

PSP/

LIVING WITH CORTICOBASAL DEGENERATION

CBD: what to expect from your care

PSP/

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PSPA is the only charity in the UK supporting people affected by Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD), which is sometimes known as Corticobasal Syndrome (CBS).

For more information about us, visit www.pspassociation.org.uk

You can use this guide to open discussions about your care with health and social care professionals and providers. This may help you access suitable support at the right time. The pages that follow highlight recommendations for good care, but you are unlikely to need all of these at once.

Use the questions provided to help you discuss your needs as they arise and plan ahead for future care.

Thank you to CBD Solutions for their financial support with the development of this guide.

FOLLOWING

DIAGNOSIS

HAVE YOU BEEN:

- Offered a follow-up appointment with a neurologist?
- Offered written information including access to supporting organisations?
- Offered a care plan and been involved in its development?

ORGANISING

YOUR CARE

HAVE YOU BEEN:

- Given the details of a named key worker/point of contact?
- Offered regular reviews of your care and medication, through your multidisciplinary team?
- Offered a referral for prompt management of symptoms by a specialist palliative care team?

MOVEMENT

AND BALANCE

HAVE YOU BEEN:

- Referred to a physiotherapist and/or an occupational therapist to help maximise your independence?
- Assessed and treated for risk factors related to your current and future needs e.g. osteoporosis, falls, visual disturbance?
- Assessed for equipment, adaptations and/or safety measures to meet your current and future needs?

COMMUNICATION

AND SPEECH

HAVE YOU BEEN:

- Assessed by a speech and language therapist for your communication needs, or reviewed if your needs have changed?
- Referred for further assessment if you need communication aids?
- Given help to ensure any communication aids work well with other assistive equipment that you may use?
- Given the opportunity to ensure your wishes are included in your care plan?

SWALLOWING

AND NUTRITION

HAVE YOU BEEN:

- Assessed and offered support/ treatment if you have saliva problems?
- Assessed for any swallowing, eating and drinking difficulties or associated issues such as chest infections or breathlessness?
- Given the opportunity to discuss alternative ways to receive nutrition, such as tube feeding?

BLADDER AND

BOWEL

HAVE YOU BEEN:

- Given advice from a dietitian on diet and fluid intake?
- Given advice on bowel care by the community nursing team?
- Assessed by the continence nurse and given access to appropriate products?

THINKING AND

BEHAVIOUR

HAVE YOU BEEN:

- Asked about any changes to your thinking or behaviour?
- Referred for a formal assessment if needed?
- Informed about access to emotional support for you and your carers?

FATIGUE

AND SLEEP

HAVE YOU BEEN:

- Referred to an occupational therapist for advice on fatigue management?
- Assessed and given advice if sleeping patterns are a problem?
- Given a medication review if sleeping is difficult?

PAIN

MANAGEMENT

HAVE YOU BEEN:

- Assessed by a physiotherapist if limb stiffness is a problem?
- Advised how to communicate that you have pain if your speech is affected?
- Referred to the specialist palliative care team to help with complex pain symptoms?

PLANNING

AHEAD

HAVE YOU BEEN:

- Offered an opportunity to discuss any future care concerns and given support and advice about planning ahead for future care?
- Given an opportunity to discuss end of life care if wished?
- Given prompt access to specialist palliative care services, if needed?

WHAT CAN I DO IF MY

NEEDS ARE NOT MET?

If you do not receive the care or treatment you need, or have any problems, discuss this first with the relevant health or social care professional, or care provider.

If this does not improve the situation, make a formal complaint or appeal to the service involved. They should be able to provide information or advise how to do this.

IF YOU NEED FURTHER

INFORMATION

If you need more information or support, or would like to order our publications, contact our helpline.

PSPA Helpline 0300 0110 122

helpline@pspassociation.org.uk

info@pspassociation.org.uk

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IF YOU NEED FURTHER

HELP OR SUPPORT

PSPA resources for people affected by CBD: <http://tiny.cc/zgqd6y>

PSPA resources on benefits:
<http://tiny.cc/h7rd6y>

PSPA resources on Continuing Healthcare Assessments (CHC):
<http://tiny.cc/hdsd6y>

PSPA resources on other sources of funding: <http://tiny.cc/zltd6y>

PSPA resources for Health and Social Care Professionals:
<http://tiny.cc/y1td6y>

PSPA Research opportunities:
<http://tiny.cc/rmrd6y>