

1.2 Introduction:

Living With Progressive Supranuclear Palsy

This Help Sheet provides information for people who have been diagnosed with Progressive Supranuclear Palsy (PSP) and their family members and carers. It gives some suggestions for coming to terms with the diagnosis, understanding the condition and making the most of life with PSP. At the moment there are no treatments known to cure PSP, but there are a range of medications, therapies and strategies that can help those affected to make the most of living with the condition. The information here is presented as a guide; it is important to discuss all symptoms with your neurologist and other health professionals.

PSP is a rare neurological condition affecting the parts of the brain that control walking, eye movements, balance, speech and swallowing. PSP has a wide range of symptoms, but few people experience them all and symptoms vary from person to person. It is a progressive condition, meaning that the symptoms tend to worsen over time. However, the severity and rate of symptom progression varies widely.

PSP is a condition that affects not only the person diagnosed, but also their close family members and carers. When we talk about 'living with PSP' we are referring to the person who has the condition as well as those close to them, often referred to as 'carers', those who are also going through many changes as they adapt to 'living with' the condition.

Coming to terms with a diagnosis of PSP

Most people will experience a range of feelings after being diagnosed with PSP. In most cases the person diagnosed and those close to them will experience a grief response. The grief response may include a variety of feelings: fear, sadness, denial, anger or concern for the future. Some people may experience a feeling of relief at having a name for the difficulties they have been experiencing after searching so long for answers.



*For PSP information and support phone
Parkinson's Australia on 1800 644 189*





It is important to have the opportunity to work through feelings of grief. Many people find it helps to talk to a counsellor. Parkinson's Australia offers support and information to help in coming to terms with a diagnosis of PSP, including information about counsellors in your local area.

Remember, you are not alone and help is available.

Telling others

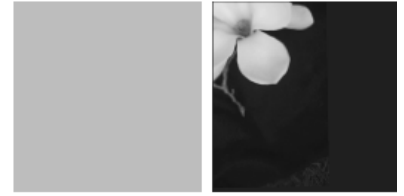
Many people find it helps to talk about the diagnosis with others in their network of family members and friends. This not only helps share the load and but also opens the door for support. Telling people can be a difficult process, so here are some suggestions to consider when deciding how and when to tell other people about a diagnosis of PSP:

- Think about timing. Some people prefer to wait until they feel emotionally ready to discuss the diagnosis, but waiting too long can cause others to feel hurt and some may misunderstand symptoms.
- Decide who you need to tell personally. Hearing the news via someone else may have a negative effect on some people. For example, if you plan to tell co-workers, tell your supervisors first.
- It can be easier to first tell someone with whom you feel comfortable. This may be a family member or friend, or a health worker.
- People may exhibit a range of reactions and some people may need time to adjust. It may help to have someone else present to offer support if needed.
- Offer them information about PSP, such as PSP Australia's 'Understanding PSP' brochure. Parkinson's Australia can provide further information and support to any interested party.
- Think about what you want or need from the person you are telling. This may include emotional support, practical help with transport or household tasks, time off work etc.

Understand the condition

PSP is a complex and challenging condition. Understanding its symptoms and progression, as well as management strategies and treatments, are the first steps to making the most of life with the condition.

Information about PSP is available through Parkinson's Australia. Offices in each state provide access to PSP resources such as books,



newsletters and papers. Your local library may not have specific PSP information, but will have information on topics such as living with a serious illness.

The internet is a great way of getting informed about PSP and the services that can help. Second-hand computers are now available at low cost and every library and community centre provides free or inexpensive computer access as well as assistance or short courses to help you learn to use them. If you are not able to access the internet, ask a family member or friend to access information for you.

There are a number of Australian and international websites providing a range of information about PSP, including management strategies, personal stories and research developments. Beware, however, as there are also unhelpful sites containing poorly researched information or promises of “cures” that are designed to exploit, sensationalise and cause fear. Recommended websites are listed in the PSP Australia Help Sheet: 3.5 *Where Can I go for Help?*

There are also websites with information about the various services and systems that may help and ‘chat rooms’ where people can link up with people living with PSP around the world. The internet is also a useful tool to reduce isolation; it is a way of staying in touch with family and friends when living with PSP makes it difficult to get out.

Seek expert advice and assistance

It is very important that people with PSP seek the advice of health professionals with expertise in the condition. This includes a neurologist and, depending on your symptoms, may also include a physiotherapist, occupational therapist, speech therapist or counsellor.

Use a team approach

Making the most of life with PSP requires a team effort between the person with the condition, their families and carers, their neurologist, their health professionals and the various services that are available to help. Good communication between all members of the team will help to ensure needs are met and symptoms are well managed.



Here are some tips for communicating with health professionals:

- Prepare for the visit. Write down any questions and key points such as symptom changes.
- Remember, PSP is a rare condition and many of the people you go to for help may not know what PSP is or understand the needs of those affected.
- Provide your health professionals with a copy of the PSP Australia Help Sheet: *Information for Health Professionals*.
- Don't be afraid to ask questions or to ask for a simple explanation of any technical information or jargon used.
- Be prepared to be pushy or take someone along who is able to take on this role if needed.

Help is available

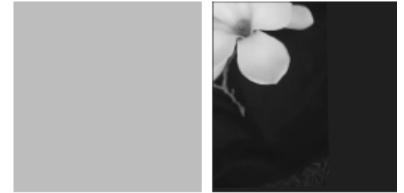
Living with PSP poses many challenges, but you don't have to do it on your own. It is important to get help and to communicate your needs in order to make the most of life with PSP. Help is available, including:

- Emotional support – counselling to help with issues such as coming to terms with the diagnosis, coping with change and managing feelings of grief and loss.
- Support groups, where people with PSP and their carers can meet others who are living with PSP or with other chronic conditions.
- Financial support, including income support, allowances, concessions to help with the cost of essential services such as gas and electricity and financial counselling with advice on budgeting and managing debt.
- Aids and equipment to help with daily living.
- Transport and travel assistance.
- Personal care and home help, including assistance with bathing, dressing, home-delivered meals and housework.

The health service systems can be confusing and difficult to access if you don't know what is available. The Commonwealth Respite and Carelink Centre - telephone 1800 052 222 - is a good starting point. See also PSP Australia's 'Staying Independent' Help Sheets, including: 3.5 *Where can I go for Help?* Or contact Parkinson's Australia.

Research for PSP

Research activities into the cause, treatment and cure of PSP are ongoing in Australia and overseas. Most research activities do require recruitment of patients. Parkinson's Australia will often have



information about these trials and studies. Your doctor or neurologist would ultimately decide if you are suitable for entry to these studies.

The Australian Brain Bank Network collects details of patients interested in leaving their brain for scientific research. Visit: www.nnf.com.au/platforms/abbn or telephone (03) 8344 1900.

Keep future needs in mind as well as immediate needs.

PSP is a progressive condition, meaning that it tends to worsen over time. It is important to plan for future needs and to put the necessary support and assistance in place before the need arises. For further information see PSP Australia's Help Sheet *3.4: Planning For the Future*.

Living with symptoms

Many of the symptoms of PSP can be treated or managed. It is important to remember that PSP affects different people in different ways. It has a wide range of symptoms but few people experience them all and the rate of symptom progression varies widely.

For information about strategies, medications and therapies to help manage the symptoms of PSP, see PSP Australia's series of 'Managing Symptoms' Help Sheets.

Remember

- Help is available
- You are not alone
- You can only do your best, no-one is perfect
- Try to find something, however small, to enjoy in each day
- Plan for the future
- Live for today.

For further information about living with PSP, including the full range of PSP Australia Help Sheets, visit: www.psp-australia.org.au

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June 2009

Help Sheet 1.2

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Page 5



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