

3.5 Staying Independent: **Where Can I Go For Help?**

This Help Sheet gives a general overview of the types of help available to people with PSP and their families and carers. It also outlines some of the key helping organisations and points of contact. Services can vary depending on where you live.

Where can I go for PSP information and support?

Parkinson's Australia

Parkinson's Australia can give support and information over the phone or in person via family meetings in their state offices. Most state and territory offices also provide access to a range of books, brochures and audiovisual resources about Parkinson's and related conditions such as PSP.

To speak to Parkinson's Australia in a **language other than English** phone 131 450 and ask for an interpreter in your language to connect you to Parkinson's Australia in your state or territory. This is a free service.

Support groups

PSP Australia is a support group for people with PSP and their families and carers. PSP support groups meet regularly in some areas. For more information visit: www.psp-australia.org.au or telephone Parkinson's Australia on 1800 644 189.

Parkinson's support groups also welcome people with PSP and their families and carers. These operate in metropolitan and country areas across Australia and provide a friendly, supportive and encouraging environment where people can meet to share their feelings and experiences and learn from others. Meetings may include practical tips and advice, group discussions, social outings and education sessions from health professionals. Parkinson's Australia can put you in touch with a support group in your area.



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





PSP on the internet

- PSP Australia's website includes information about PSP, the full range of Help Sheets and links to other useful sites. Visit: www.psp-australia.org.au
- 'Cure PSP' is run by the Society for Progressive Supranuclear Palsy in the USA. Visit: www.psp.org
- 'We Move' is an international website providing information about movement disorders such as PSP and resources such as an on-line discussion forum. Visit: www.wemove.org
- The UK/European PSP Association also has a range of resources. Visit: www.pspeur.org

Where can I go for information and support in relation to living with neurological conditions, disability and chronic illness?

The Chronic Illness Alliance aims to build a better focus in health policy and health services for all people with chronic illnesses. It does this through education and research projects. Phone: 03 9882 4654 or visit: www.chronicillness.org.au

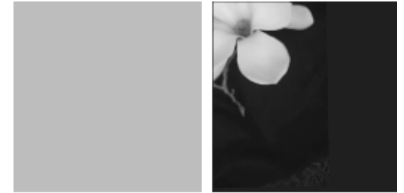
The Brain Foundation is an Australian registered charity which raises money to fund on-going, crucial research in Australia into brain diseases and all other known neurological disorders as well as brain and spinal injuries. Phone: 1300 886 660 or visit: www.brainaustralia.org.au

Brain Injury Australia works nationally to ensure that all people living with acquired brain injury have access to the supports and resources they require to optimise their social and economic participation in the community. Phone **(02) 8507 6555** or visit: www.braininjuryaustralia.org.au

Where can I go for help with daily living?

When asking for help with daily living it is important to be realistic. It is easy to be overly-optimistic about your capabilities, for example, to answer 'Yes' to a question such as, "Can you wash and dress yourself?", even though such a task takes many hours to complete and some parts of the task are impossible on some days. It is better to be realistic and answer from the perspective of the times when symptoms are at their worst and allow for the fact that symptoms continue to worsen over time.

Movement disorder clinics provide specialist programs on ways to manage daily living. This is especially useful for people with conditions such as PSP and Parkinson's. Parkinson's Australia can advise if there is a clinic in your area.



Independent Living Centres provide information and advice about aids and equipment that can help with daily activities, such as medication alarm boxes and easy-to-use cutlery. Phone: 1300 885 886 or visit www.ilcaustralia.org.au

Community Care Services help people with a disability and those who are frail-aged to live independently in their own homes and enjoy quality of life for as long as possible. Contact the Commonwealth Respite and Carelink Centre on **1800 052 222** during business hours for free and confidential information on respite, community aged care, disability and other support services available locally, interstate or anywhere within Australia. For emergency respite support outside standard business hours, call **1800 059 059**.

Local organisations can also provide various services and supports to help with daily living, including:

- Local councils/Shires
- Community health centres
- Neighbourhood houses or community centres
- Recreation and leisure services
- Migrant resource centres

Centrelink provides financial support for people in need, including people with a disability and those seeking work. Phone Centrelink on 132 717. For more information about financial and legal issues, see PSP Australia's Help Sheets on Planning Ahead and Income Security, Work, Concessions and Financial Assistance.

Where can I go for help for carers?

Caring for someone with PSP is physically and emotionally demanding. It is important for carers to look after themselves and take regular breaks. 'Respite' is the word commonly used for services that can help carers take a break from their caring role.

Contact the Commonwealth Respite and Carelink Centre on 1800 052 222 during business hours for free and confidential information on respite and other support services. For emergency respite support outside standard business hours, call 1800 059 059.

For further information about support for carers contact the Carers Association in your state or territory on 1800 242 636 or visit: www.carersaustralia.com.au. See also PSP Australia's Help Sheet 3.1 *Caring for Carers*.

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Where can I go if I'm not satisfied with a service?

Health complaints authorities operate in all states and territories, along with services focused on promoting the **rights** of people with disabilities and of the aged. The Aged and Community Care Information Line on 1800 500 853 can provide details of organisations in your area.

The Aged Care Complaints Investigation Scheme is available to anyone who has a complaint or concern about an Australian Government-subsidised aged care service (residential or community care). Phone: 1800 550 552.

Aged Care Advocacy is a free and confidential service promoting the rights of people receiving aged care services.
Phone: **1800 700 600**

The National Disability Abuse and Neglect Hotline is an Australia-wide telephone hotline for reporting abuse and neglect of people with disabilities who are using government funded services. Allegations are referred to the appropriate authority for investigation.
Phone: 1800 880 052

The Human Rights Commission works to resolve complaints of discrimination or breaches of human rights under federal laws. Contact the complaints Infoline: 1300 656 419 or email: complaintsinfo@humanrights.gov.au for information on lodging or responding to a complaint.

People with Disability Australia is a national peak disability rights and advocacy organisation that can provide rights-related information, advice and referral services for people with disability and their associates as well as short-term individual and group advocacy assistance. Phone: 1800 422 015 or visit: www.pwd.org.au

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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