

3.1 Staying Independent: **Caring for Carers**

This Help Sheet gives information for people like you who are caring for someone with PSP. It discusses the importance of looking after yourself and suggests some of the ways that you may find support and assistance to help you in your caring role.

Who Are Carers?

You may not think of yourself as a carer, but this is the term generally used to refer to anyone who provides unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail.

Caring for someone with PSP

Caring for someone with PSP is physically and emotionally demanding. It can also be rewarding at times and many carers experience satisfaction at being able to help their loved-one in need. Even so, it is unlikely that you can not do it all on your own.

People with PSP progressively lose many of the abilities needed for daily living and their care needs increase over time. It is important to put strategies in place in the early stages of the condition so that your needs and the needs of the person you care for continue to be met into the future.

Understanding PSP

PSP is a complex condition. It is important to understand that the changes it brings are due to the condition and are beyond the control of the person affected. For example, symptoms such as slow movements, problems making eye contact and lack of facial movements can be misunderstood by others as disinterest or non-appreciation on the part of the person with PSP. Understanding the symptoms and using



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





strategies to manage them, as outlined in PSP Australia's series of *'Managing Symptoms'* Help Sheets, can help you to maintain a positive relationship with the person you are caring for.

It is also important for people diagnosed with PSP to be aware of the physical and emotional stress that carers experience. Understanding and cooperation will help to maintain everyone's independence and quality of life.

Looking after yourself

The best way you can care for anyone else is by looking after yourself. When you attend to your own wellbeing you boost your quality of life. In turn, your wellbeing ensures you have the energy and capacity to face the challenges coming your way. This means you can provide more effective support to the people around you.

Some of the things you can do to look after yourself include:

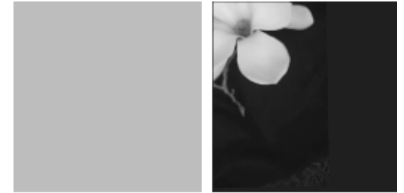
- Look after your diet and get regular exercise.
- Manage stress by taking time to relax and by talking to others.
- Maintain your social contacts and lifestyle.
- Be realistic about what you can and can't do.
- Ask for help. Even if you don't need it now, getting help will become more and more important in the future.
- Make time for yourself every day, this can be as simple as taking a few moments in the garden to relax.
- Take regular breaks.

Taking a break

'Respite' is the word commonly used for the services that can help you to take a break from your caring role. While you have a break, paid care-workers take over the role of attending to the needs of your loved one. There are lots of different forms of respite available including:

- In your home, giving you the opportunity to go out or get on with other tasks around the house.
- In a residential facility, which may allow you to take a holiday, visit family or friends, or just catch up on some sleep.
- Emergency respite if you suddenly become ill or injured.

There are a number of respite services available for people with



specific cultural needs and languages other than English. It is also possible to arrange culturally specific respite, where workers speak the same language as your loved one. Some day-care and residential facilities cater to specific cultural groups or have workers with the same culture and language.

Call the Translating and Interpreting Service (TIS) on 131 450 if you speak a language other than English. They will contact any service you need and interpret for you over the telephone.

The Commonwealth Respite and Carelink Centre on 1800 052 222 provides information on respite and Carer Support Groups. For emergency respite support outside of standard business hours phone 1800 059 059.

The Carers Association in your state and territory on 1800 242 636 can provide telephone support and advice on dealing with grief. They can also refer you to their carer counselling service.

Easing the cost of caring

Many people who care for someone at home can receive financial assistance from the Commonwealth Government in the form of a Carer Allowance, which is not means tested. You will need a health professional's report to establish your eligibility. Some carers are eligible for a Carer Payment as well, however, eligibility criteria and means testing applies. Contact Centrelink on 132 717 or visit www.centrelink.gov.au

Planning for Emergencies

Planning for future emergencies will give you and the person you support peace of mind. Planning ahead ensures you can let other people know what is required for effective care should you suddenly be unavailable as a carer. It is a good idea to develop an emergency care plan. Carers Australia has developed a kit to help you develop such a plan. You can obtain an Emergency Care Kit by contacting the Carers Association in your state and territory on 1800 242 636.

Help Sheet 3.1

Staying Independent:
Caring for Carers

Call 1800 059 059 if you need to arrange emergency respite.

For more information, see PSP Australia's Help Sheet: 3.4 *Planning for the Future*.



Balancing Work and Caring

Balancing work and caring can be a challenge. As a carer you may want to work but need extra support and flexibility to remain in the workplace.

The benefits of work for carers include financial security, mental and social stimulation and personal wellbeing. Work also provides a change from the routines of caring.

Some workplaces have policies that enable employees to maintain caring responsibilities. Some industrial awards and agreements include provisions for carers. Laws such as those covering equal opportunity can also offer some protection. For further information contact the Carers Association in your state or territory on: 1800 242 636.

Getting support

Support is available for carers, including:

- Carer support groups where you can meet others who are going through similar experiences.
- Education and training to help you discover ways to look after your own health and wellbeing and learn skills that can help you manage as a carer.
- Professional counselling which may be face-to-face, over the phone or via the internet, and can help you to explore different ways of coping.
- Carer respite (as outlined in *Taking a break*, above)
- 'Surviving the Maze', an internet-based series of carer specific fact sheets that will point you in the right direction for all your caring needs. Visit www.survivingthemaze.org.au

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, or contact Parkinson's Australia.

Some of the information in this Help Sheet has been reproduced from materials produced by Carers Australia and state and territory Carers Associations. All content has been checked by Carers Australia.

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