



Parkinson's  
Disease Society

## Living Alone with Parkinson's

Many people with Parkinson's disease live alone and manage very successfully. The single life has its own benefits and much can be done to improve the quality of life and alleviate the worries of those who are concerned about living on their own. This information sheet provides useful information about the support available and also has advice and tips from a number of people with Parkinson's who live alone.

Although many people feel that their single status will make their situation worse, a great deal of constructive advice and support is available to help people living by themselves feel safer, more positive and less alone.

### General considerations

For many single people, the issue of retaining their independence and safety in their own home is paramount and causes the greatest worry.

In terms of basic home safety, a common concern is fear of falling, but a lot can be done to make the home less hazardous, including the following:

- Rearrange furniture and rugs to make rooms safer, eliminate trailing electric leads and fix loose carpets.
- Add grab rails around the house (stairs, bath or shower, for example).
- Brighter lighting can make moving around much safer.
- Use item 'grabbers' (long-handled tools) to pick up objects.
- Kitchen gadgets such as long-handled scissors, special bottle openers and key turners can help.

- Bathroom gadgets such as large-handled hairbrushes, tap turners, pump toothpaste and shampoo dispensers can also help.

### Domestic services

If you find coping at home difficult, you may be entitled to certain services such as a home help, meals on wheels or laundry services. If you think you need such assistance, contact your social services department (social work in Scotland) who will arrange for your needs to be assessed. This involves someone, often a social worker, visiting you at home to find out what support you need and then arranging services for you as appropriate. The Parkinson's Disease Society (PDS) booklet *Choices: A Guide to Health and Social Care Services* gives more information.

### Financial matters

Living alone can also be difficult financially and it can be hard to enjoy life if money is tight. Make sure that you are receiving all the benefits and help to which you are entitled. This is also important if you are recently single because you have been widowed, separated or divorced.

The PDS has a number of information sheets on financial and employment matters. These can be viewed on the PDS website ([www.parkinsons.org.uk](http://www.parkinsons.org.uk)), or print copies can be ordered by phoning Sharward Services Ltd, our distribution house. If you need advice to help you manage debts, your local Citizens Advice Bureau can also help. Their address can be found in your local phone book, from your local reference library or via their national website ([www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)).



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## Safety issues

When you have Parkinson's, having a phone can be a lifeline. There are many phones with special features to overcome common problems that disabled people can experience. If you do not have a phone, help may be available to enable you to get one. The Disabled Living Foundation has a useful fact sheet *Choosing a Telephone, Textphone and Accessories* which provides details of the different types of phones available. It may also be a good idea to carry a mobile phone with you when you are out in case of an emergency. Your local occupational therapist can also advise further on phones. See 'Further practical information and advice' below for contact details.

Community alarms are a more sophisticated form of help which may be worth considering if you worry about being on your own and how to cope with things like falls. A community alarm allows you to call for help in an emergency, either by hitting a special button on your phone or by pressing the alarm on a special device worn around your neck or wrist. When the alarm is activated, it alerts people at a 24-hour response centre who then get the appropriate help. Centre staff can also help with other, non-emergency advice. Many local authorities run community alarm schemes, as do agencies such as Age Concern (Aid Call Freephone 0800 772266, [www.aidcall.co.uk](http://www.aidcall.co.uk)) and Help the Aged, whose SeniorLink response centre staff will chat with you if you are feeling low. Further details are available from the website [www.helptheaged.org.uk](http://www.helptheaged.org.uk) (search for SeniorLink) or by phoning 0845 603 4576.

There is a charge for most of these systems, but some people may qualify for a free system. The criteria will vary according to the system used.

Help the Aged also publishes a leaflet called *Your Safety* which can be accessed via the website (see above), email: [adviceleaflets@helptheaged.org.uk](mailto:adviceleaflets@helptheaged.org.uk).

Your local police station has a crime prevention officer who can visit you to advise on making your home as secure as possible.

In the winter, consider keeping a stock of basic foods so that you have enough supplies to keep you going for a few days in an emergency.

Keep details of your doctor and close relatives/friends in an obvious place (perhaps behind the front door) so people know whom to contact in an emergency.

## Sleeping

- Many people find satin or silky-type slippery sheets a great advantage, particularly to make turning over in bed easier.
- A duvet, rather than sheets and blankets, can be lighter to move under and easier to handle.
- You can tie a device such as a rope with knots in it or a mini rope ladder to the end of the bed to help you to pull yourself up. Get advice from an occupational therapist before you do this to ensure that the device you are using is safe. See 'Further practical information and advice' below for contact details.
- See also the PDS information sheet on *Sleep and Night-time Problems*.

## Dressing

- Sit down if you can or try to stand next to a sturdy piece of furniture, such as a dressing table, which you can lean on for support.
- Replace any fiddly dressing devices where you can; for example, change trousers



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with zips to elasticated waists, and change buttons to Velcro fastenings.

- The PDS publishes an information sheet on *Clothing*. Some Disabled Living Centres also employ clothing advisers who can give individual advice. The Disabled Living Foundation also has a range of fact sheets on clothing.

### **Bathing**

- Consider a bath seat and grab rails.
- To avoid dropping the soap, buy a soap mitt or make one from a pair of tights.
- Put a non-slip mat in the shower/bath.

### **Accepting help with practical issues**

Sometimes it can be difficult to accept the need for help with practical tasks, but they can make life easier to manage, particularly when you live alone. As Gary Hattie says:

“I had a problem accepting that I might need alterations to my house – that meant I was *disabled* and I’m not disabled! However, I crossed this barrier eventually and got grab bars fitted in the shower and also a chopping/cutting aid for cheese. They do help.”

Jill Martin uses a number of gadgets to make her life easier, such as an ‘adjustamatic’ bed, a lifting chair and a ‘helping hand’ grab device. Jill uses a stick and no longer wears heels, to make walking easier and reduce the likelihood of falling. She says bathing and getting dressed are the hardest things to manage alone. “I now have to accept that it may take a long time to get dressed,” she says. Jill has bought clothing to make dressing easier, for example with buttons on the front instead of back zips, and with elasticated waists.

Jill also has had an alarm system fitted so she can contact people for help when needed, and someone comes four mornings a week to help with household chores. Small changes such as these can help you feel safer and more comfortable at home.

### **Further practical information and advice**

If you have any concerns about activities of daily living such as dressing, bathing or cooking – or are considering adaptations to your house or buying equipment – we recommend that you seek advice from an occupational therapist first.

Occupational therapists treat people of all ages who have physical, social or mental health problems to improve their everyday function, maintain independence and reduce the problems that disability can cause in all aspects of daily life. As well as activities in the home, their advice can cover work, leisure and relaxation.

Where appropriate, occupational therapists will also advise on suitable equipment. In some areas, it may be possible to borrow the equipment rather than having to buy it. Where you do have to buy, the occupational therapist will suggest the best kind of equipment for your needs and how to get hold of it. Sometimes the occupational therapist may also suggest adaptations for your home. Again, in certain areas, the local authority may supply technicians to make the changes.

Occupational therapists can also help with assessing an individual for a grant to cover such changes.

You can usually refer yourself to occupational therapy via your local social services department (social work in Scotland)



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or through your GP, hospital doctor or Parkinson's Disease Nurse Specialist (if you have one). See the PDS information sheets *Occupational Therapy and Parkinson's* and *Equipment* for more information.

The Disabled Living Foundation provides information and advice on equipment to help people with disabilities. As well as their helpline, they have a number of centres throughout the UK where you can get professional advice and try out equipment. In most centres you need to make an appointment first. Contact:

Disabled Living Foundation  
380–384 Harrow Road, London W9 2HU  
Helpline: 0845 130 9177 (Mondays to Fridays  
10am–4pm) Minicom: 020 7432 8009  
Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)  
Website: [www.dlf.org.uk](http://www.dlf.org.uk)

### **Emotional and psychological considerations**

Physical issues are more visible and sometimes easier to come to terms with than emotional ones. For some people living alone, isolation, loneliness and depression can prove more difficult to deal with.

Depression is very common and affects some 40–50% of people with Parkinson's. Those who live alone may be particularly prone to reactive depression, and these feelings can sometimes seem overwhelming. There is more information in the PDS information sheet *Depression and Parkinson's*.

Gary Hattie says: "It is easy when you're on your own to get very frustrated with yourself when things go wrong or you can't do what you used to be able to do. You have to deal with this in your own way – but deal with it

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positively. The 'downers' are annoying but remember it is commonplace with Parkinson's and you are not the only one depressed.

Try to find something that helps you turn it around. I find a diary helps; it reminds me how I got through previous 'downs'. Use the phone – pick it up and speak to someone, ideally someone who will understand and cheer you up, but speak to somebody. I have tried to deal with depression on my own, and one day soon leads to a week. My advice is to nip it in the bud."

### **Where to find support**

It is easy to let little worries grow into big ones when you have no one close to share them with.

There are many people who can help. If you have a particular worry or need to talk something over, call the PDS Helpline (freephone: 0808 800 0303). The line is available Mondays to Fridays, 9.30am–9pm, and Saturdays, 9.30am–5.30pm (except bank holidays). Your local PDS branch can provide support and company to you as a single person via a phone call or home visit, or through the many social and informative events that branches hold. Many branches also have Community Support Workers who can help you access local services and offer you general support in coping with Parkinson's. They may also be able to link you with another person with Parkinson's who lives on their own, for mutual support. For more details of your local branch, contact the PDS Helpline on 0808 800 0303.

If you are of working age or younger, the PDS group for younger people with Parkinson's, YPN (Younger Parkinson's Network), can offer



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you support and opportunities to meet other younger people with Parkinson's who live on their own. Further details are available via the PDS Helpline.

If your area has a Parkinson's Disease Nurse Specialist, they can offer support and will give you advice if you are feeling particularly down. However, if you find your depression remains a major and ongoing problem, it is important that you talk to your GP or specialist doctor. Treatment with antidepressants can be very beneficial in easing depression in people with Parkinson's. Counselling, which can be arranged through the GP or specialist, can also be helpful.

Gary Hattie says: "Living alone, the main barrier I found was to get myself to go out and live my life. The longer this stage goes on, the harder it is to beat, but beat it you must. I know because I went through it on my own for about four years before I gave myself a talking to in order to get out there. I was fortunate – I had the support of my neighbours, George and Susan, who helped me through what I call my 'going out problems', also the downs; they're not nosy neighbours, but caring – there is a big difference. When you live by yourself, it is very hard all of a sudden to talk to people about what's wrong with you, you tend to want to deal with it yourself."

Some people say that making a daily list of tasks gives them more focus and a sense of achievement – it is often helpful to break down large tasks into more manageable, small 'bites'. Others find a regular routine of activities helps structure the day. It is good to give yourself objectives, but be kind to yourself and allow more time.

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Mr Mackie comments: "Set aside a day to tackle things. You do require a great deal of patience – I am lucky in being a very patient man! I am also fortunate in that I am a retired engineer, and there are many things that I have been able to adapt around the house to make life by myself easier.

Don't try to tackle too much. Accept your limitations – that you will be slower, and so on. I don't drive but I can walk about half a mile – enough to make it to the pub when I feel like it. Public transport is OK not brilliant, one bus an hour only, but it gets you up to the main road. My biggest problem is I am not much good at cooking. Every once in a while I invite some people round to prove that I'm still capable of making a meal without poisoning anyone!"

Coping on your own can also increase your stress levels.

Phil Carter, who lives alone and is self-employed, says: "this can be difficult. However, there are ways of coping. Try to keep yourself busy – try sport for example." He has also found YPN very helpful: "A great bunch of people."

Gary Hattie also finds YPN very supportive: "I am very fortunate, I know, because when I finished work I had YPN Scotland to keep me occupied. I do feel you have to do something. I also build things. It's good to keep the grey matter stimulated.

When I first finished with work I made myself some ground rules:

- eat properly
- take medication on time
- keep yourself occupied



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- once a week be creative
- don't mope about and if you do phone someone
- keep your sense of humour!"

Those living alone who haven't got many close friends or relatives nearby can become lonely. If you are feeling cut off, there are things you can do. As well as contacting the PDS, find out about the many activities that will usually be available locally. One of the best places to find out what is going on is your local library, which will have lists of local social activities, events, education and leisure facilities, classes, etc. Many also have local newspapers and magazines, and access to computers and the internet.

Most areas have a variety of community services available such as day centres, drop-in centres, lunch and social clubs. Activities available range from simply chat and tea, to recreational activities like arts and crafts; some even supply services such as chiropody and hairdressing. If you are unsure what is available, the local branch or PDS area officer may be able to advise.

If you have difficulty getting out and are 70 or over, you could try the following organisation which organises visits and outings for older people:

Contact the Elderly, 15 Henrietta Street,  
London WC2E 8QG  
Tel: 020 7240 0630  
Website: [www.contact-the-elderly.org](http://www.contact-the-elderly.org)

### **Pets**

Some people find having a pet a great comfort, making them feel less isolated. Pets have even been shown to relieve stress and to lower blood

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pressure. Remember, though, that some can get underfoot and all pets involve a commitment.

You might be concerned about what would happen to your pet if you had to go into hospital. For people over 60 years of age, the Cinnamon Trust may be able to help. This is an organisation that aims to help people over 60 years, or terminally ill people, stay with their pets for as long as possible. With the help of over 4,500 volunteers, the services they offer include dog walking, for people with limited mobility, and pet fostering. Further details can be obtained from the Cinnamon Trust on 01736 757900 or website: [www.cinnamon.org.uk](http://www.cinnamon.org.uk)

The Trust is, unfortunately, not in a position to help those under 60 years, but the following animal welfare organisations may be able to advise further:

- The National Animal Welfare Trust has an emergency pet care scheme for members (tel: 020 8950 0177 or [www.nawt.org.uk](http://www.nawt.org.uk)).
- The RSPCA (tel: 0300 1234 555)
- The Cats Protection League (National Helpline: 03000 121212 email: [helpline@ccts.org.uk](mailto:helpline@ccts.org.uk))
- The Blue Cross (tel: 01993 822651)
- The Pet Fostering Service Scotland provides an emergency care service for anyone of any age living in Scotland who has to go into hospital or respite care and is temporarily unable to look after their pet (tel: 01877 331496).
- Age Concern and Help the Aged have a useful information sheet, Leisure Ideas, which contains information about pets. For further details see [www.helptheaged.org.uk](http://www.helptheaged.org.uk) or email: [adviceleaflets@helptheaged.org.uk](mailto:adviceleaflets@helptheaged.org.uk).



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- There may also be an animal lover in your local PDS branch or local YPN group who might be willing to help.

### **Maintaining privacy**

Although there are some advantages to lone living, some people can find themselves prey the unwanted attentions of others. In particular, some older men have reported that well-meaning people can fail to respect their privacy and visit frequently, uninvited and without warning. Help is welcomed, but not intrusion, so neighbours and friends must try to get the balance right.

An advantage of lone living is that it forces you to keep physically and mentally active by looking after yourself and you may find you make more of an effort to go out and do things, which will reap its own rewards. You do not have the additional worry of a carer to think about. Many people find sleeping on their own is much easier too!

The future remains a big worry for many single people who fear that they may not be able to cope. There are, however, many options available in terms of care; but planning is paramount. More, and earlier, thought needs to be spent on planning the future. Although this may be hard, the earlier you start to plan for the future the more control and choice you may have.

Jill Martin, who is coping well on her own, is making all the adaptations necessary in order to remain independent. Her cats provide company and she wants to remain living at home as long as possible so she doesn't have to lose them. However, more residential places (eg. Anchor Trust Homes) do take animals now, because they recognise how important they are to people.

The PDS booklet *Choices: A Guide to Health and Social Care Services* provides information on what to consider when looking into care services and care, residential and nursing homes when you have Parkinson's. Remember, however, that help is also available to enable you to stay at home for as long as you wish.

Keep active, eat well and learn to relax – the mantra of Parkinson's care applies to people living on their own especially. If you are not coping well alone, help and advice are at hand – please take advantage of the support available.

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215 Vauxhall Bridge Road, London SW1V 1EJ, UK

**Tel:** 020 7931 8080 **Textphone:** 0800 111 4204 **Fax:** 020 7233 9908

**Helpline:** 0808 800 0303 (The Helpline is a confidential service.)

Calls are free from UK landlines and some mobile networks)

**Email:** enquiries@parkinsons.org.uk **Website:** www.parkinsons.org.uk

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