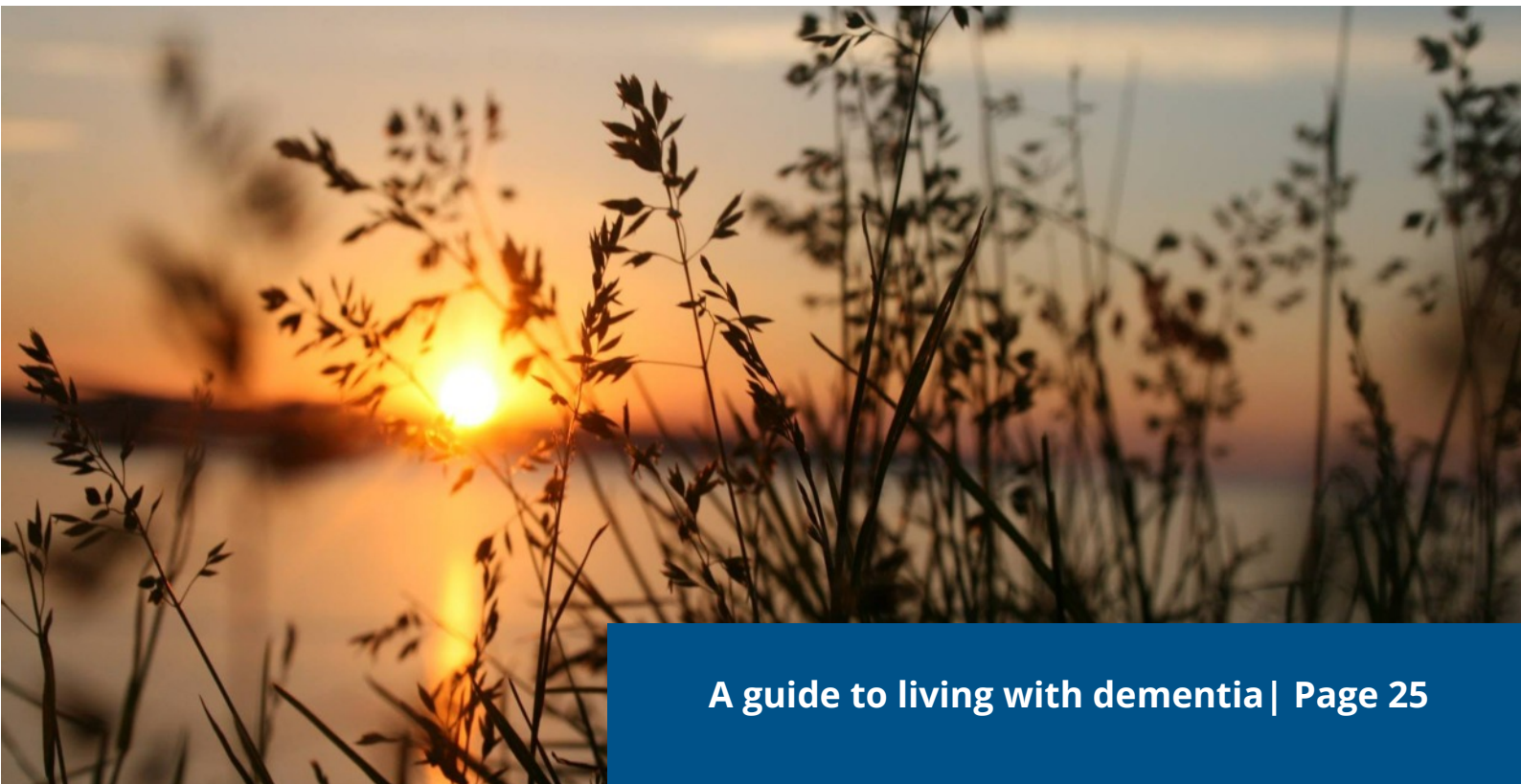
If a person has a diagnosis of dementia and is working or volunteering, then they do not necessarily have to disclose that they have dementia to the employer.

However, if they require their employer to make "reasonable adjustments" in accordance with the Equality Act, then they will need to declare their diagnosis.

As dementia is a progressive condition, the person will eventually need to give up working or volunteering, so they should be encouraged to have a discussion with their employer about their eventual retirement. This way, the process can be properly managed, and retirement can happen at the right time for all parties concerned.

Death

Dementia is a terminal diagnosis; however, many people don't die from dementia, but from something else. It is a difficult subject, but it is worthwhile having a conversation about what arrangements that person wants for their death. They might not want to be alone or they might want to be in a certain place. If these wishes are clearly expressed, then it gives the family and clinicians a plan to work towards. Their ideal arrangements might not be possible, but with the knowledge of what they want, it can be possible to arrange something close to it. It is a difficult, moving and intimate experience to be with someone in their last moments.



Hilary Cragg

Partner / Elderly Law

As a Partner and practicing solicitor, Hilary has a particular interest in issues concerning elderly and vulnerable clients. She deals with all related legal matters, from will writing and Lasting Powers of Attorney to care home funding issues and disputes about care. Hilary came to the law after careers in retail, training and banking. She joined Nash & Co in 2008 as a trainee solicitor and qualified in March 2010.

Hilary is an Accredited Member of Solicitors for the Elderly (SFE), a Committee Member of the Devon & Cornwall Regional Group for SFE, and a Full Member of STEP (Society of Trust and Estate Practitioners).

Hilary is highly active in raising awareness of dementia. As part of the Prime Minister's Dementia Challenge Team she has talked to ministers in both the House of Lords and House of Commons about supporting people living with dementia and regularly speaks at conferences.

Through local Dementia Action Alliance groups, Hilary is a Dementia Friend, Dementia Champion, and Purple Angel Ambassador.



Hilary writes a regular blog about Elderly Client Law -www.elderlylaw.wordpress.com. You can also find her on Twitter (@hilarycragg).

Hilary is also author of the book "Compassion with Dementia", a comprehensive and essential handbook for carers, families, professionals and anyone affected by dementia.

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