

THE CARER AND PARTNER

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Information for Carers and Partners

Living with Parkinson's



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Disclaimer

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How about some feedback?



We are developing our resources for carers and partners and would appreciate your feedback about this resource or other ways we can assist.

You can supply your name and address or remain anonymous.

Name (optional) _____

Address _____

Telephone _____

Comments _____

Please return to:

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About this Booklet

NOTES

This booklet is for people who find themselves up close to Parkinson's. One day you hear that your spouse or a close family member has been diagnosed with this condition. You discover that Parkinson's is a progressive neurological disorder of the brain. It can affect people in many different ways. It can interfere with a person's movement, coordination, visual perception, information processing, reaction time and maintenance of attention.

Symptoms can change gradually or rapidly. They may even vary in the same day from hardly noticeable to very severe.

Close personal relationships are also affected by the condition. Generally, your relationships change as the condition progresses. From being part of an independent and mutually supportive partnership, you gradually become the carer.

This booklet is organised into five parts. The first part covers the early years with Parkinson's. The second and third parts aim to help carers with some of the many challenges they face. The fourth part encourages carers to take care of themselves and the fifth part touches briefly on services available to carers.

The Association's companion booklet *Parkinson's disease – Information for people living with Parkinson's* discusses symptoms, treatment options, research and daily living strategies. This booklet focuses on the person who stands beside the person with Parkinson's.

At all times it is important to remember that just as Parkinson's is a very individual condition, so each couple is different and has different needs and ways of coping.

NOTES

The Early Years with Parkinson's

When first diagnosed, many partners report feeling very irritated by the suggestion that one of them is a 'carer'. Neither one sees themselves as taking care of the other.

Eventually we stopped frothing at the mouth when we heard the word 'carer'. Five years after diagnosis, we sometimes mentioned 'carers' in a general way. Even now, after nine years we are still affronted by the suggestion that Pete is my carer. Jan, age 65

It may take ten or fifteen years to slowly move from two adults taking care of each other to a relationship of a carer and a person with Parkinson's. Eventually, the person with Parkinson's has someone in their life who meets the legal definition of 'carer'.

Early dealings with health professionals

A person with Parkinson's and their partner or close family member will be dealing regularly with health professionals.

Ideally you should have a medical specialist (neurologist or geriatrician) who is knowledgeable about Parkinson's and is easy to talk to. This may require seeing more than one - and it is acceptable to seek a second opinion.

As a partner or close family member, you are part of the team working with health professionals and the person with Parkinson's. You spend a lot of time with the person with Parkinson's and can provide a unique insight into the situation. You are entitled to attend medical appointments to support the person with Parkinson's.

At times you may need to speak up for yourself and the person with Parkinson's, so you want to feel comfortable about asking questions and taking notes on the diagnosis or medications.

Treatments

During the early stages of Parkinson's, the doctor or specialist may not suggest the use of medications. Eventually, however, medications play a big part in the management of Parkinson's, there are several issues to consider.

Some medications used to treat other medical conditions may negatively affect the Parkinson's condition. Be sure to read the brochure, *Medications to be used with caution for people with Parkinson's Disease* available from your state Parkinson's association.

The brochure *Medications to be given with caution to people with Parkinson's Disease (for Health Professionals)*, is available from your state's Parkinson's association or can be sent to your health professional.

Parkinson's medications can cause side effects, including but not limited to the following:

- weight changes
- constipation
- vivid and disturbing dreams
- hallucinations
- enhanced depression and anxiety
- changes in sexual awareness
- increased tendency towards obsessiveness, eg gambling, shopping .

Depression and anxiety are frequently related to the Parkinson's condition and seeking medical advice can be very helpful.

Your doctor, specialist or Parkinson's nurse specialist can provide information on medications and their side effects. The brochure, *Medications used in the treatment of Parkinson's Disease* is available from your state Parkinson's association.

The library has educational materials including books, videos and DVDs. We also run educational seminars, all of which are recorded and available for borrowing.

Each state has services unique to its area. Many organisations can assist carers with their role and provide support and information.

Important organisations include:

- Parkinson's WA 08 6457 7373
- Carers WA (Freecall: 1800 242 636)
- Commonwealth Respite & Carelink Centres (Freecall: 1800 052 222)
Your local government authority
- Dept. Human Services: Centrelink Carers (132 717)
Older Australians (132 300)
myGov (132 307)
- Carer Gateway (Freecall: 1800 422 737)
- My Aged Care (Freecall: 1800 200 422)
- Independent Living Centre of WA (9381 0608)
- MedicAlert (Freecall: 1800 882 222)

Further information is available from:

- your doctor or specialist
- Parkinson's Nurse Specialist
- websites
- books
- videos and DVDs.

- sadness to see your loved one suffering.

All of these emotions are completely normal. Here are some ways to manage them:

- recognise how you are feeling
- understand that it is OK to feel this way
- learn how to release negative feelings
- focus your feelings on positive behaviour
- talk about how you are feeling
- get help for depression
- laugh a lot
- learn how to relax
- be open to the caring and support of others.

Getting Help

The association would like to encourage you to become a member of Parkinson's Western Australia and use the resources available in our library, on our website www.parkinsonswa.org.au, and through our bi-monthly newsletter. You can also obtain a referral for the person with Parkinson's to our Parkinson's nurse specialist service.

Planning for your future

Many people put off planning for their future, especially financial and legal matters. Planning ahead is always a good idea and even more important when you receive a diagnosis of Parkinson's.

It is important to ask whether your savings and superannuation will be enough to support you both? Here are some strategies to help you with this challenge:

- review your finances
- reduce unnecessary expenditure
- set up a budget
- check your health insurance.

In time, you will find new ways to define yourself. A major change in your life can provide the opportunity to develop new skills and interests.

Legal issues

Although most people do not like to think about legal issues, now is the time to start to put your affairs in order. You may find that your spouse or partner is gradually less able to manage. Over time you will take on more of the role of a carer with increasing responsibility for legal and financial matters.

For peace of mind and a sense of security, there are two main legal matters to sort out.

- A **will** is a legal document which sets out the wishes of a person for the distribution of their property upon death. If you do not have a will, your assets are divided and distributed according to legislation set by government.

- **Power of Attorney** and **Enduring Power of Attorney** are legal documents which give another person the authority to make financial and legal decisions on your behalf. They can only be drawn up while you can still sign your name and make decisions. An Enduring Power of Attorney remains valid if you become unable to make decisions but a Power of Attorney lapses at that point.

The person with Parkinson's and the spouse or partner should both appoint an Enduring Power of Attorney. If anything happens to either of you, you would both have someone entrusted to manage your affairs.

If you are not familiar with legal matters, consider talking to a lawyer or financial adviser. There may be costs associated with these services. Legal Aid or a local community legal centre may be able to assist you at a reduced cost. Contact your Commonwealth Carelink on 1800 052 222 to find these services in your local area.

Hospitalisation

Most people spend some time in hospital. People with Parkinson's may have to be hospitalised to manage an unrelated medical condition or to improve the medical management of their Parkinson's.

Here are three recommendations when preparing for hospitalisation:

1. Be sure to discuss any planned hospitalisation with your specialist, your doctor or Parkinson's nurse specialist well in advance.

- making time to exercise regularly. This will increase your energy levels and give you a break from your daily routine
- eating regular healthy meals
- taking adequate sleep and rest – exhaustion can add to stress
- talking to a physiotherapist, occupational therapist or your doctor for advice on how to lift and support the person with Parkinson's.

Emotional support

Parkinson's is a life-changing illness. It impacts on everyone close to the person with Parkinson's. You may feel overwhelmed by the rapid changes and the increasing needs of the person you care for.

All kinds of conflicting emotions may arise for carers. You may experience:

- feeling guilty because you do not want to be a carer or because your partner has the disorder and you do not
- denying that your partner has Parkinson's or that it is affecting them
- anger about having to look after the person with Parkinson's, or because Parkinson's has taken your life away
- fear as to the severe disabilities that may happen to the person with Parkinson's in the later stages of the condition
- happiness in being able to spend time caring for the person with Parkinson's
- being over-stressed by this demanding illness and close to physical and emotional exhaustion

Respite options include:

- In-home respite on a regular basis for a few hours a week, when a trained carer comes into your home
- day care centres through the HACC program
- planned residential respite care in a hostel or nursing home facility, while you take an extended break. Not everyone is eligible for residential respite so it is important to be assessed if this type of respite is sought
- planned 'one-off' carer respite periods which provide the carer with a break from the caring role. These are short-term and tailored to meet individual needs.

Commonwealth Carer Respite Centres are located in every state. They are the first point of contact for carers to access the services they require. To find out more about available respite services, call your nearest Commonwealth Carer Respite Centre on 1800 059 059 (24 hours). Your state association may also have information on respite.

Looking after your health

Caring for a person with Parkinson's demands physical strength and stamina. If you are not in good health, caring for the person with Parkinson's will become harder to manage. It is common for carers to neglect themselves in their dedication to helping the person with Parkinson's.

It is as important to take care of yourself as it is to take care of the person with Parkinson's. Considering your own needs can be difficult. Carers are often vulnerable to stress-related illnesses and feel guilty if they take time out for themselves.

Tips for keeping healthy include:

- going out and participating in enjoyable activities

2. Always give a list of the medications used by the person with Parkinson's (with dosages and times) to hospital staff.

3. Read the following brochures which deal with medication and hospitalisation for someone with Parkinson's:

- *Medications to be given with caution to people with Parkinson's Disease (for Health Professionals)*
- *Parkinson's Disease and Hospitalisation: Guidelines*
- *Medications to be used with caution for people with Parkinson's Disease*
- *Medications used in the treatment of Parkinson's disease.*

These brochures are available from your state Parkinson's association.

Driving

Parkinson's can affect the ability to self-evaluate. As a carer or partner, you may perceive the person's driving skills differently than does the person with Parkinson's. Talking about the issue of driving is important, and it can be helpful to speak with your doctor.

In the early stages of Parkinson's, drivers often modify their driving habits, for example, by driving shorter distances and by avoiding peak hour traffic and night time driving.

However, as the condition progresses problems may develop which could result in impaired performance. These may include:

- reduced physical reaction time
- impaired problem solving
- fluctuations in physical symptoms

- tremor
- fatigue
- difficulty attending to dual/multiple tasks, for example, listening to the radio, negotiating traffic or conversing with passengers
- problems with concentration
- on/off phenomenon.

A brochure entitled *Parkinson's and Driving* provides information on:

- driving, Parkinson's and medication
- insurance regulations
- mandatory self-reporting
- what happens if the doctor's advice is ignored
- assessment requirements for driving
- specialist driver assessment and retraining services
- alternative transport options.

Please call 08 6457 7373 for a copy of the *Parkinson's and Driving* brochure.

The Later Years with Parkinson's

Becoming a Carer

A carer is a person who provides ongoing care or assistance to another person who has a disability, a chronic illness or a mental illness, or who is frail and needs assistance in carrying out everyday tasks. Carers may receive income support but are not employed to provide care. Carers are usually family members or relatives but they may be friends or neighbours (*Carers Recognition Act 2004 Western Australia*).

There are many types of support groups. Some are mainly older people; others are mostly younger, working people. Some groups emphasise social activities, some concentrate on aspects of Parkinson's and others go for educational and attitudinal topics. To find a support group that suits you, contact the Parkinson's association or carers association in your state.

Carer's allowances

Carers may be eligible for government benefits such as the Carer's Allowance which is free of income or assets tests and is not taxable. Call Centrelink on 13 2717 to find out about your eligibility and to obtain the relevant application forms for this or similar allowances.

Taking time out

Every carer needs time out to re-energise. Go for a walk, do some gardening, exercise or enjoy your special hobby. Activities like swimming, going to a gym or joining a sporting team are all beneficial. Exercise can improve physical health, increase energy levels and help clear the mind. Find time to relax, because being a carer can be demanding and stressful. Try meditation or Tai Chi.

Carer 'burnout' is a kind of emotional and physical exhaustion. It happens when carers try to shoulder all responsibility. To help avoid this, you need regular breaks from the person you are caring for. You will then return to them refreshed and able to impart new enthusiasm into the daily activities of your partnership. Encourage them to continue with exercises and hobbies, and meeting family and friends while you are away.

Respite care

Planned respite care offers some scheduled time out. You can take a break, knowing that the person with Parkinson's is well looked after. Respite care allows you to have personal free time for a few hours a day or several weeks.

Caring for Carers

Your support networks

Family and friends

One way to cope with the stresses of being a carer is to have a good support network. Friends, family and colleagues can all contribute to your role as a carer. Trying to meet all the needs of the person with Parkinson's can cut both of you off from others. You may end up feeling isolated and alone. So try to find people to help you every day.

Keeping in touch

Resolve to keep in touch with friends and family. Although it may take some effort to organise, meet up for a coffee, a chat or a movie every week. Use the phone and email. Invite friends over to share hobbies or set up a working bee for a big household or gardening task.

Support groups

Being part of a support group can be helpful. Meeting people who are living with Parkinson's is a good way to widen your support network. Talking together and sharing ideas and information can give you a great boost. You may find new ways of dealing with Parkinson's. You and the person with Parkinson's may be invited to participate in interesting research projects or to speak to student and community groups about the condition.

Not everyone wants to join a support group. Some resist the idea of 'those sick people'. Others believe they can deal with their condition on their own. Some younger or recently diagnosed people with Parkinson's, with mild symptoms, find it confronting to observe elderly people with Parkinson's in a wheelchair or go-cart. Usually this resistance wanes. Most people find inspiration and wisdom in fellow members of their support group.

A carer can provide care from two hours a week to 24 hours a day, seven days a week.

As things gradually change and the condition progresses, your lives are gradually changing. The person with Parkinson's finds it harder to do everyday motor tasks such as, slicing bread, turning over in bed, taking things down from the top shelf. They may decide to stop driving. They may need help taking a shower or going to the toilet. Your mutual partnership is slowly moving to a more dependent relationship and one day you realise you have become a carer.

You are now doing tasks the person with Parkinson's once managed for themselves and decisions on social, financial and family outings fall more on your shoulders. Tasks can include organising visits to friends, selecting items while shopping, identifying the correct person to contact for financial matters, selecting suitable clothing for the day's activities, and completing physical tasks which require advanced manual dexterity.

Challenges for Carers

The changing nature of Parkinson's symptoms makes caregiving a challenging experience. Every person with Parkinson's is affected differently by the condition, which means that every carer's experience will differ. Being a carer is very rewarding, but it can also be quite stressful.

It is important that the person with Parkinson's maintains a sense of control. It is good if they can decide when to undertake a major change, such as giving up driving. Try to avoid saying 'you must or you must not'.

Relationships

You may find that your relationships with people change over time as you slowly take on more of the carer's role. The person with Parkinson's is physically less able to participate, and their energy swings may make them less willing to plan activities.

Being alert to the feelings of the person with Parkinson's and encouraging them to join in activities that affirm their self-assurance will be beneficial to your relationship. This may not always be easy but keep trying.

Sharing your feelings with someone you trust can help you to cope better and make others around you more aware of your needs. Each person should feel safe to express their needs and to have their feelings considered and accepted.

Counselling is a good option if you need to talk to someone confidentially. Counsellors will assist you in a variety of ways including managing stress, identifying coping skills and obtaining emotional support. Carers associations in each state offer counselling services at little or no cost to carers. Contact your state carers association about the services they offer. Your closest carers association can be contacted on 1800 242 636.

One of the real sticking points in our relationship was the shift in the balance of responsibility in practical tasks such as shopping, cleaning the house, doing the cooking, washing and ironing. We really tried to keep our channels of communication open and eventually it paid off. Harmony prevailed and now I actually gain lots of enjoyment from my changed responsibilities. Luke, age 58

Mobility

Mobility issues may need to be considered with the person with Parkinson's. You may find yourself playing a more significant role in dealing with these issues which may include:

- aids for showering in the home
- walking and balance aids in the home and while on outings
- applications for ACROD stickers
- restrictions on access to holiday accommodation and methods of travel.

I do most things for June. She has trouble getting out of bed, getting dressed and eating. Her voice is very soft and she talks quite slowly. Jock, age 76

The Independent Living Centre of WA is an excellent resource. For equipment call 1300 885 886 or for enquiries call 08 9381 0608. The Centre is situated in The Niche, 11 Aberdare Road, Nedlands.

Easywear Australia - is an Australian company - specialising in design and manufacture of clothing for a variety of clients including people with Parkinson's. Visit the website www.easyweraustralia.com.au or phone (08) 9445 2333.

Accommodation options

Planning where you are going to live is very important. It may be better to downsize your home to something smaller or easier to access for the person with Parkinson's before the condition forces you to move. Things to take into consideration may include:

1. The number of stairs and steps to negotiate.
2. The level of shelving. High shelving and very low shelving may become difficult to reach.
3. Suitable access for walking frames.
4. The maintenance requirements of the garden.
5. Whether you still need the large shed or garage?
6. The need to de-clutter your home so it is easy to move around?

Eventually you may no longer be able to care for your partner at home. Discussing residential care can be particularly difficult. By speaking about it openly, you may be able to agree on the type of nursing home that suits both of you. You can explore the different aspects which point to the appropriate time to move to long-term care.

Communicating with the person with Parkinson's

As the condition develops, it may become difficult for the person with Parkinson's to express themselves. Be patient and do not rush them. They may have trouble getting their thoughts and words together. Ask questions with simple answers, such as 'yes' or 'no'. Sit or stand directly facing them and give them your full attention. You can also try using other methods, such as writing or typing.

I really found it challenging to accept my husband's masked face – it took me a long time to understand I must look past this and to the person. I had to stop trying to identify just with the face. We are back to the great discussions we used to have and gain greater enjoyment in just being together, listening to our favourite music. Tracy, age 72

Our Parkinson's nurse specialist was very helpful when I lost patience. I tried to do everything for Stuart. I just ended up so frustrated – but the nurse pointed out how I was turning Stuart into 'something to or for whom things are done'. As I have learned strategies from the nurse, patience has returned. I now allow plenty of time for Stuart to complete his morning ablutions. We have purchased easy-to-slip-on clothes with some velcro fastenings. When meal times seem to become extended I think how great it is to have time to just sit and be. Louise, age 68

The brochure, *Parkinson's Disease and Communication*, is available from your state Parkinson's association.

Sexuality

Parkinson's can impact on sexual relationships. It may affect a person's physical abilities to engage in sexual intercourse. Some of these problems can be rectified and are best discussed with your doctor.

Couples have their own ideas about what makes for a healthy and satisfying sex life. You and your partner need to decide what works for you. You both may need to change the way you think about or engage in sexual activities. Speaking to a professional or seeing a sex therapist or counsellor may help as long as both partners are open and willing to take part.

Often discussions on sexuality are very clinical and dry. We wanted to liven up. We can still have fun! Where there's a will, there's a way. Lots of ways! Tony, age 62

Depression and anxiety

About half of the people diagnosed with Parkinson's will experience depression at some stage. Severe depression is seen in about 20 to 40 per cent of cases. Sometimes, the depression can be more disabling than the Parkinson's itself. Correct diagnosis and treatment are essential for maintaining a high quality of life. Depression is treatable and a person can recover with the right advice and help.

Good resources are available.

- Contact your Parkinson's nurse specialist to discuss a plan for the person with Parkinson's.
- Access information from your state Parkinson's association.
- Watch the DVD *Depression and Parkinson's Disease*. (available from your state association)

More on dealing with health professionals

Over time, you begin to provide most of the care and support for the person with Parkinson's. The decisions made with health professionals will impact on you as well as the person with Parkinson's. You should feel comfortable to contribute and have a say in treatments and care plans. If you feel you are not being included in consultations and decision-making, talk to your health professionals about this.

Emergencies

Suppose something happens to you or the person you care for? Do you have an emergency plan in place? An easy way to draw up a plan is to get an Emergency Care Kit from Carers WA on 1800 242 636. This kit contains a Carer Emergency Card, Medi-List and Emergency Care Plans that are easy to fill out. A contact number is provided should you require assistance in completing the forms.

Key elements of your emergency plan

- MedicAlert bracelets or necklaces are useful for people with Parkinson's. They contain information on an individual's condition, for example, allergies, Parkinson's or special needs. This information is essential in an emergency, for correct diagnosis and treatment. To find out more call, MedicAlert on 1800 882 222.
- Include the state Parkinson's association brochures on medications and on hospitalisation in your kit.
- Do not hesitate to call for an ambulance if you think you cannot handle a medical situation.