

Section 3

Caring for someone with PSP

This section includes:

- The stages of caring
- Staying healthy
- Practical help – Carer’s Assessment
- Getting help
- Balancing work and caring
- How the PSP Association can help



Caring for someone with PSP



Introduction

This section has been specially compiled to offer support and advice for anyone caring for someone living with PSP.

As you know, the condition affects people differently and every case is unique. Similarly, every carer approaches this often unexpected role in their own way. You might not see yourself as a carer – you might think of yourself as ‘just’ a partner, relative, friend or good neighbour - but we use the term to describe people who are helping others live with PSP.

However there are many areas of common ground that affect the majority of carers. Sometimes, just knowing that your feelings are normal is all the reassurance you need.





The stages of caring



Caring for someone with PSP

Caring for someone with PSP is likely to be a new role for you, one you never expected to take on. If you are just finding your feet, give yourself plenty of time to adjust. This is probably new for both of you, so work together to enable quality of life as the condition progresses.



Like many things in life, there are stages to caring. Just as living with PSP is like travelling along a road, caring is a journey in its own right. There will be times when you feel confident in your new role and moments when you worry that you are not doing things right. The main thing to know is that all these feelings are perfectly normal and have been experienced by many others before you. Some people think that there are clear stages to the caring process, but others don't feel this at all.



It might be useful to know what some of these stages are like – but remember everyone is different and some, all or none of these reactions and feelings may apply to you.

Shock

When you first step out on the road to caring, you might feel some initial shock and worry about the uncertainty ahead. You might feel that life has changed and things will never be the same again. But often, in the early days help and support – especially from friends and people close to you – is forthcoming. This can help prevent you feeling quite so overwhelmed by the new situation you find yourself in.

Sometimes you might feel scared, angry, sad, lost or anxious. You will probably find that these feelings fade as you get used to the new situation. At the very beginning of the caring process, some people make big decisions, like giving up their job or planning to move house. Often, it is wise to give yourself time to adjust before you do any of these things.

Loss

Many carers do tell us they have feelings of loss. When someone is diagnosed with PSP it is likely that it will gradually affect their future plans. Carers can experience feelings of loss in different areas of their lives, such as loss of their long-intended plans, loss of freedom, and sometimes feelings that they have 'lost' certain aspects of their relationship with the person affected by PSP, due to their role as a carer.

All these feelings are quite normal and you will probably find that you gradually learn to adapt and adjust to the new situation and are able to seek positive outcomes and make new, if different, plans.

Reality

This is when you start to adjust to your new-found role and gradually work towards some kind of routine that works for both you and the person with PSP. Again, there can be moments when you might feel guilty or resentful.

Some carers find that they let things go that they often used to enjoy, such as hobbies and a social life. Although it is tempting to do this, and easy to understand why it can happen, it is best not to make any hasty decisions. This is

the time when carers can start to feel tired and feel that caring is dominating their life. It's really important to look after your own health and eat a good diet.

For further information see page 6 of this section.

Sometimes, it's easy to neglect your own needs because you feel you have to put all your energies into caring. Try not to take on too much and if you feel under strain remember to talk to your GP who can monitor your own needs.

Acceptance

There is no clear timeline for when you reach the point of acceptance of the situation. If you have been a carer for a while now, you have experience of caring and some idea of what to expect on a day-to-day basis. Because PSP is a progressive condition, you have probably learned to deal with, and accept changes as they occur. It's good to be able to recognise if things are starting to feel harder to deal with, or if a new and extra level of care is now required.

But it's important to remember to try and get all the help and support you can. If you have not already, seek a carer's assessment.

For further information see page 8 of this section.

When the going gets tough...

It's only natural that now and again, you might feel as if things aren't going well. You might feel overwhelmed by the responsibilities of caring and guilt at these feelings. If this happens try to keep in mind that:

- Everyone has off days so don't be too hard on yourself
- A change of scene can work wonders, even if it only means getting out of the house for a quick walk round the block
- Try and get enough sleep at night
- If possible, do some exercise – a walk, swim or even a class can help lift your mood
- Don't overdo your to-do list. Too much pressure can make you feel overwhelmed
- Talk to people who help you to feel positive – on the phone, online or face-to-face
- Have a rough plan of the day's expectations, but be flexible – accept that events can change the course of every day
- Can family and friends help out? Have a list of chores ready to delegate. Often, friends and family are only too willing to help out in any way they can.



Staying healthy



As a carer you instinctively know that staying well is in your best interests – as well as for the person with PSP. Caring can be a very rewarding role but it can also be tiring. Making sure you eat well and looking after your health needs is as important as looking after the person you are caring for.



Tell your GP that you are a carer. The Government requires surgeries to have a register of carers and you should get priority when arranging appointments.



Consider asking your GP to refer you for advice on correct moving and handling techniques. Your back may well be a critical part of your caring toolbox and it needs protecting!

It is tempting to put your own health needs low on what seems like a very long list, but if you are in good shape – physically and emotionally – you will be better able to fulfil your role as a carer.

- Try and eat healthily, ensuring you have a good mix of protein, carbohydrates, fruits and vegetables. And remember each day is different. Sometimes you will be able to cook a meal from scratch, other times you will be relying on convenience foods. Be flexible
- Enjoy your food. Sometimes you might find mealtimes quite challenging, especially if the person you are caring for has swallowing difficulties. It might be worth spending a little time planning new or different menu choices

- Try and get some exercise every day – even if it is just a walk to the post box or a stroll round the supermarket
- Treat yourself every now and again. Carers often feel guilty about thinking of themselves but it is essential for you to think of yourself in order to be able to manage your role as carer.



Practical help - Carer's Assessment



Regional Variations

We have used the term council or trust when referring to the bodies you can seek help and support from. Depending on where you live this will mean:

England and Wales – your local council, local authority or social services

Scotland – your local council, local authority or social work department

Northern Ireland – your Health and Social Services Trust

Carers are often tempted to think that they do not need an assessment when so much is already going on in the life of the person with PSP. But the law says that anyone who is providing – or intending to provide – a substantial amount of care on a regular basis can have a Carer's Assessment.

What is it?

The aim of a Carer's Assessment is to find out more about your needs. It has nothing to do with the person you are caring for – it is about your needs, not theirs.

It is not just about hands-on caring either. If the person with PSP is affected by behavioural changes, for instance, you might have to invest a considerable amount of time

ensuring that they are safe. When you prepare for your assessment, consider the impact that caring has on you – such as your own health, relationships and work. And don't forget to mention the things that you can no longer do due to your caring role.

How do I get an assessment?

Everyone in a caring role is entitled to a Carer's Assessment. This will be carried out by the local authority social services department in the area where the person you are caring for lives. If you don't live in the same area as them, this means you will have to apply to their local council or trust for the assessment.

The aim of the assessment should be outcome-based:

- To highlight any more support you might need in your caring role
- To enable you to maintain your own health and wellbeing so that you can balance caring with other work and family commitments.

You can apply for an assessment whether or not you live with the person you are caring for. You can also apply if you are caring full time, or if you are working as well as caring.

The assessment will look at any help you might need in order to carry out your role as carer, and how the caring role affects you. It will also consider how much caring you can manage, whilst still having time for your other interests and activities away from caring.

Top Tip

Carers UK publish a good *Carers Assessment Guide*, available by visiting www.carersuk.org to download a copy, or call the CarersLine on 0808 808 7777 to request a copy by post

Be sure to request a further Carer's Assessment when circumstances change

NHS Choices provide an online essential guide to social care. Visit www.nhs.uk/carers or call 0808 802 0202 for more information.

Getting help



Sometimes, when you are in a caring role, it is difficult to admit that you can not do everything. As PSP progresses, you will probably need to find other people to help with caring. Finding the right kind of help is important for your peace of mind as the carer, as well as the person you are caring for.

There is a range of options available – some will depend on your financial situation.

These include:

- Asking friends or family to help out
- Employing someone to help
- Arranging residential respite care so that you can have a break.

Use the support around you - establish a support network

Caring for someone can be physically and emotionally demanding. Sometimes you might feel like you are the only person having to deal with everything caring requires.

Think about establishing a strong network of people around you - your family, friends and any others who can help if times get tough.

Sometimes, you might feel that you ought to be able to cope with everything life throws at you. There might be times when you feel that your caring role is quite demanding and that seeking help might be a sign that you can not cope. But don't be afraid to admit that you would



appreciate some help. It can be hard for us to accept it, but as a carer, it can be vital. Sometimes, family and friends are unsure of what kind of help they can give.

They may be a bit vague, and say things like 'let me know if I can do anything.' In that situation it is good to have some clear role they can help out with, such as asking if they can collect some shopping or pop in one afternoon a week to sit with the person with PSP so that you can go out.

Sometimes, people don't offer their help, thinking you might be offended. It's good to reassure them early on in your role as a carer that support will often be very welcome!

Balancing work and caring



If you are combining working and caring, you have statutory rights for flexible working under the Work and Families Act 2007. Ensure you let your employer know about your caring responsibilities.

Carers UK have some very useful leaflets to download on www.carersuk.org

If you have a job as well as caring for someone with PSP, there is no doubt it can be difficult at times. You may feel that you are juggling all the demands of work and caring and sometimes wonder how you can possibly keep all the balls in the air at once.

You may be tempted to give up work straight away, but it is important to explore all the options first. Many people really enjoy their working life – the challenges, friendships and financial benefits it brings.

Over half of all carers in the UK do some kind of paid work as well. Your needs will vary from someone who is in a full-time caring role. Depending on your personal situation, you may decide to tell your employer about your caring responsibilities. If you are not sure what to do, talk to colleagues and your human resources department about ways your workplace could support you.

Other organisations that can help

Striking the right balance between your role as a carer and looking after your own health can be really challenging. As well as help and support from friends and people close to you, the PSP Association is also here when you need us.



In addition, advice, support and information on all aspects of caring can also be obtained from the following organisations:

Age UK

Provides advice and information for people in later life.

Publications, online support and telephone advice

Telephone: 0800 169 6565

Website: www.ageuk.org.uk

Carers UK

Offers practical information and advice, practical and emotional support.

Telephone: CarersLine 0808 808 7777

Website: www.carersuk.org

Northern Ireland

Telephone: 028 9043 9843

Website: www.carersuk.org/northernireland

Scotland

Telephone: 0808 808 7777

Website: www.carersuk.org/scotland

Wales

Telephone: 0808 808 7777

Website: www.carersuk.org/wales

As PSP progresses, you may also find some other information useful in **Section 4 – Later in Life**.



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

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

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

The PSP Association

PSP House

167 Watling Street West, Towcester

Northants NN12 6BX

"I can't thank you enough for your time –really valuable information here. Although I have support from lots of health care staff without you I feel I would be on my own, you make all the difference".

Deborah