



Living Alone with Parkinson's

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PDS Information Sheet

Many people with Parkinson's live alone and manage very successfully. For some people, the lack of a carer can be alarming. However, the single life has its own benefits, and much can be done to improve the conditions and alleviate the worries of those who live on their own.

Many concerned with Parkinson's fall into the trap of assuming that most people have a carer living with them. In fact 28% of the UK population – 6,729,000 people – live in one-person households, and this includes many people with Parkinson's.

For many, living alone is a choice, bringing its own pleasures, even when Parkinson's comes on the scene. However, for others, the diagnosis of Parkinson's feels catastrophic; many feeling that their single status will make their situation worse. However, a great deal of constructive advice and support is available, to help people living alone feel safer, more positive and less alone.

Practical Issues

General Considerations

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

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

- Rearranging furniture and rugs to make rooms safer and eliminating trailing electric leads and fixing loose carpets.
- Adding grab rails around the house (stairs, bath or shower etc.)
- Brighter lighting (can make moving around much safer)
- Using item "grabbers" (long-handed tools to pick up objects)
- Kitchen gadgets, such as long-handled scissors, special bottle openers, key turners, etc.
- Bathroom gadgets, such as large handled hairbrushes, tap turners, pump toothpaste and shampoo dispensers etc.

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 you need and then arranging services for you as appropriate. The PDS booklet, *Meeting Your Health and Social Care Needs (code B49)* gives more information.

Financial Matters

Living alone can also be extremely difficult financially. 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.

For further help, ring the PDS Welfare and Employment Rights Department on 020 7932 1340. They publish a range of fact sheets on financial matters and can also give you individual advice as appropriate. If you are employed, they can also advise on employment issues. If you need advice to help you cope with debts, your local Citizens Advice Bureau can also help. Their address can be found in your local phonebook or from your local reference library or via their national website: www.nacab.org.uk

Safety Issues

- When you have Parkinson's, having a phone can be a lifeline. There are many telephones that have special features to overcome common problems that disabled people can experience. If you do not have a phone, help may be available to allow 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. A mobile phone may also be a good idea to carry with you when you are out in case of an emergency. Your local occupational therapist can also advise further on telephones. See *Further Information and Advice* at the end of this section 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 falls etc. These allow you to call for help in an emergency, either by hitting a special button on your phone, or 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) and Help the Aged, whose 'SeniorLink' response centre staff will

also have a chat with you if you are feeling low. Further details are available from their website: www.helptheaged.org.uk - search on SeniorLink or by phoning 01255 473 999. 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 publish an information sheet called *Living Alone Safely*, which can be accessed via their website or obtained by phoning them on 020 7278 1114.

Make your home as secure as possible, so you feel comfortable. Your local police station has a 'Crime Prevention Officer' who can visit you to advise on this.

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.

Pin 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.

Other Practical Tips

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 use to help you to pull yourself up with. Get advice from an occupational therapist before you do this, to ensure that the device you are using is safe. See *Further Information and Advice* at the end of this section for contact details.
- See also the PDS information sheet on *Sleep and Night-time Problems (FS30)*.

Dressing

- Sit down if you can, or try to stand next to a dressing table, etc., which you can lean on for support.
- Replace any fiddly dressing devices that you can, for example, change trousers with zips to elasticated waists; change buttons to Velcro fastenings.
- The PDS publishes an information sheet on *Clothing (code FS31)*. Some Disabled Living Centres also employ clothing advisers who can give individual advice. The Disabled Living Foundation also has a fact sheet on clothing.

Bathing

- Consider a bath seat and grab rails.
- To keep the soap from dropping, buy a soap mitt, or make your own from an old 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. 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, a chopping/cutting aid for cheese, etc. They do help."

Jill Martin uses a number of gadgets to make her life easier, such as an adjustomatic bed, lifting chair, and 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, with buttons on the front, no back zips, elasticated waists etc.

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 information and advice

If you have any concerns about activities of daily living such as dressing, bathing, cooking, adaptations to your house, or are considering 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 with activities of daily living. 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 buying 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 they may also suggest adaptations for your home. Again in certain areas, technicians can be supplied by the local authority 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) or through your GP, hospital doctor, or Parkinson's Disease Nurse Specialist (if you have one). See the PDS leaflets, *Occupational Therapy and Parkinson's (Code B47)* and *Equipment (FS59)* 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 in order to visit the centre. Contact:

Disabled Living Foundation,
380-384 Harrow Road, London, W9 2HU.
Helpline: 0845 130 9177 (Mondays to Fridays 10 am – 1 pm) Minicom 0870 603 9176
Email: advice@dlf.org.uk
General website: www.dlf.org.uk
Factsheet website:
<http://factsheets.disabledliving.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, affecting up to 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* (FS56).

Gary Hattie says, *'It is very 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 cope in dealing with this in your own way - but deal with it positively. The downers are annoying, but remember it is commonplace with Parkinson's and you are not the only one depressed. Try and 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 that 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 also many people who can help. If, you have a particular worry, or need to talk something over, the PDS Helpline nurses (freephone: 0808 800 0303 9.30am – 5.30 pm Mondays to Fridays,

except bank holidays) are there to help. Your local PDS branch can provide support and company to you as a single person, via a phone call, a 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 Branch Support Unit at the PDS national office on 020 7932 1306/020 7932 1338.

If you are of working age or younger, the PDS's group for younger people with Parkinson's, the YAPP&Rs (Young Alert Parkinson's Partners and Relatives) can offer 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 (PDNS) he or she can offer support, and will give you advice if you are feeling particularly down. However, if you find your depression remains a major and on-going problem, it is important that you talk to your GP or specialist doctor. Treatment with anti-depressants 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 kick up the backside 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 neighbours - 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 sense of achievement - it is often helpful to break 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.

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 round the house to make life by myself easier.*

'Don't try and tackle too much. Accept your limitations; that you will be slower, etc. I don't drive - I can walk about half a mile - enough to make it to the pub of an evening 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 works for himself, says '*this can be difficult*'. However, '*there are ways of coping*'. *Try and keep yourself busy - try sport for example.*' He has also found YAPP&Rs very helpful, '*A great bunch of people.*' See the PDS publication *At Your Leisure (B75)* for more information on sports and leisure activities.

Gary Hattie also finds YAPP&Rs very supportive, '*I am very fortunate I know, because when I finished work I had YAPP&Rs 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
Once a week be creative
Don't mope about, and if you do, phone someone*

Keep your sense of humour! These may look petty, but try and stick to them and see how hard it is.'

Those living alone who haven't got many close friends or relatives nearby can become a little lonely. If you are feeling cut off, there are things you can do. As well as contacting the PDS, many activities will usually be available locally. One of the best places to find out what is going on is at your local library - which will have lists of local social activities, events, education, 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+, you could try the following organisation which organises visits and outings for older people:

Contact the Elderly, 15 Henrietta Street, London WC2E 8QG. 0800 716 543
Website: 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 lower blood pressure. Remember though that some can get under-foot, and all pets are a commitment.

You might be concerned what would happen to your pet if you had to go into hospital. For people over 60 years of age, the Cinnamon Trust maybe able to help. This is an organisation which aims to help people over 60 years or terminally ill people stay together with their pets for as long as possible. With the help of their 3000+ 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

The Trust are unfortunately are 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 (contact 020 8950 0177 or www.nawt.org.uk).
- The RSPCA (0870 333 5999)
- The Cats Protection League (08702 099099)
- The Blue Cross (01993 825500)
- The Pet Fostering Service Scotland provides an emergency care service for anyone of any age living in Scotland who has to go into hospital/respite care etc. and is temporarily unable to look after their pet. (01877 331496).

Help the Aged have a useful information sheet on Pets. (www.helptheaged.org.uk/ 020 7278 1114).

There may also be an animal lover in the local branch or local YAPP&Rs group who might be willing to help.

Maintaining privacy

There are some advantages to lone living and many people prefer living this way. Some people, however, can find themselves a prey for the unwanted attentions of others. Some older men particularly have reported that well meaning people can fail to respect their privacy, and visit frequently, uninvited, and without warning. Help is wanted, not intrusion, so neighbours and friends must try and get the balance right.

Advantages of lone living include the fact that it forces you to keep physically and mentally active 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!

Facing the Future

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 may have 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 (e.g. Anchor Trust Homes) do take animals now, recognising how important they are to people.

The PDS has a booklet called *Choices: Planning for the Future* (B70) which provides information on what to consider when looking into care services, 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. The PDS publication *Meeting Your Health and Social Care Needs* (B49) has more information.

Keep active, eat well, and learn to relax - the mantra of Parkinson's care applies to people living on their own especially. If you aren't coping too well alone, help and advice are out there - please take advantage of the support available.

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