 Planning Ahead

Managing today can be difficult enough, without having to also think about the future when caring for someone with PSP or CBD. However, life ahead can be made easier by having prepared key legal arrangements early on, particularly with these diagnoses, where communication can be increasingly compromised, and there may be cognitive impairment, including difficulty conceptualising all sides of an issue, impulsive responses, confusion, yes and no either becoming mixed-up or not retaining the meaning of the words, and decision-making affected.

As a carer, you are likely to be advocating on behalf of your loved one, so knowing their wishes from the beginning is important for you and your family. It may also give you a sense of being more in control and ready, having the legal documentation required for times when medical decisions might need to be made with little notice.

Power of Attorney

Power of Attorney is a legal document that allows you to make decisions on behalf of another. Power of Attorney can only be set-up while the person still can weigh up information and make decisions for themself, known as 'mental capacity'.

The most common form of power of attorney is Lasting Power of Attorney (LPA), of which there are two types; Health & Welfare, and Property & Financial Affairs.

Health & Welfare LPA’s cover aspects like medical interventions, daily routines, respite and moving into a care home.

Property & Financial Affairs LPA looks at directives for managing bills, collecting pension or benefits, looking after your accounts and selling property.

Procedures vary the four nations so it is important you get the correct advice.

 Age UK have a comprehensive guides for:

England & Wales <https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/power-of-attorney-information-guide/>

Scotland <https://www.ageuk.org.uk/globalassets/age-scotland/documents/ia---factsheets/legal-and-family/leg-1-power-of-attorney-jul-2022.pdf>

Northern Ireland <https://www.ageuk.org.uk/globalassets/age-ni/documents/information-guides/ageukig21_powers_of_attorney_inf.pdf>

Living Wills, Advanced Directives / Advanced Decisions

These terms are used interchangeably and all mean the same thing, to describe your wishes for when you may not be able to communicate these.

PSPA provides an **Advanced Decision Guide** for those with PSP or CBD <https://www.pspassociation.org.uk/wp-content/uploads/2019/05/IS-Advance-Decision.pdf> with a large amount of detail to support you.

This is designed to be used with the record sheets from Compassion in Dying.



The charity Compassion in Dying are highly expert in planning ahead and have an advance decision pack, which provides a template you can complete at home. Order one free via this link: <https://compassionindying.org.uk/order-living-will-advance-decision-pack/>

PSPA also has specific information on topics such as **Tube Feeding** to help you explore options <https://www.pspassociation.org.uk/wp-content/uploads/2019/05/IS-Tube-Feeding.pdf> and other sensitive issues like **Brain Donation for Research** to give you details on what else you may wish to consider in advance <https://www.pspassociation.org.uk/wp-content/uploads/2019/05/IS-Brain-Donation.pdf>

Knowing whether your loved one would wish to be resuscitated if they had a cardiac arrest. If they do not, then a **Do Not Resuscitate (DNACPR)** order can be put in place. This NHS link explores the topic, what it entails and legal requirements to put this in place: <https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>

Making a Will

A will states what you want to happen to your possessions and money when you have died. You can write a will yourself if you carefully follow rules or make one though a solicitor. Government guidance on making a will, including what ensures a will is legal, can be found here: <https://www.gov.uk/make-will>

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Around since 1988, Will Aid is an annual campaign helping legal professions raise money for charities by supporting people to write their will, without having to pay the usual solicitor fees. Instead, participating firms suggest a donation of £100 for a basic single will and £180 for a basic mirrored will (usually for couples). It also allows you to file with Certainty the National Will Register for free (saving £25 plus VAT). This doesn’t hold a copy of your will, but information on which solicitors keeps your will. For more information and to use the Find a Solicitor search, go to <https://www.willaid.org.uk/>

Other Sources of Advice



The Citizens Advice Bureau can be replied upon for the most up to date information. When you go onto their website, it will ask you which national version you require so the pages will be tailored for Wales, England, Northern Ireland and Scotland. Link to the home page: <https://www.citizensadvice.org.uk/>

Home

You may need to consider whether your loved one’s home environment is going to accommodate the person’s long-term needs, whether it requires adapting or a potential move elsewhere. There are many things that can be done from stairlifts to ramps, door widening, installing wet rooms, changing existing room use and garage conversions. Discuss options, feasibility, grant availability and VAT exemption with an occupational therapist from adult social care (your local authority / council) even if you would be self-funding, advice should be forthcoming.

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