



Looking after a person with PSP or CBD can be demanding. If you have just started out on this journey, you now have the opportunity to lay foundations that will make it easier for both of you in the long run. If you have already been caring for some time, then you need to recognise the importance of caring for yourself in order to fulfill this commitment. In effect, you are a 'carer' twice over - for the person with PSP and for yourself!

Let's look at how some of this can be achieved.

## PRACTICAL HELP

### Carers Assessment

Everyone in a caring role is entitled to a Carers Assessment from the Local Authority Social Services. The point of having such an assessment is to discuss with Social Services the help you need with caring, plus help to maintain your own health so that you can balance caring with your life, work and family commitments. Even if you suspect that you may have to pay for whatever assistance is identified, it is well worth having a Carers Assessment to ensure that you are 'in the system' and should provide sources of information and practical support.

Carers UK publish a good Carers Assessment Guide, available at:

<http://www.carersuk.org/Information/Helpwithcaring/Carersassessmentguide>.

If you don't have internet access, find someone who has or ask your local library to download the information for you. Alternatively, call the CarersLine on:

0808 808 7777 Wed/Thurs only or 020 7922 8000 at other times.

As your circumstances change, you should apply for another assessment.

### Your GP

Remember to tell your GP that you are a carer. It is a Government requirement for surgeries to have a register of carers and they should give you priority when needing appointments.

You should also consider asking your GP to arrange for a physiotherapist to train you to lift without injuring yourself. Your back may well be a critical part of your caring toolbox and it needs protecting!

The Government has also launched "Carers Direct" within NHS Choices at <http://www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx> with helpful information on assessments, wellbeing, financial and legal aspects and much more. For those not on the 'net, there is a Helpline number: 0808 802 0202 or email [CarersDirect@nhschoices.nhs.uk](mailto:CarersDirect@nhschoices.nhs.uk) for free, confidential advice.

## FINANCIAL HELP

You may be entitled to Carers Allowance and Carers Premium – see our leaflet on Work, Benefits and Finance for full details (this can be downloaded from our website).

If you are working and also caring, you have statutory rights for flexible working under the Work and Families Act 2007 - ensure you advise your workplace of your caring responsibilities.

Carers UK have some very useful leaflets to download on <http://www.carersuk.org/Information/Workandcaring>

### Road Tax Exemption

If the person you are caring for is in receipt of the higher rate mobility element of Disability Living Allowance, they should be exempt from paying road tax. If they don't drive but you do, you can be nominated to get the exemption in their place. Contact the Disability Living Allowance Unit and ask for exemption certificate DLA 404 – Tel. 0845 712 3456.

## RESPIRE CARE

Being a carer can be physically and emotionally exhausting, and respite may come to be a vital component of your ability to be a carer. Respite comes in many shapes and sizes and you should choose what suits you and allows you some space for yourself.

Some local authorities may give you Direct Payments or even Vouchers which can be used very flexibly to suit your situation – see the Department of Health website <http://www.dh.gov.uk/> for details.

### Brief Respite

For brief respite of a few hours or even a day - consider Day Care Centres in your area. Details are available through the Social services and/or your GP.

There are also 'sitter' services that many carers find useful. Your local social services should be able to provide advice, or contact Crossroads at:

[www.crossroads.org.uk](http://www.crossroads.org.uk) and click on "Local Schemes", or call 0845 4500350 to find your local branch.

Friends and family will often be pleased to help out for a few hours and remember that the person with PSP may well enjoy a change of social scene!

## Longer Periods

For longer respite, you need to look for a suitable care home that can provide suitable services for short stays - this may or may not be funded by the Social Services subject to the type of care package you are able to access.

The care home staff will need to understand the demands of the disease, especially if there is speech, behavioral or falling problems. We suggest that you try to make an appointment to speak to the staff who will be directly involved, and provide them with copies of the relevant leaflets within the Carers Information Pack, including a completed copy of the 'Into Hospital' leaflet. You should also ensure they are aware of the telephone number of your PSP Nurse Specialist, and that it is a 24/7 service. If you are in any doubt about the home's understanding of how to care for people with PSP or CBD, ask your PSP Nurse Specialist to make contact with them before admission.

Another option is to get a member of your family to 'live in' while you take a break. This has the added advantage of educating the family about the complexities of being the 'main carer' in a family!

It is also worth considering hospices near you for a short stay, as some hospices are moving towards caring for patients with neurological conditions. You can approach them direct, or obtain a referral from your GP. As yet, there is no national list of hospices offering services for people with neurological conditions, but you can find where your nearest hospices are by contacting Hospice Information:

<http://www.hospiceinformation.info/findahospice.asp> and then click on the "UK and Ireland" or the "International" tabs). Alternatively call 0870 903 3903.

Don't be put off by the tag 'hospice' - it is not a last port of call but rather a specialised service for those with complex conditions.

It is a good idea to plan respite breaks into your calendar on a regular basis - this gives you something to look forward to and becomes part of the care routine. The earlier you set this up, the easier it is for both you and the person with PSP or CBD.

## USE THE SUPPORT AROUND YOU

"It's good to talk"!!

### Establish a Support Network

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

Many local authorities provide Carer support groups and your GP should be able to give you details. Apart from the opportunity to meet others facing similar challenges, they will know where the best practical help is available in your area. For the UK, it is also worth contacting Carers UK [www.carersuk.org](http://www.carersuk.org) (click on "Information", then "Help in Your Area").

It is also very useful to subscribe to Carers UK and receive their regular magazine to keep you up to date with the many changes and initiatives within the Caring community.

Membership Hotline – 020 7566 7602

Alternatively, call the CarersLine on 0808 808 7777 Wed/Thurs only or 020 7922 8000 at other times.

Don't dismiss the value of counselling - it can be very useful to have somewhere to go to deal with difficult feelings and tensions that may arise when caring for someone close to you. Your GP may be able to arrange this.

### The PSP Association

Remember that our Specialist Nurses are available to talk - for advice or just to bounce ideas off!

If you have elected to be on our local telephone contact lists to network with other PSP carers and former carers in your area, you should receive an updated Telephone Contact list with every Support Group invitation. If you wish to join the list, then contact PSP Care and Support on 01327 322415.

There is also the PSP Forum on our own website [www.pspeur.org](http://www.pspeur.org) where you can pick up lots of ideas from other carers and get (and give) peer support.

You are also most welcome at the many care and support meetings throughout the country, to which you are invited on a regular basis. Making time to get to these meetings is a useful way of establishing 'time off' and setting up your carer network to enable you to attend. It also gives you a chance to meet your Specialist Nurse and local Development Officer, keep up to date with research progress and meet other PSP carers.

Above all - remember you are not alone - there are many ways you can receive help and support - you only have to ask!

If this is difficult for you - consider this:

Caring is a gift we can all share