

Section 2

Living with PSP

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Living with PSP



Introduction

In this section we aim to offer plenty of practical information, including details of some of the healthcare professionals who may be involved throughout the course of your illness, advice on how to help manage decreasing mobility and information on statutory benefits that might be available.

At the time of publication in 2013, there are on-going welfare reforms. As the benefits system is already complex, we are signposting you to the organisations that have specific, relevant and up to date information.





Health and Social Care Professionals



Who they are and how they can help



Most people will see a number of health professionals during their illness. PSP is a rare disease and because of this most GPs will only come across one person with the condition during their working life.

To help you, here is a thumbnail description of the health and social care professionals who may be involved in your care. As PSP varies greatly from person to person, you won't necessarily meet all of them, and the list isn't meant to be exhaustive. Health professionals involved in your care may include:



General Practitioner (GP)

Your GP will be the primary carer. This means that they are responsible for looking after your health. GPs deal with an enormous range of health concerns, normally as part of a practice that offers all kinds of supporting services. If a GP cannot deal with a problem, they will refer you to other services, such as a hospital for tests or to a specialist consultant.

At some point during their illness many people with PSP will see:

Multi-Disciplinary Team (MDT)

This is a group of health and social care professionals involved in someone's care. They work together to co-ordinate care and support. The MDT also plan treatment tailored to the person's individual needs.

Neurologist

Neurologists specialise in the diagnosis, symptom management and on occasion the continuing assessment and care of people living with diseases of the central and peripheral nervous systems and the muscles. They may also be involved in research into conditions such as PSP.

Occupational Therapist (OT)

The aim of the occupational therapist is to help you continue daily routines with as much independence as possible. They can advise on strategies to reduce the risk of falls, fatigue management, moving, handling and wheelchair provision. They can also offer advice on aids that can make daily life at home more manageable, such as grab rails and wet rooms.

Dietitian

Dietitians work closely with your speech and language therapist to advise on appropriate diet, help you maintain a healthy weight and offer advice on food consistency where swallowing may be difficult.

Orthoptist and Ophthalmologist

Orthoptists investigate, diagnose and treat defects of binocular vision and abnormalities of eye movement. They work very closely with ophthalmologists, who helps with the management of the symptoms. This may involve eye exercises, special lenses or eye surgery.

Physiotherapist (Physio)

Physiotherapists will advise you how to maintain good posture, muscle strength, and reduce the risk of falling. In

addition they will help to minimise the stiffening of joints and help you to adjust to changes in mobility by providing advice on aids that may be of benefit. The physiotherapist may also be involved in supporting you should you experience difficulties with breathing and coughing.

Your carer may also benefit from advice from the physiotherapist on the safest way to assist you with your day to day activities.

Social Worker and Care Manager

Social workers and care managers provide support to enable access to appropriate care for both yourself and your carer. They also offer advice on regular respite breaks and residential care as well as how to access appropriate local services.

Speech and Language Therapist (SLT or SALT)

Speech and language therapists are able to carry out assessments if you are experiencing problems with communication and can offer advice on suitable communication aids.

They also work very closely with your dietitian should you experience swallowing difficulties.

District Nurse (DN)

District nurses manage health care for people in their own homes or in residential care. They offer advice on a wide range of issues, from palliative care, equipment provision and medication support. Community nurses work alongside them visiting people in their homes and providing nursing care (not personal care). This would

include things such as the monitoring of your care needs. Both nurses have links with GP surgeries, the palliative care team and they provide follow-up care when people have come home from hospital.

Community Pharmacist

Based in the local pharmacy, they are responsible for the sale and supply of prescription and over the counter medicines. They are also available to offer advice on medicines, symptoms and general health matters.

Community Matron

Community matrons are community based senior nurses who work with people who have long term and complex conditions. They are involved in co-ordinating care and ensuring people have access to services.

Community Psychiatric Nurses (CPNs)

CPNs are nurses trained in mental health. They work with people who are experiencing depression, anxiety and dementia as well as other mental health conditions. They offer practical advice on a range of issues from medication to coping skills.

Continence Adviser

These are usually registered nurses specialising in supporting people at home with any bladder and bowel issues. They offer advice on medications, continence supplies and equipment. They liaise with other health and social care professionals including district nurses and GPs.

Clinical Psychiatrist

They specialise in the diagnosis and treatment of mental illness, prescribing and monitoring medication needs for people with mental health conditions such as anxiety, depression and addiction. They work with multidisciplinary teams to support people with mental illnesses, including dementia.

Clinical Psychologist

These experts support people experiencing severe psychological distress. Access to a psychologist can be made through a psychiatrist or palliative care team. Among the treatments they offer may be psychotherapy, cognitive behavioural therapy and relaxation techniques.

Geriatrician

Geriatricians specialise in the care of the elderly and deal with a wide range of conditions. They also offer advice on symptom management, access to community services and advanced planning.

Palliative Care Team

This group of specialists is likely to include doctors, nurses, social workers, dieticians, complementary therapists and chaplains. Together, they address the physical, spiritual and social concerns that arise with advanced progressive illness. Between them they can offer support for symptom management and planning for the end stages of illness. They will support the person affected and people close to them. The palliative care team will usually be linked to a local hospice that may also provide day care and in-patient respite care.

Advance care planning



If the diagnosis of PSP is fairly recent, it might seem odd to have to give thought to how you would like to be cared for in the future. But it is important to look at advance care planning early on.

Advance care planning is entirely voluntary and no-one has to do this unless they want to. It is a chance for you and the people who provide your care – for example, doctors and family members – to discuss the way you would like your care to proceed as the condition progresses.

It's an opportunity for you and your carers to express thoughts, preferences and wishes about your future care. It is a personal process, unique to you, the person with PSP.

PSP is a progressive illness, where the symptoms change over the course of time. That is why it can be helpful to both you and your carers to talk about your wishes – to help make plans. Not everyone will want to do this so remember whatever route is chosen, that is fine.

See section on *Advance care planning* in Section 4 of this guide.





Statutory benefits



If you have worked hard all your life it might feel uncomfortable to apply for support and financial benefits.

The benefits system is going through a period of welfare reform at the moment. As things are changing fast and are quite complex, use this section as a guide to signposting you to the information you need.

Sometimes the number of forms can seem overwhelming and the process isn't helped by the varying assessment standards and availability of support.

Top Tips

Once you are 'in the system' then things become a lot easier

- There is a lot of help available to assist you
- Many of the forms consist of 'tick' boxes and are not as daunting as you might think.

Advice

There is plenty of local advice available, including:

- Your local branch of Carers UK.
Telephone: 0808 808 7777
Website: www.carersuk.org to find your local carers service
- Your nearest Citizen's Advice Bureau
- Your local branch of Age UK
Website: www.ageuk.org.uk

- The various Government Helplines, stated on the application forms
- *The Disability Rights Handbook*. Published by the Disability Alliance 0207 250 3222, Website: www.disabilityalliance.org
- The PSP Association Helpline, Information and Advisory Service. Telephone: 0300 0110 122
Email: helpline@pspassociation.org.uk

Health Benefits

Regional variations

Eligibility for various benefits varies from place to place in the UK – for example, people in Wales are eligible for different benefits to people in England. Always talk to your GP in the first instance, as they will have up to date information.

You *may* be entitled to:

- Exemption from prescription charges
- Free eye tests, free or subsidised glasses or contact lenses
- Free talking books and newspapers.

VAT Relief

People with PSP should not have to pay VAT on equipment or services related to their disability, including disability aids such as lifts and adjustable beds, and home adaptations to help with their disability.

Check HRMC for up to date information.

Website: www.hmrc.gov.uk

Council Tax Reduction and Benefits

You may be entitled to a reduction or to help paying your Council Tax (Rates in Northern Ireland).

For further information search for *Council Tax Reduction* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).

Housing Benefit

You may be entitled to Housing Benefit for a number of reasons. For further information search for *Housing Benefit* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).

Housing Adaptations and Equipment

The owner, tenant or landlord can apply for financial help with housing adaptations and equipment. Maximum limits vary depending on which area of the UK you live in.

For further information search for Financial help or the *disabled/ home and housing* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland)

Charitable Support

Many local and national charities offer support. Some are open to everyone, others are nationality-based or established to support people with a certain professional, trade or faith background.

- Turn2us provide a comprehensive list of charity help available.
Website: www.Turn2us.org.uk

The Disability and Carers Service

The Disability and Carers Service is part of the Department for Work and Pensions (DWP). It provides financial support for customers claiming disability benefits and their carers – for example, Disability Living Allowance and Carer’s Allowance. Visit: www.dwp.gov.uk for more information

When completing forms

- Be realistic rather than optimistic
- Do not say the person can do something when in reality it causes them pain or exhaustion
- Focus on your worst day and fill in the form on that basis – that’s when you need the help
- Try to give a clear picture of the situation. For example, if the question is: ‘Can you wash and dress?’ Don’t just say ‘Yes’ if the real answer is ‘It takes me two hours with frequent rests and I need someone to help with fastenings’
- To make a successful claim it’s worth seeking experienced help. You might want to consult your GP, OT or Physio before submitting a claim. They might also be willing to write an assessment report for you
- Keep a copy of your application form handy as you may receive a phone call to confirm details and it is important that you provide the same information as the application form
- It may help to keep a diary of activity, to have something to refer to.



Driving



There may be a point when you are no longer able to drive. This loss of freedom can be very hard to accept, especially if you have always used a car.



Has PSP affected your driving ability? Can you judge distances accurately? Do you experience confusion regarding the rules of the road? Are you able to physically and mentally act quickly in the event of any emergency? Ultimately you have to consider your safety, and the safety of those around you.



If you are a driver, you must report your diagnosis to the DVLA as soon as possible. This does not automatically mean that your driving licence will be withdrawn immediately. The DVLA may ask you to take part in a driving assessment before making a decision.

For further information search for *DVLA medical enquires* at www.gov.uk or www.nidirect.gov.uk (Northern Ireland).

Please Note: You must advise your insurance company of any diagnosis or change in condition that may affect your ability to drive, as failure to do so may invalidate your policy.

Top Tip

Notify the DVLA as soon as possible after diagnosis. It is a criminal offence not to do so.

Driver Licensing Enquires

Telephone: 0300 790 6801

Textphone: 0300 123 1278 Fax: 0300 123 0784

Monday to Friday 8am to 7pm Saturday 8am to 2pm

Driving options

- If someone else can drive, it may still be possible for you to get out and about. If getting in and out of the car is difficult for you, adaptations may help. Ask your occupational therapist for advice
- There may be local transport schemes, such as volunteer drivers, in your area. To find out what is available contact:

The Community Transport Association

Telephone: 0845 130 6195

Website: www.ctauk.org (UK)

Website: www.communitytransport-ni.com (Northern Ireland)

- **Regional Driving Assessment Centres** aim to help people maintain mobility through driving. For more information, and to find your nearest Driving Assessment Centre, visit: www.rdac.co.uk or contact: Regional Driving Assessment Centre, Unit 11, Network Park, Duddeston Mill Road, Saltley, Birmingham B8 1AU. 0845 337 1540, email: info@rdac.co.uk

- **Motability**

This scheme allows people on certain benefits to enjoy a new car, scooter or powered wheelchair without the worry of owning and running one. Today, around 600,000 disabled people and their families benefit from the scheme

Check eligibility by contacting Motability on: 0845 456 4566 or www.motability.co.uk for more information.

Top Tips

Blue Badge Scheme

These are issued by your local authority. They offer the use of disabled parking bays and many other parking concessions. Some cities, including London, operate their own schemes, so check locally

If you receive the higher rate mobility component of Disability Living Allowance (DLA), or the enhanced rate mobility component of Personal Independence Payment (PIP) you do not have to pay road tax. If you receive the standard rate of PIP you are entitled to a reduction of 50%.

For further information search *Vehicle exempt from car tax* at www.gov.uk or nidirect.gov.uk (Northern Ireland).

Disabled Person's Railcard

This offers a third off most fares. Check with your local station regarding eligibility
www.disabledpersons-railcard.co.uk

Bus Discounts

Your social services department will advise on any local bus discounts available.



Complementary therapies



Some people affected by PSP like to try complementary therapies in addition to the help and support they receive from conventional medicines.



Complementary therapy offers a different approach to more traditional methods – usually involving the body, mind and spirit. This holistic approach may help you to feel ‘more in control’ of the situation.

Before having any complementary therapy, discuss it with your GP to ensure that it is the right option for you.



We are often asked about the use and possible benefits of complementary therapies for PSP. While we have no evidence that any complementary therapy can modify the duration of the condition, some people tell us that the use of therapy has helped to alleviate symptoms and may therefore be worth considering.

Most complementary therapies, as the name implies, ‘complement’ rather than replace modern medicine. The NHS is starting to acknowledge that complementary therapies may provide some benefit.

Some hospices provide short courses of complementary therapy free of charge. However, if this is not available then your GP may be able to refer you to a reputable therapist in your area, Please be aware that most complementary therapists will charge for their services.

What might help?

It is generally thought that relaxation can help to reduce anxiety and stress, which can be brought on by many of the problems associated with everyday living for people with PSP and their carers. Complementary therapies may provide you with relief from symptoms associated with:

- Tension/stress
- Anxiety/panic attacks
- Depression
- Pain
- Musculoskeletal problems
- Constipation
- Temperature control
- Sleeplessness/fatigue.

Finding a therapist

Always use accredited therapists. Check the individual websites for information. Care should be taken to find a reliable therapist, preferably one who is recommended by and connected to a recognised authenticating and regulatory body. Any therapist dealing with someone with PSP will need an understanding of the disease and any other conditions the person with PSP might be experiencing.

Acupuncture

Acupuncture is part of the ancient and complex system of traditional Chinese medicine.

The British Acupuncture Council (BAcC), 63 Jeddo Road,
London W12 9HQ.

Telephone: 0208 735 0400.

Website: www.acupuncture.org.uk

Shiatsu

Shiatsu is an ancient Japanese form of massage, which again has its origins in Chinese medicine and works on the same theory as acupuncture.

The Shiatsu Society (UK), Eastlands Court, St Peters Road,
Rugby, Warwickshire CV21 3QP.

Telephone: 0845 130 4560

Website: www.shiatusociety.org

Email: admin@shiatsu.com

Reflexology

Reflexology is based on the principle that all the organs of the body have corresponding reflex points on the feet.

The Association of Reflexologists, 5 Fore Street, Taunton,
TA1 1HX

Telephone: 01828 351010

Website: www.aof.org.uk

Aromatherapy

Aromatherapy uses essential oils from plants which are applied to the skin, mixed in water or inhaled.

The International Federation of Aromatherapists,
20A The Mall, Ealing, London, N5 2PJ
Telephone: 0208 567 2243
Website: www.ifaroma.org

Massage

Massage stimulates and energises the body and leads to a feeling of calmness and relaxation.

The British Massage Therapy Council (BMTC), 17 Rymers Lane, Oxford. OX4 3JU.
Website: www.bmtc.co.uk

Reiki

Reiki was developed in Japan in the 1800's and the theory is based on practitioners being able to draw on and channel healing energies from the patient's own body.

The UK Reiki Federation, PO Box 1785, Andover. SP11 0WB.
Telephone: 01264 773774.
Email: enquiry@reikifed.co.uk

Relaxation and meditation

Meditation techniques are believed to encourage simple healing and spiritual growth. There are many centres and health clubs throughout the UK offering meditation.



Holidays



Holidays can provide a vital break – and a welcome change of scene. It is important to be realistic about your level of disability and any extra requirements you have when planning a holiday. But the good news is that there is plenty of help and advice available.

Accessibility, insurance, medical facilities and possible extra costs are likely to be additional factors you need to think about when booking a holiday.



It is a good idea to talk to your GP to seek advice on fitness to travel and to ensure that you have enough of your medications to take with you. Before leaving, check out access to toilets en route, particularly on planes if travelling long distances.

You will also need to have hospital details and contacts for emergency medical assistance at the destination and should check whether your dietary needs can be met.

You may wish to make contact with your travel company 48 hours before departure to check that your arrangements are recorded and in place. If you have room in your suitcase you may wish to pack *'Your Personal Guide to PSP'*.

Above all, having made all these preparations – have a very good holiday!

Top Tip

Discuss any holiday plans with your GP first and don't plan too far in advance as some symptoms can change quite quickly.

Funding assistance

Some charities will offer financial support for holidays. Turn2Us is a charitable service which helps people access money that may be available to them - through welfare benefits, grants and other help.

Website: www.turn2us.org.uk

Saga Respite for Carers Trust

Saga Respite for Carers Trust may be able to help with the cost of a much-needed holiday for carers and their companions.

Eligibility criteria:

The carer should:

- be over 50
- have been caring for someone for over a year
- not had a significant holiday away from their caring role in the last year
- and not be a professional carer.

You can nominate yourself or be nominated. Download a form from www.saga.co.uk or send a self addressed envelope to: The Trust Manager, Saga Respite for Carers Trust, The Saga Building, Enbrook Park, Folkestone, Kent CT20 3SE.

Vitalise holidays

Vitalise is a national charity providing short breaks and holidays (respite care) for people with physical disabilities and their carers.

Telephone: 0303 303 0145

Website: www.vitalise.org.uk

General help and advice

These organisations can help you to tailor your holiday to meet your needs.

- ***Rough Guide to Accessible Britain***

Full of ideas for accessible days out across the UK. This book is free for all blue badge holders.

Telephone: 0800 953 7070. It can also be downloaded from the website: www.accessibleguide.co.uk

- **Tourism For All**

Provides advice on accessible holiday accommodation

Telephone: 0845 124 9974

Website: www.tourismforall.org.uk

- **RADAR (Royal Association for Disability and Rehabilitation)**

Visit www.radar.org.uk for up to date information or to obtain a RADAR Key which will open most public disabled toilets

- **DPTAC**

The Disabled Persons Transport Advisory Committee (DPTAC) is an independent body advising Government on the transport needs of disabled people.

Website: www.dptac.independent.gov.uk

Transport

Information on all types of public transport for people with disabilities is available.

For further information search for *transport-disabled* at www.direct.gov.uk or www.nidirect.gov.uk (Northern Ireland).



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

"How professional the PSPA have been – a Gem".

Steve