



LIVING WITH DEMENTIA

THE PRACTICAL, FINANCIAL & LEGAL CONSIDERATIONS

A diagnosis of dementia can be a frightening moment for you and your loved ones. It's important to know that you're not alone and that there is a great deal of support to help you meet the challenges ahead. This guide is intended to give you straight to the point information on some of the practical and legal steps you can take to plan for the future.



EARLY STAGE CARE



GETTING SUPPORT AT HOME

Simply having a diagnosis of dementia is not necessarily sufficient to receive funding and support. The benchmark for who is able to access government funded care is based around how that affects the individual's day to day life. In the early stages of the disorder it's very likely that someone with dementia may fall below this threshold.

All local authorities are obligated to provide services to meet the requirements of individuals which meet a certain level of need. Typically due to budget constraints, many local authorities across the UK have tightened up the criteria under which they are willing to provide care services. Where in the past people who were struggling with domestic tasks and basic personal care would meet the criteria, now only those with more serious personal care and medical needs are likely to be eligible.

A person's judged level of need from April 2015 will now be determined by government at a national level rather than independently by your local authority. This change is part of the 2014 Care Act which also creates a duty for local authorities to carry out an assessment and provide support for carers in their own right.



CALCULATING THE COST OF CARE

Your local council will carry out an assessment of your needs to determine whether you qualify for support. If you are found to be eligible, the cost of that service will then be based on a means assessment of your circumstances.

The current National thresholds for funding support are;

Assets of more than £23,250 you will be required to fund the full cost of your care

Assets between £23,250 and £14,000 will receive partial funding on a sliding scale

Assets of less than £14,000 receive full funding for care

The financial assessment will consider;

- Income
- Savings
- Shares & bonds
- Some additional benefits
- Trust funds

HOME AND PERSONAL CARE



For a person with Dementia who is looking to maintain their independence whilst remaining in their home, new technology has provided a new and cost effective method of supporting them with maintaining their independence. All local authorities now offer a range of assistive technologies which can be used alongside traditional support services, these are also often available to purchase privately.

MONITORING SYSTEM

As dementia progresses the need to have peace of mind that you or a loved one can call for help during a time of need becomes an increasing worry. Concerns around falls as well as the dangers in

AUTOMATIC MEDICATION DISPENSERS

For those living with dementia taking the right medication at the right time of day can be a virtual minefield. In many cases the person may have a complex regime made up of multiple

around falls as well as the dangers in event of a fire or a gas supply being left on are something which cannot normally be monitored where the person lives alone.

Home monitoring systems allow families to fill this gap and add an additional level of safety to the home environment. Modern systems are linked in to gas and fire sensors so that an operator is made aware of any alert. Beyond this, wearable technology can give security in case of a fall, but also as dementia progresses, and the risk of wandering increases, pendants and pressure sensors can alert an operator where the person has left and not returned to bed or has left the home.

Complex regime made up of multiple tablets which need to be taken at various intervals throughout the day.

Automatic dispensers offer a great potential solution to this problem. They can be refilled by a family member or pharmacist and contain a number of compartments which release at the required time whilst alerting the person in the house that it is time to take the medication.



Whilst technology can seemingly provide solutions for a number of common problems for people living at home with dementia, it is important to acknowledge that in some cases this may not be sufficient to cope with severe physical and cognitive impairment. For example, although fall sensors can alert a responder to a potential fall it cannot prevent falls from occurring.



MID TO LATE STAGE CARE

24 HOUR CARE OPTIONS

Where Dementia has progressed to a stage where there is agreement that it is no longer safe for the person to remain at home, it may be necessary to consider a 24 hour care environment where the person has access to trained care staff around the clock. The type of home which is most suitable will depend on the severity and complexity of the person's symptoms.

Within the UK there are four main bands of care home which have services that are suited to helping people with different levels of need these are:



RESIDENTIAL CARE

A care home environment for people who do not have complex nursing needs. This type of home may be suitable for people with dementia where they are able to accomplish tasks with prompting and some hands on assistance and where there are no high risk behavioural issues associated with their condition.



RESIDENTIAL WITH DEMENTIA CARE

Staffed by carers with specialist dementia training this band of home is again not suited to care for people with physical nursing needs or severe behavioural problems, but are more able to provide for residents with dementia which requires more intensive input



NURSING CARE

Delivers care for people who require the assistance of a registered nurse to meet their needs. This band of home is primarily staffed to assist people with a high level of physical need, but in the case of many end stage dementia residents it may often be the case that their physical care may come to outweigh their mental health needs. Therefore, where there is not a high level of aggression or other complex behavioural issues this band of home may be suitable for people with dementia.



NURSING CARE WITH DEMENTIA

This is the highest band of standard care home generally available. The home is equipped to handle people with high levels of physical need and complex mental health issues. It is staffed by specially qualified nurses and carers with mental health training.

FUNDING CONSIDERATIONS

Moving into a care home is likely to be an unsettling time for families and the added stresses of understanding the financial implications of this decision can make things all the more difficult. A recent pledge in the 2014 Care Act by the government is set to change the existing system from 2016 onwards so for someone moving into a home in 2015, it's important to understand what this means for your finances.

THE CURRENT SYSTEM

- Everyone with more than £23,250 in assets is expected to meet the full cost of their stay in a care home. Once this drops below £14,250.00 your care will be free;
- Unlike home care your house will be taken into consideration unless your partner or another vulnerable relative is still living there;
- Some forms of income are disregarded in the assessment including Disability Living allowance, Attendance Allowance;
- Also excluded are portions of some pension schemes in particular if there is a partner still living at home;
- You are not necessarily compelled to sell your home immediately as the council may lend you money for care against the value of your property under a scheme called deferred payments. This loan is interest free during your stay in care and is only reclaimed if you decide to see the property;
- Giving money away to friends or relatives may not avoid bringing these assets into consideration. Gifts of this type may be seen as “deprivation of assets”, meaning that it was done to avoid them being considered in the calculation of the persons charge for care meaning they may still be factored in and regarded as belonging to that person;

FUNDING CARE FROM 2016

- From April 2016 a cap will be set on care fees meaning that potentially the maximum that a person will need to pay towards their care is £72,000;
- Be aware though that this is based not on what you've actually paid out, but on the maximum amount your local authority would have spent in theory if they'd been paying for the cost of care. If your weekly fees are more than the local authority's maximum fee then anything over this will not count towards you reaching the £72,000 total;
- In addition the government defines “costs of care” as not including costs of board and lodging. The cost of board and lodging will therefore be subtracted from the councils contribution meaning that it may take even longer to reach the cap;
- The limits on Assets will be raised making more people eligible for support. People with assets below £118,000 will be eligible for some financial support whilst the threshold for fully funded care will be raised to £17,000 worth of assets;
- Deferred payments where the council loan you the fees for your care will no longer be interest free and will be charged at 4%;

What if I dispose or transfer my property and/or assets now. Will this mean I don't have to pay as much for care home fees in the future?

The above question is one of the most common when considering estate planning and it is crucial to be aware that by gifting, transferring, setting up a trust or disposing of your assets in order to reduce your overall capital does not necessarily mean that you would then be eligible for state funded care.

The key test that a Local Authority applies when considering whether there has been a deprivation of capital is whether those assets have been intentionally or deliberately disposed of in order to avoid an individual from paying for care home fees themselves out of their income or capital.

The Local Authority can take a notional capital assessment of any assets if it feels there has been a deliberate deprivation.

It is for the Local Authority to prove that there was a deliberate deprivation and in practise that isn't necessarily straight forward to establish. For example, there may well be a

perfectly reasonable purpose for the transfer such as to provide a lifetime trust for the children therefore passing assets onto the children but at the same time protecting those assets in the event of a child's death, bankruptcy or divorce. You can therefore see that there are genuine reasons whereby you may want to set up a trust other than to avoid care home fees.

The Charging for Residential Accommodation Guide (CRAG) 2009 provides useful guidance on what may or may not constitute deprivation of property and CRAG states it would be "unreasonable to decide that a resident has disposed of an asset in order to reduce his charge for accommodation when the disposal took place at a time when he was fit and healthy and could not have foreseen the need to move into residential accommodation".

You should therefore seek legal advice regarding setting up a Trust well in advance of ill-health to ensure that you don't fall foul of the deprivation of capital rules.

✚ CONTINUING HEALTH CARE ✚

In the case of dementia people in the later stages of the disorder are likely to require 24 hour specialist nursing care to meet their needs. If the primary need for their placement becomes very heavily related to providing for their health needs (physical or mental), over their need to just be in suitable accommodation, then they may be eligible for Continuing Health Care funding.

Under this scheme, the NHS would step in to meet the cost of the person's placement in full. Unlike support from the local authority this payment is not means tested meaning, that any assets owned by the person will not be taken into account when taking into account the amount of funding they will receive for their ongoing care.

- In order to be considered for continuing health care funding the person must meet the criteria in an initial checklist which can be carried out by a registered nurse, social worker or other qualified staff.
- If their needs are suitably high this will trigger an MDT (multi-disciplinary meeting) which is a more in depth review of that person's needs.
- This meeting will involve all interested parties including families, anybody involved in the person's day to day care, a specialist nurse assessor and a Social worker representing the local authority. At this meeting the person's needs will be applied to a more in depth criteria which explores different areas of their physical and mental health.

It is important to know that depending on the person's level of needs it is possible to move in and out of eligibility for continuing health care funding. Confusingly for families who have a relative with dementia this may occur when the person's Dementia becomes more severe and things like complex behavioural management issues are reduced.



A LEGAL VIEW ON CAPACITY AND MAKING DECISIONS

An important and common concern when a loved one is diagnosed with dementia is what will happen when they can no longer make decisions for themselves. The simple answer to resolving this particular issue is to appoint a Lasting Power of Attorney as soon as possible and certainly before the dementia has progressed to such a stage whereby that person no longer has capacity to make decisions themselves.



WHAT IS A LASTING POWER OF ATTORNEY (LPA) ?

Sometimes an LPA is referred to as just a Power of Attorney or POA. They all mean the same thing. An LPA is a legal document that is drawn up and signed by the Donor & Attorney(s) formalising the appointment and then the document needs to be registered with the Office of the Public Guardian (OPG) for it to be approved and valid. There are set forms created by the OPG.

- **Donor** = Person giving an LPA
- **Attorney** = Person appointed by Donor to make decisions on their behalf & in their best interests.



WHY DO I NEED ONE?

- A registered LPA will allow your appointed Attorney(s) to handle your affairs if you become unable to do so yourself.
- Even if you are perfectly fit, healthy and mentally capable now, sadly the truth is that this may not always be the case. It is therefore crucial that any LPA is given whilst you still have capacity because you can't grant one if you have lost capacity!
- For example, later in life you may suffer from Dementia or Alzheimers or you may be involved in a serious accident leaving you in a coma or with brain damage and entirely unable to make any decisions for yourself. If this happened then your attorney would basically step into your shoes and make decisions as you would do for yourself.
- Your attorney would make decisions for you in your best interests and therefore being an attorney is a very serious responsibility. It provides peace of mind for the Donor in the event something unforeseen does happen to them.





HOW MUCH DOES IT COST AND HOW LONG DOES IT TAKE TO SORT OUT?

- There is a £110.00 registration fee per LPA (so a maximum £220.00 for both LPAs). You may be entitled to registration fee exemption or partial fee remission based upon your income / benefit entitlement.
- Legal fees range from £250- £500 + VAT per LPA. If you are quoted more than £500+ VAT for one LPA then you are instructing a very expensive legal firm!
- The forms are very tricky and fiddly and any mistakes can be fatal to an application so seeking legal guidance is highly recommended. Furthermore, if you do make a mistake then you may have to re-do the forms and pay the registration fees again!
- As a general rule it takes between 8 - 12 weeks to register the LPA from submission of the application to the OPG. There is a minimum statutory waiting period of 4 weeks and therefore you rarely find the OPG register the forms in less than 6 weeks.



WHAT IF I DON'T GET ONE AND I LOSE CAPACITY?

- If you don't get an LPA in place and you do lose capacity then your nearest and dearest would have to consider someone making an application to the Court of Protection for Deputyship.
- This usually takes about 6 months and can be even longer depending on the specific case. Much longer than registering an LPA!
- Costs associated with the Court of Protection, involve a £400.00 application fee, medical assessment fee which can be anywhere between £100 - £400, legal fees are a minimum of £850 + VAT, there are insurance bond fees depending on the size of the estate and fees charged by the OPG to monitor and keep tabs on the appointed Deputy. Usually fees eclipse £2,000.00 and some applications cost much more indeed.

WHAT SORTS OF DECISIONS CAN MY ATTORNEY MAKE?

There are two different types of LPA's:



PROPERTY & FINANCES

The LPA for property and financial affairs allows you to authorise another person to make decisions on your behalf in relation to your property and financial affairs and to generally manage your financial affairs



HEALTH & WELFARE

Health and Welfare issues can be extremely vast but generally they deal with the following matters:

- Where the Donor should live and who they should live with;

- This might include the buying and selling of property;
- The managing of various bank or building society accounts, stocks, shares and investments;
- Or just the day to day management of your income and outgoings;
- An Attorney can do exactly what the Donor can do providing they act in their best interests and the LPA doesn't restrict certain activities;
- Whether the Donor should go into a nursing or residential home;
- Whether the Donor should reside with a family member;
- Daily care including dietary specifics;
- **Whether the Donor would like the Attorney to consent or refuse life sustaining treatment on the Donor's behalf; (this is extremely important)**

Ultimately, if there was a disagreement between the health care provider and the close family members then the health provider's authority would trump that of the "next of kin".

If there was a Health & Welfare LPA in place and the Donor lost capacity then the Attorney could make decisions on their behalf and in line with their best interests, subject to any restrictions or wishes contained in the LPA.

Other than the obvious points, a key difference between a Property & Finance LPA and a Health & Welfare LPA is that a Health and Welfare LPA is only able to be used in the event of the Donor losing capacity. With an LPA for finances the Donor may simply choose to allow the Attorney to make financial & property decisions on their behalf and in accordance with their best interests whilst he/she does have capacity.



WHAT IF I HAVE A LIVING WILL?



It is important to note that a registered Lasting Power of Attorney for Health & Welfare would effectively overrule a pre-existing Living Will. So if you have a Living Will then it would be logical and sensible to record the important parts of that Living Will within the body of the Lasting Power of Attorney, that way the Donor's wishes in the Living Will aren't nullified.

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