

## 3.4 Staying Independent Planning for the Future

*This Help Sheet discusses the importance of planning ahead for things such as the management of financial affairs, health issues and care needs in the future. The information here is a guide. You should seek legal advice about your particular circumstances.*

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Progressive Supranuclear Palsy (PSP) is a progressive condition, meaning that the symptoms tend to worsen over time. However, the severity and rate of symptom progression varies widely in different people. Many people with PSP find it increasingly difficult to communicate their wishes and to conduct their own legal and financial affairs as the condition progresses. It is therefore important to discuss future plans as soon as possible after diagnosis. This will help to avoid some of the stress of having to make difficult decisions in crisis situations.

### **Living and lifestyle**

A diagnosis of PSP usually demands a reconsideration of existing plans for the future. There are a number of issues you may wish to consider:

- The need for an increasing level of support and care as the condition progresses.
- The likelihood of a shortened life-span.

Planning ahead may include considering different housing options, such as the possibility of downsizing or of moving closer to family members or to health and support services. It is important to consider the future needs of carers and close family members as well as those of the person with PSP.



## **Planning for Emergencies**

Developing an emergency care plan can give peace of mind. It lets other people know what is required for effective care if the person's carer suddenly becomes unable to provide that care. Carers Australia has developed a kit to help in developing such a plan. You can obtain an Emergency Care Kit by contacting the Carers Association in your state or territory on 1800 242 636.

If you ever need to arrange emergency respite outside of normal business hours, telephone your local Commonwealth Respite and Carelink Centre on 1800 059 059.

## **Legal and Financial Matters**

People with PSP may experience a range of difficulties associated with managing their legal and financial affairs. For example, symptoms such as movement and vision problems can make it difficult to sign documents or to attend appointments. Even though people with PSP remain mentally aware, problems with organising thoughts and ideas are common, along with communication difficulties and slowness of thought. It is therefore important to put strategies in place for managing the person's legal and financial matters into the future. The following are some suggestions for you to think about, but you should discuss these matters with a financial advisor or solicitor.

### **Bank accounts**

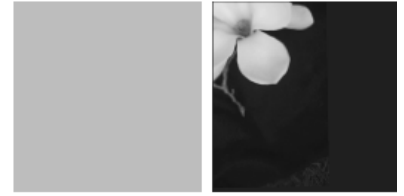
Planning ahead may include ensuring that bank accounts can be operated when it becomes too difficult for the person with PSP to do so independently. Your bank can set up a joint account or provide for joint signatures on accounts.

### **Power of Attorney**

Most Australian states and territories provide a legal arrangement where individuals can nominate someone they trust to act on their behalf. These may be called Powers of Attorney or Guardianship. These powers can be used for many purposes, including operating a bank account and paying bills. A general Power of Attorney does not cover personal, medical or lifestyle decisions and ceases to have effect if the person becomes mentally impaired.

### **Enduring Power of Attorney**

An Enduring Power of Attorney can be executed so that if a person is no longer able to make their own decisions, someone else can make decisions on their behalf. Powers may be given in relation to financial, medical and/or lifestyle decisions. An Enduring Power of Attorney can only be made if the person is legally competent at the time of signing; it continues until the person's death, unless revoked.



Contact Parkinson's Australia for information about Powers of Attorney and related provisions in your state or territory.

### **Wills**

A will gives instructions about how the estate of a deceased person should be distributed. Planning ahead means making sure your will is up-to-date, knowing who the executor is and knowing where the will is kept. You should discuss this with your solicitor.

### **Decisions about medical treatment**

People with PSP have the right to make decisions about their health care, now and in the future. Medical treatment should only be given with the person's informed consent and anyone has the right to refuse consent. Decision-making about medical treatment needs to involve being fully informed about the benefits and burdens of treatment.

People with PSP may find it more and more difficult to communicate their choices as the condition progresses. It is important to discuss these matters and to consider formalising the person's wishes in relation to medical treatment when the condition progresses.

The legal system offers a range of ways to ensure that an individual's wishes are recorded and carried out in relation to medical treatment.

Different provisions and terms are used in different states and territories, but may include:

- An Enduring Power of Attorney covering health matters (sometimes called a Medical Power of Attorney), which allows the person to appoint someone they trust to make medical decisions on their behalf.
- An advance directive, which is a formal written document where an individual can express their wishes about medical treatment and care. Advance directives are legally binding in some states and territories, meaning that if these documents have been completed, the patient's agents, next-of-kin and doctors are obliged to follow them.

Contact your solicitor, local community legal service or Parkinson's Australia for further information about provisions that apply in your state or territory.

If no formal orders are in place, the closest relative is legally allowed to consent to medical treatment and is expected to make decisions that, to the best of their knowledge, reflect the known wishes of the person.

### **Advance care planning**

Advance care planning involves thinking about and discussing with doctors, family members, carers and other important people, the medical treatments wanted or not wanted if you or the person making the advance care plan were unable to communicate or make medical decisions and were seriously ill, had an accident or were dying.

A guide to advance care planning is produced by *Respecting Patient Choices*, a program involving key health care providers in all states and territories. For further information contact Parkinson's Australia or visit: [www.respectingpatientchoices.org.au](http://www.respectingpatientchoices.org.au)

### **Funeral arrangements**

Taking time to discuss, plan and pre-arrange your funeral can provide reassurance and peace of mind. It not only ensures your wishes are carried out, it reduces the stress on family members and carers at a difficult time.



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

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