

ADVANCE DECISION GUIDANCE

Information for people living with PSP and CBD

This factsheet is for you if you have Progressive Supranuclear Palsy (PSP) or Corticobasal Degeneration (CBD) and you would like to plan ahead and record your wishes for future care and treatment. Please note that this guidance is only applicable to people living in England and Wales. If you live in Scotland or Northern Ireland please contact PSPA's Helpline and Information service on 0300 0110 122 for more information.

This factsheet is designed to accompany the Advance Decision form and guidance notes provided for free by Compassion in Dying. You should read the Advance Decision guidance notes thoroughly before completing your form.

It can be difficult to make decisions about what you want to happen if you lose capacity (the ability to make or communicate your own decisions). It is a good idea to speak to your GP or any other health professionals involved in your care about your treatment options. You may also wish to call our helpline and information service.

Remember, planning ahead is an entirely voluntary process. You do not have to do it if you do not want to.

**INFORMATION STARTS
HERE**

Why plan ahead?

You may have recently been diagnosed with PSP or CBD, or you may have known you have it for some time. Either way, if you have a degenerative condition it can be difficult to think about your future. However, planning ahead for your care and treatment can be helpful for you, those close to you, and your healthcare team. It can:

- Empower you to make informed decisions about your future treatment, in your own time
- Help to ensure that your wishes will be respected if you cannot make decisions for yourself
- Help to initiate what can be a difficult conversation with those close to you about your wishes for the future
- Make sure those close to you understand your wishes
- Make sure your healthcare team know your wishes and are able to follow them.

Symptoms of PSP and CBD can be unpredictable and may deteriorate rapidly. They can cause you to lose 'capacity' (see the box below). For example, symptoms such as slowness of thought, difficulty recalling information, disorientation and problems with communication, cognition and mood can make it impossible to make decisions about your daily life. Also, behavioural changes such as apathy may lead to withdrawal from any attempts to engage in planning for support or care. So, it's a good idea to write down your wishes whilst you are able to.

If you do lose capacity, unless you have made an Advance Decision (see page 3 or appoint a Lasting Power of Attorney for Health and Welfare (see page 7), your healthcare team will decide what treatment and care you receive. Decisions will always be made in your best interests, but what your doctors consider to be in your best interests may not be what you feel is right for you. To ensure your wishes are known and followed by your healthcare team, it is a good idea to plan ahead and record them.

What is capacity?

Capacity is the ability to make a decision for yourself. It is time and decision specific. This means that whether or not you have capacity depends on when the decision needs to be made and what the decision is. So, you might lack capacity to make a decision on one day but be able to make that decision at a later date. This might be, for example, because you have dementia and your ability to remember information differs from one day to the next.

Also, you might have capacity to make some decisions but not others. For example you might have capacity to decide what you want to eat every day but not to understand what will happen if you refuse life-sustaining treatment.

The law says that people must be assumed to have capacity unless it is proven otherwise. However, if a decision needs to be made about your health or care and a healthcare professional thinks that you might lack capacity, then they will need to assess whether or not you have capacity to make that decision.

What if I am unable to communicate what I want?

If you are struggling to communicate your wishes, the law states that all practicable steps must be taken to help you to make and communicate decisions for yourself. These steps could include asking someone who understands you well to help with communication (such as a family member or carer) or finding a time or place where you are at ease and better able to express yourself. Time should be taken to see if another day or different circumstances would suit you better.

How to plan ahead?

Advance Decisions

An Advance Decision allows you to write down any medical treatments that you do not want to have in the future, in case you later become unable to make or communicate decisions for yourself. It will only be used if you cannot make or communicate a decision for yourself. The legal name is an Advance Decision to Refuse Treatment (ADRT), and it is also sometimes called a Living Will or an Advance Directive.

Advance Decisions are legally binding in England and Wales, as long as they meet certain requirements. This means that if a healthcare professional knows you have made an Advance Decision, they have to follow it. If they ignore an Advance Decision then they could be taken to court.

You **can** use your Advance Decision to:

- Refuse any medical treatment, including life-sustaining treatment such as resuscitation, artificial nutrition and hydration, breathing machines and antibiotics.

You **cannot** use your Advance Decision to:

- Ask for something illegal, such as assistance to end your life
- Refuse to be offered food and drink by mouth or to refuse care that keeps you clean and comfortable. This is because these things are part of basic care, which healthcare professionals have a duty to provide
- Choose someone else to decide about treatment on your behalf. Choosing another person to make decisions about your health and care is done by making a Lasting Power of Attorney for Health and Welfare
- Demand certain treatments. This is because doctors do not have to give you treatment just because you ask for it. Doctors decide whether treatment is medically appropriate for your condition and then you decide whether or not you want that treatment.

What treatments can I refuse in my Advance Decision?

It is important that you speak to your doctor about your Advance Decision. They will explain your treatment options and how refusing a treatment might affect you.

What you want for your future care and treatment is a very personal choice and everybody is different. You do not have to make an Advance Decision if you do not want to.

If you refuse treatment within an Advance Decision, you will still be provided with medications/interventions to help you to be as comfortable as possible with your symptoms. For example:

- Pain caused by falls/injury
- Pain caused by muscle rigidity and difficulties with movement
- Muscle spasms and cramps
- Pain and stiffness in upper neck/back which can lead to headaches, pain in shoulders and a sensation of 'muzzy/foggy head'
- Pain caused by other conditions
- Poor saliva control
- Problems with eyes requiring eye drops.

You may feel that if your condition reaches a certain point, or when your symptoms progress to a certain level, you would only want to receive treatments to keep you comfortable and pain-free and not to prolong your life.

Filling in the form

Anyone over the age of 18 who has capacity can write their own Advance Decision, but it has to include specific wording and meet certain criteria to be legally binding. Compassion in Dying's template form meets this criteria and you can obtain a copy from them or PSPA for free. Before you begin, it is important to read the guidance notes that accompany the Advance Decision.

You can use section 4 of the form to refuse medical treatments. In section 4 you can refuse life-sustaining treatment in any, all or none of the four scenarios which include; (A) dementia, (B) brain injury, (C) diseases of the central nervous system and (D) terminal illness. To include any of these four scenarios in your form you should tick the 'include' box next to it. If you do not want to include the scenario tick 'do not include'.

If you do not want to refuse 'all life-sustaining treatment', or if you would like to refuse treatment in other situations, then you can write your own refusal in section 4(E). To do this you must state the treatments that you want to refuse and the situations in which you want to refuse them (see page 12 of the guidance notes for more information).

Below is a table that you may find helpful when thinking of how to phrase your refusals of treatment. Don't worry if you don't see what you want to write in the table – the statements below offer things to consider, but what you write in your Advance Decision is entirely up to you. It is a good idea to talk to your healthcare team about the decisions you make before you sign your Advance Decision; your doctors can explain your options, discuss your wishes with you and make sure you understand the consequences of any decisions you have made.

STEP 1

If I have lost capacity to make decisions about my medical treatment, I refuse

STEP 2

If you want to refuse all life-prolonging medical treatments, you can then write:

All medical treatments, procedures or interventions aimed at prolonging or artificially sustaining my life (including but not limited to CPR; mechanical ventilation; clinically assisted nutrition and hydration of any kind; antibiotics for life threatening infections

OR, if you want to refuse only certain medical treatments you need to write each treatment individually. Below are examples of specific treatments you may wish to refuse:

- **Cardiopulmonary resuscitation (CPR)**
- **Mechanical ventilation**
- **Artificial nutrition and hydration**
- **Antibiotics for life-threatening infections**
- **Any other medical treatments that require hospital admissions**

STEP 3

If you want your refusal of treatment to take effect only when you have lost capacity and your condition has reached a certain stage, you should then write:

If the symptoms of my PDP/CBD have reached a stage such that

AND then explain the circumstances when you would not want any more treatment. Below are some examples:

I am unable to communicate or engage in any social interaction

I am immobile and can no longer feed myself

OR, if you want to refuse medical treatments in every situation as soon as you lose capacity, you can write...

In every situation

Advance Statement

An Advance Statement allows you to record your wishes, feelings, beliefs and values in case you later become unwell and need care or medical treatment.

It provides a space for you to write down anything that is important to you in relation to your health and wellbeing. For example, you can use it to express your preferences for care or to detail any values or beliefs that inform the decisions you make. It gives those around you (your family, carers, and healthcare team) a clear idea of what you want if you are unable to communicate this yourself.

The law states that anyone who makes a decision on your behalf must act in your best interests, and when deciding what is in your best interests, the decision-maker must, amongst other things:

- Consider your wishes and feelings (this includes anything you have said to other people and things you have written down)
- Consider any values and beliefs that would be likely to influence the decision.

An Advance Statement is evidence of your wishes, feelings, values and beliefs therefore it must be considered when any action is taken on your behalf.

What can I include in my Advance Statement?

An Advance Statement gives you the chance to write down anything that is important to you. This can be about any aspect of your life, health or care, such as:

- Your food preferences
- Your religious or spiritual views
- Information about your daily routine
- Any fears you have around treatment or care
- Information about your personal care, such as whether you prefer a bath or a shower
- If you like to sleep with the light on
- Your preference over where you would like to be cared for, for example at home, in hospital or in a residential home.

The more information you can give to doctors the better they will be able to understand your wishes.

REMEMBER: An Advance Decision and an Advance Statement only come into effect if you cannot make a decision for yourself, or cannot communicate. If you have capacity you will continue to make all your own decisions.

Frequently asked questions

What if I can't sign for myself?

If you cannot sign your Advance Decision you can make a mark where your signature should be or ask someone else to sign it on your behalf. Either way, at least one witness must be present. The Advance Decision is then signed by the witness.

What if I'm finding it hard to think about what I want?

The process of making an Advance Decision can take time. There is a lot of information to take in and it can feel overwhelming. Do not worry if it takes longer than you expected – these are important decisions and there are lots of things to consider. You may find it useful to speak to someone from your healthcare team. Alternatively, someone from PSPA will be very happy to speak with you. You can contact our helpline and information service on 0300 0110 122.

Can someone I trust make decisions for me?

You can give an individual, or several people, power to make decisions about your health and wellbeing if you are unable to make decisions yourself by appointing a Lasting Power of Attorney for Health and Welfare (LPA).

A Lasting Power of Attorney (LPA) allows you to give someone you trust the legal power to make decisions on your behalf in case you later become unable to make decisions for yourself. The person who makes the LPA is known as the 'donor' and the person given the power to make decisions is known as the 'attorney'.

In an LPA for Health and Welfare, your attorney can make decisions about anything to do with your health and personal welfare. This includes decisions about medical treatment, where you are cared for and the type of care you receive, as well as day-to-day things like your diet, how you dress and your daily routine.

You can list any instructions that your attorney must follow, or any preferences that you would like them to take into account when making decisions on your behalf.

You must also choose whether or not you want your attorney to be able to make decisions about life-sustaining treatment. If you choose not to, then all decisions about life-sustaining treatment will be made by your healthcare team, unless you have made an Advance Decision to Refuse Treatment.

The form is legally binding once it is registered with the Office of the Public Guardian. There is a fee to register a LPA, although if you are on certain benefits you may be exempt from paying the fee.

If you choose to make both an Advance Decision and a LPA, whichever is more recent will always take priority.

For more information about LPAs, please contact Compassion in Dying on 0800 999 2434 or email info@compassionindying.org.uk

Useful contacts

PSPA Helpline and
Information Service
Tel: 0300 0110 122
helpline@pspassociation.org.uk
www.pspassociation.org.uk

Compassion in Dying
Telephone: 0800 999 2434
info@compassionindying.org.uk

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**STARTS
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