

# Section 4

## Later in life

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# Later in life



## Introduction

This section covers a range of subjects that may be relevant to people with PSP and people close to them as the condition progresses.

Remember not all of this is relevant to everyone and a lot of the information contained here is intended to give you the facts on certain issues, leaving you to make your own personal choices, at a time that's right.





# Respite care



Respite care offers you a break from your normal environment and can also give your carer a welcome opportunity to recharge their batteries too. There are many types of respite available.



## Brief respite

Brief respite can be useful when your carer needs to go out but does not want to leave you alone. Your local social service department should be able to provide advice on how to access this service.

Friends and family will often be happy to help out for a few hours, and you may find that you enjoy a change of social scene too. Don't be nervous about asking for help from friends rather than struggling on alone.

As the condition progresses, you may sometimes feel that your social life is reduced and getting the opportunity to catch up with old friends in this way can be refreshing as well as practical.

## Longer periods

For extended respite, look for a care home that can provide suitable services for your stay. This may or may not be funded by the local authority depending on the type of care package you are able to access.

Because PSP is quite rare, not every member of staff will have heard of the condition and it is advisable to let them have as much information as possible about how it affects you.



Staff will need to understand the demands of the condition, especially if there are speech, cognitive or falling problems. Try to make an appointment to speak to staff who will be directly involved and provide them with personalised copies of the *All About Me* leaflet at the back of this pack.

If they need further information, give them the contact details for our helpline, information and advisory service.

Another option you might like to consider is to approach a friend or family member to see if they would be able to 'live in' whilst your carer takes a short break.

It is also worth considering nearby hospices for a short stay. You can approach them directly, or by referral from your GP. You may associate the term hospice with end of life, but in fact they can offer a range of specialised services for people with complex conditions, such as PSP, and their families, from a very early stage.

It's a good idea to plan respite breaks into your calendar on a regular basis - this gives both of you something to look forward to and becomes part of the care routine.

You can find your nearest hospice by contacting Hospice Information:

[www.hospiceinformation.info/findahospice.asp](http://www.hospiceinformation.info/findahospice.asp) and then click on relevant country tab. Or call 0870 903 3903.

## Direct Payments

If you receive help from social services you will be able to apply for Direct Payments. These let you choose and buy the services you need yourself instead of getting them from the local council. They are available in England, Scotland and Northern Ireland. If you live in Wales or Scotland, contact your council directly.

You can only get Direct Payments if you have been assessed by social services as needing care and support services.

For further information search for *Direct Payments* at [www.gov.uk](http://www.gov.uk) or [www.nidirect.gov.uk](http://www.nidirect.gov.uk) (Northern Ireland).



# Continuing healthcare (CHC)



For most people with PSP, assistance and care will be provided by the local social care team. Social care provision is means tested and therefore you may find that you need to make a contribution towards the costs of providing this.



However, should your needs become more complex and health based, you may be entitled to receive CHC funding.

## What is it?



CHC is the name given to a package of care that is arranged and solely funded by the NHS for individuals who are not in hospital, but who have complex, ongoing healthcare needs. It is only available for those that meet specific eligibility criteria. Not everyone with a disability or a long-term condition will be eligible, as the assessment is based on the existence of complex needs rather than a specific diagnosis.

CHC can be provided in any setting, including your own home, a care home or a hospice. If you live in a care home, for example, CHC will cover care home fees, including accommodation, personal costs and healthcare. If you stay in your own home it covers your personal care and healthcare costs and may also cover support for your carer.

The assessment required to apply for CHC is very detailed, and will require written evidence from key health and social care professionals involved in your care, as well as information from you and your family.

## Tips on applying for NHS continuing healthcare

- The health and social care professionals involved in your care should be able to co-ordinate the application process for you. Speak to your GP, social worker, district nurse or community matron to get the ball rolling
- Compile a history of the type of care that you need, and how frequently you need it. This may come in handy if you are refused CHC in the first instance, because you will be able to pinpoint any subsequent changes in your condition that may suggest a further application later
- Keep a brief note of all communication with health and social care providers about your needs. Include the date, time and name of the person you spoke to
- Keep a copy of all correspondence
- If possible try to attend all assessments and hearings in person, or get a family member or friend to go on your behalf.

If you have any queries regarding CHC please speak to our helpline, information and advisory service.



# End of life decisions



## Planning ahead

For most of us, talking about end of life choices is not easy and can sometimes feel overwhelming. Some people prefer not to think about it all, as it may bring to mind issues about their illness and their future, which they are not yet ready to think about. Others prepare as soon as they can giving everyone a chance to talk and share their feelings. It can give you peace of mind to be prepared emotionally and practically. Planning your future with the people in your life may help you, your family and friends to feel more confident and reassured with what lies ahead. This process is known as advance care planning.



## What is advance care planning?

It can be difficult to open a discussion about advance care planning because it involves many end of life choices. Not everyone will want to have such a conversation, and if you choose not to then that is fine.

However, taking part in advance care planning will ensure that your wishes and preferences will be known to others, and will enable those responsible for your care to make decisions on your behalf if you become unable to make decisions for yourself. When you have PSP it is often best to have these discussions as early as possible, before any issues with speech or cognition make it difficult to communicate your preferences.

Advance care planning does not need to be in writing, with the exception being any Advance Decisions to Refuse Treatment. However, it may be handy for you to

have a written record of your preferences to be passed on to everyone who needs to know about your wishes. Remember to keep a copy safe, and to review it regularly so that you can make any changes or update it as you wish.

Advance care planning is a discussion between you and those who care for you - your family and friends, doctors, nurses, social workers or care home managers. It is a chance for you to explore your options and express your views regarding your preferences and wishes about your future care. The process of advance care planning ensures that your wishes and preferences will be taken into account if you are unable to make decisions at some point in the future.

### **Factors affecting decision making**

If you are no longer able to make decisions for yourself - whether for some or all of the time - you are said to have lost mental capacity. The Mental Capacity Act 2007 came into force to ensure that every effort is made to include the individual in decision-making, and take into account their wishes, feelings, values and beliefs. The Mental Capacity Act applies to people in England and Wales. For Northern Ireland please refer to the Mental Health (Northern Ireland) Order 1986, and for Scotland please refer to Adults with Incapacity (Scotland) Act 2000.

A person is judged to lack mental capacity if they cannot;

- Understand the information given to them  
*or*
- Retain that information long enough to make a decision  
*or*
- Weigh up the information available to make a decision  
*or*
- Communicate that decision by any means.

This is particularly relevant for people living with PSP, where both cognitive and speech problems can eventually make it impossible to make or communicate a decision. Although simply stated, the interpretation can be complex both for you and any health professionals involved and you should take further advice if in doubt.

### **What can be included in an advance care plan?**

As part of the plan, you may wish to explore your thoughts, feelings and preferences regarding some of the following issues;

- Preferred place of care
- Advance Decision to Refuse Treatment (ADRT)
- Lasting Power of Attorney (LPA)
- Wills
- Funeral arrangements
- Tissue donation

You can include anything in your advance care plan that is important to you. Nothing is too trivial, it is your plan to tailor as you wish, so you can add in anything that reflects your beliefs and values, and how you like things to be done.

It is important to note that advance care planning is an entirely voluntary process. You do not have to do it, and you should never feel under pressure to do so. However, if you do decide to take part, the discussions that you have around the topics mentioned above may help your family and friends to feel more confident about making decisions on your behalf in the future, whilst giving you peace of mind that your wishes will always be considered.

Your views may change over time so it is useful to have regular discussions and update the relevant documents if necessary. Please note that any decisions you make can be updated and changed whenever you want and your advance care plan will only come into action if you are no longer able to make your own decisions.

### Preferred place of care

One of the key decisions of advance care planning is where you would prefer to be at the end of your life. Often the choice of where you die depends on what you want, what help you have from family and friends and what services are available in the area you live.

There are four main places where people with PSP may wish to be:

- **At home** – Many people will want to stay at home in familiar surroundings with their close family around them. If this is your choice, family carers will require extra support during this time from the GP and health professionals. If you are linked into the community palliative care team they can also offer advice and support
- **In hospital** – If you have been in and out of hospital over the last few months, you may want to go back to your usual hospital ward when you need full-time nursing care. However, this may be difficult to organise if the ward is very busy. Many people die in hospital, but a busy ward may not be the most peaceful place. Often you will need to fit into the ward routine, rather than being looked after in the way that you would like
- **In a nursing home/care home** – For many people, a move to a nursing or care home is often triggered by

some kind of crisis – perhaps when there is a breakdown in the support you receive at home. This can happen for a variety of reasons, but there is help available that may enable you to stay at home if you wish, so you should never feel pressured into thinking that you have to move into a nursing/care home. Think about the reasons why you may be considering a move to a nursing home in the future, and if it feels like something you may really want then talk things through with your family and friends. You may also find it helpful to talk things through with your doctor or social worker. Remember, the final decision is yours, although if there are issues relating to your safety then this could be subject to change

- **In a hospice** - Hospices specialise in the care of people who are dying. Hospices are very different from hospitals. They are quieter and tailor their care to suit each person, and for this reason you may wish to explore the possibility of spending time there during the end stages of your illness. It is important to note that hospice services are not necessarily focused simply on the end stages of an illness. The care provided by a hospice (often referred to as palliative care) is a holistic or whole person approach that not only takes care of the physical needs of the individual but also looks after emotional, spiritual and social needs. They aim to support people diagnosed with a life limiting illness, and improve quality of life through expert management and treatment of symptoms, as well as providing support to family and friends. Obtaining an early referral to the hospice team (even at diagnosis) is particularly beneficial to people living with PSP because the earlier this relationship begins, the more support you can receive.



# Legal issues



## Advance Decision to Refuse Treatment (ADRT)



You may want to discuss specific life sustaining treatments that you do not wish to have. An Advance Decision to Refuse Treatment (ADRT) is a choice you can make in advance to refuse specific treatments in certain circumstances in the future. In England and Wales these were formally known as Living Wills. In Scotland it is known as Advance Directives. There is currently no legislation in Northern Ireland covering an ADRT.



Before making an ADRT, you should discuss your wishes with your doctor or another health professional involved in your care to ensure you are clear regarding which treatments you wish to decline. Any decisions you make need to be communicated to your family and your care team. An ADRT can be reviewed and amended at any time should your wishes change.

An ADRT is legally binding and only becomes valid once you lose the ability to make or communicate those decisions.

There is no set format for an ADRT but it must be in writing. You can ask a health or social care professional, such as your GP or hospital team who are already involved in your care for an ADRT form.

If you have decided to refuse specific treatments in the future you must be sure that the people involved in your care know this. Ask your nurse or doctor to help you do this.

For more information and to view template ADRT forms (England and Wales) visit [www.compassionindying.org.uk](http://www.compassionindying.org.uk)  
For more information about making Advance Directives (Scotland) visit [www.compassionindying.org.uk/scotland](http://www.compassionindying.org.uk/scotland)

### **Asking someone to speak for you**

It is possible to nominate one person or more (perhaps close friends or family members) who can be asked to provide information about your preferences, wishes, feelings and values. In this scenario, if you were unable to make a decision for yourself at some point in the future, then professionals in charge of your care would be able to consult with your named person. Whilst the named person cannot actually make a decision on your behalf, they can provide the professionals with invaluable information that can help them to make decisions for you and act in your best interests. If you decide that you would like to nominate someone to speak for you then it is a good idea to have their name recorded in your advance care planning documentation so that everybody is aware.

Naming someone to speak for you in this way is not the same as legally appointing someone to make decisions for you as your Power of Attorney. Please see below.

### **Power of Attorney**

Appointing a Power of Attorney allows you to choose someone you trust to take actions and make decisions on your behalf. This varies across England, Wales, Scotland and Northern Ireland.

## England and Wales – Lasting Power of Attorney

In England and Wales a Lasting Power of Attorney (LPA) allows you to choose someone you trust to take actions and make decisions on your behalf if you are unable to communicate your wishes. There are two types of LPA:

- Property and financial affairs LPA – for decisions including paying bills, collecting benefits and issues relating to property. It is important to note that if you decide to allow it, your LPA for Property and Finance can act on your behalf even when you have capacity
- Health and welfare LPA – for decisions including where to live, day-to-day care and medical treatment. The LPA can **only** be used if you are unable to make a particular health or welfare decision yourself.

You may appoint different attorneys for each LPA if you wish, and you can limit decisions that they may or may not make on your behalf. The attorney has a legal duty to act in your best interests at all times, considering your preferences and involving you as much as possible in the decision making process.

In England and Wales you can register a Lasting Power of Attorney with the Office of the Public Guardian. Please note that there is a charge for this.

For more information search for *Lasting Power of Attorney* at [www.gov.uk](http://www.gov.uk)

## Northern Ireland - Enduring Power of Attorney

In Northern Ireland an Enduring Power of Attorney (EPA) is registered through the Office of Care and Protection. An EPA only enables decisions on your behalf for property and finance, not healthcare needs.

For further information search for *Enduring Power of Attorney* at [www.courstni.gov.uk](http://www.courstni.gov.uk)

## Scotland – Continuing Power of Attorney and Welfare Power of Attorney

In Scotland a Continuing Power of Attorney (CPA) can be registered for financial affairs, and a Welfare Power of Attorney (WPA) for healthcare needs. You can also make a Power of Attorney which deals with both financial and healthcare needs. These have to be registered through the Office of the Public Guardian (Scotland)

For further information search for *Power of Attorney* at [www.publicguardian-scotland.gov.uk](http://www.publicguardian-scotland.gov.uk)

## Useful contacts

Age UK LifeBook - a free booklet to document important and useful information, from who insures your car to where you put your TV Licence. Visit [www.ageuk.org](http://www.ageuk.org) and search for LifeBook, or telephone 0800 169 6565.

Advance Decision to Refuse Treatment - website for professionals which contains a section for patients.  
Website: [www.adrt.nhs.uk](http://www.adrt.nhs.uk)

Dying Matters - leaflets and information on end of life care and planning ahead.  
Website: [www.dyingmatters.org](http://www.dyingmatters.org)



# Tissue donation



The topic of tissue donation is a sensitive and a very personal one. Tissue donation helps towards a better understanding of PSP, and the chance to further medical research provides strong motivation for people to donate. Anyone can become a potential donor – including people without PSP. This enables researchers to compare what happens in a brain affected by PSP with one not affected by PSP. Therefore anyone can make a valuable contribution to research into the treatment and eventual cure of PSP by donating their brain after death. If after reading through this information, you decide you would like to donate your brain tissue for use in research please ensure that your wishes are known to your family and everyone who is involved in your care. It is important to plan ahead, to ensure your wishes are met.

The PSP Association fund the Sara Koe PSP Research Centre (SKRC) which is based at the Institute of Neurology in London. The research team have many years of experience and are available to discuss the importance of brain donation with people living with PSP/CBD and their relatives, so that consent can be given in an informed way.

The first step towards donating is to gather as much information as possible so any decision you make is based on expert advice and knowledge. You can do this by contacting the SKRC who will answer any questions you may have and provide you with the forms that you will need to complete. It is important to talk to family members so that they understand your wishes. If you make

a decision to donate your brain, you are free to change your mind, should you wish to do so, at any time.

When you have registered with the SKRC there is nothing else you need do other than to keep all the paperwork in a safe place with the telephone number of the centre. Brain donation needs to take place within 48 hours after death. It is therefore important that your family contact the centre as soon as possible. The centre will co-ordinate with the funeral director, GP and the hospital as necessary. They will then liaise with the funeral director to make sure the body is safely returned.

If you would like more information on Brain Donation please contact Lynne Haddon, Administrator for The SKRC.  
Telephone: 020 7837 8370  
Email: [l.haddon@ucl.ac.uk](mailto:l.haddon@ucl.ac.uk)

# Making a will



A will is a legally binding document that sets out what will happen to your money and possessions when you die. If you die without making a will (known as dying intestate) your money will be used to pay off your debts and then shared amongst your family.

You can make your own will - some stationers provide legal packs - or you can instruct a solicitor to make one for you. It is usually best to get advice from a solicitor except in very simple circumstances.





# Leaving a legacy



## How a legacy to the PSP Association will make a difference



Whatever the value of a legacy it will help the PSP Association to support people living with this devastating disease and to provide a secure financial base to further the Association's work to find a disease-modifying treatment and an eventual cure. We need additional funding to:



- Recruit more PSP specialist care advisers
- Expand the network of local groups and make them accessible to many more families
- Increase our efforts to raise awareness of PSP among health and social care professionals
- Invest in research to find the causes, treatments and a cure – and strengthen our fight for a world free of PSP and CBD.

If you would like to discuss any aspect of leaving a legacy to the PSP Association or would like further information please telephone: 01327 356130.



# Funerals



Many people die without making any plans for their funeral. For family or close friends who are left behind, arranging a funeral can be stressful if they do not know exactly what type of funeral service you want or how you would like it carried out.



If you explore what you want with your family or friends, it will provide them with the confidence to carry out your wishes.



Many people worry about whether a funeral will be affordable for their loved ones. A pre-paid funeral plan may be possible or the person arranging the funeral maybe entitled to a benefit payment to help with the cost.

For further information search for *Funeral Payments* at [www.gov.uk](http://www.gov.uk)

# When caring ends



Looking after someone with a progressive illness can become a large part of the carer's life and the role of the carer will change as that journey goes on.

Losing someone close to you is a significant change in anyone's life and if they have been caring for that person as well, the loss can seem even greater. People cope with bereavement in many different ways. Just as dealing with PSP is uniquely personal, so is the way that people deal with the end of life.

Remember that everyone's reaction to the loss of someone is different. There is no right or wrong way to deal with grief. There is no prescriptive 'time' that grieving lasts, and sometimes grieving does not happen immediately after a death.

It's always a good idea to talk to your GP as soon as you can. If you feel it would help, they are able to refer you to a range of services that can help support you as you adjust to life after caring. You may find it helpful to talk to a counsellor or bereavement support group.



# How the PSP Association can help



## The PSP Association Helpline, Information and Advisory Service



We offer advice, information, practical and emotional support to people living with PSP. Sometimes you may feel like you could do with a listening ear. We know how reassuring that can be and encourage you to get in touch with our helpline, information and advisory service.



Our telephone and email service is completely confidential and we aim to respond to all enquiries within 24 hours (during normal office hours). Our opening hours are Monday to Friday from 9am until 5pm.

Telephone: 0300 0110 122

Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

If you call us and are unable to get through, please leave a message with your name and telephone number and we will return your call as soon as we can.

We often experience busy periods to the service and if we do not answer straight away then we may be taking another call. Please be reassured that if you leave a message we will return your call as soon as someone is available.

*Please note we are unable to return calls to telephone numbers with an anonymous call-barring system.*

Telephone calls are charged at the cost of a local rate call (depending on your service provider). If you are

calling from either a mobile or a landline that has inclusive minutes, your call will be free (but the call will use your allocated minutes).

### **Local Groups**

Our network of local groups is growing. These are opportunities for people living with PSP/CBD, carers, family and friends, health and social care professionals, to share information, encouragement and refreshments.

Many of the groups invite visiting speakers such as benefits advisers and health and social care professionals, to share expertise on managing PSP on a daily basis.

### **Specialist Care Advisers**

Our team of Specialist Care Advisers (SCAs) work to ensure that people affected by PSP have access to good local support. They focus particularly on more complex cases and work to ensure there is a local keyworker to coordinate care wherever possible (or acting as such where one is not available).

They are on hand to help local health and social care providers gain a greater understanding of the care needs of people with PSP they are supporting, to ensure that services meet agreed standards of care and are accessible. SCAs also focus on raising the profile of PSP – informing, influencing and educating by the delivery of regional training and educational events.

### **PSP Website**

Our website offers accurate, timely and relevant information on all aspects of PSP, including the latest news on research and events [www.pspassociation.org.uk](http://www.pspassociation.org.uk)

## **PSP Forum**

We have our own forum, which can be accessed via <http://psp.healthunlocked.com>

The forum gives individuals the opportunity to connect with others affected by PSP and those working with the condition. It's also an opportunity to find out what other people living with PSP are doing and thinking.

## **How to contact us:**

Telephone: 0300 0110 122

Email: [helpline@pspassociation.org.uk](mailto:helpline@pspassociation.org.uk)

The PSP Association

PSP House

167 Watling Street West, Towcester

Northants NN12 6BX

*"It is so nice to talk to someone who is listening to me."*

**Beryl**