

Living alone with Parkinson's

Many people with Parkinson's live alone and manage very well. But it's natural to feel lonely sometimes or worry how to get help when you need it. This information sheet looks at some of the issues related to living alone and what you can do to maintain your independence for as long as you want.

Staying connected

Everyone with Parkinson's is different. For some people, living alone is not an issue. Others may sometimes feel isolated or lonely.

Many people with Parkinson's have told us that they get a lot of emotional support by making time for family and friends, and meeting others with similar experiences. Living alone can sometimes make meeting others a bit more difficult, but there are ways to stay connected. You could try the following.

Making the most of social contact

You don't have to see lots of people or go to big events such as a party to feel connected. Something like starting a conversation with a neighbour or inviting a friend around for tea can help.

Joining a club or class

This might be something that relates to a passion or hobby you have. For example, a language course or a photography class.

Organising a regular outing

Getting out at regular times can help establish a routine. This might be something like going to the cinema, going to a book club or an exercise class.

Volunteering

This can be a great opportunity to meet like-minded people while doing something you enjoy. Volunteering can also be a good alternative if you're no longer in paid work but would like to utilise your skills.

Meeting others with similar experiences

We offer lots of ways of meeting people affected by Parkinson's, including our local groups and peer support service. You can find out more on page 9.

An online forum is also a good platform to meet others who share the same interests. This might be especially useful if you live in a remote area, or find it difficult to get out and about. You can visit the Parkinson's UK online forum at parkinsons.org.uk/forum.

Find out more: see our information sheet *Using computers and the internet*. Organisations such as AbilityNet may also be helpful. See page 7 for contact details.

Relationships

Some people may live alone because they do not have a partner.

If you're single and interested in dating, there's no reason Parkinson's should stop you. We've heard from many people living with the condition who have developed long relationships after diagnosis.

Some people live alone because their relationship has broken down. If your relationship has ended, it's important to try and come to terms with what has happened.

For some people we've spoken to, a separation or divorce can be a very difficult experience. Others have told us that they saw the end of their relationship as a change for the better. Whatever the circumstances, if your relationship does end, it can feel overwhelming and you may worry about what the future will hold. But there will be others going through a similar experience and it's important to remember there is support available to help you.

Organisations such as Relate offer counselling for people coming out of a relationship. Their contact details can be found on page 8.

Your Parkinson's local adviser can also offer emotional support to you.

Find out more: see our information sheet *Intimate relationships and Parkinson's*.

Mental health

Everyone feels lonely at times. But constant feelings of loneliness or isolation can have a negative effect on your mental health, so it's really important to get help before the situation gets worse. Finding ways to cope with your thoughts and feelings will improve your mental health and help you to better manage all the practical issues that Parkinson's can cause.

Talking to someone you trust about your feelings may be helpful. You may choose to talk to someone who knows you well, such as a partner, relative or friend. But some people like to speak to someone who is not close to them. This could be a health or social care professional, a Parkinson's nurse or your Parkinson's local adviser. You could also speak to a professional counsellor. They will help you look at your life and the feelings you have in a safe environment. They won't give you medical advice, but they'll give you space and time to consider

“Having lunch with a friend each week is an anchor for me. I get out, eat well and have company. It breaks up my day and I get to chat about my life as well as theirs. Having a designated day keeps arrangements simple, and if either one of us can't make it, we can pick where we left off the following week.”

Paul, an artist who exhibits his work regularly in West Yorkshire

your feelings and actions to give you an idea of what you find hard and why. This can help you to sort out your feelings, accept your situation or make changes to your life.

Many GP surgeries have counsellors attached to their practice or can give you information about other local counsellors. There are also other counselling organisations that can give you information and details of private counsellors. These include Relate and the British Association for Counselling and Psychotherapy (see pages 7 and 8 for more details).

We also have a peer support service, where you can speak to trained volunteers who have a similar experience of the condition as you. You can find out more at parkinsons.org.uk/peersupport or by calling our helpline.

You may also find it useful to attend the Parkinson's UK self-management programme, where you can meet other people with the condition to talk about best ways to navigate life with Parkinson's.

You can find out more at parkinsons.org.uk/selfmanagement or see page 9.

Depression and Parkinson's

If you have lasting feelings of extreme sadness for weeks or months, you may be depressed.

Depression can be common among people with Parkinson's, whether someone is living alone or not. A person who is depressed will typically feel a lack of interest in or pleasure from usual activities and may also feel down or hopeless almost every day.

Depression can be treated. Speak to your GP, Parkinson's nurse or specialist.

Find out more: see our information sheet *Depression and Parkinson's*.

Pets

Suggesting getting a pet if you live alone may seem a cliché. But studies have shown that owning a pet, such as a dog, can have a therapeutic effect and improve quality of life.

As well as providing company, having a pet may also motivate you to keep active and get out and about.

Keeping a pet is a long-term commitment and you should always seek advice from specialist organisations or charities before making any decisions. See pages 7 and 8 for details of organisations.

Daily living

Some people with Parkinson's who live alone find that they can manage their symptoms well day to day and don't need any help. But, as the condition progresses, some people may find they need some support doing everyday activities, including:

- bathing
- getting dressed
- shopping
- laundry

- making meals
- washing up
- cleaning

If you find daily activities difficult, talk to your GP, Parkinson's nurse or specialist about what sort of practical support you may be able to access. An occupational therapist or social services assessment may be helpful.

Your Parkinson's local adviser can also provide details of, and links to, local services. See page 9.

How can an occupational therapist help me?

An occupational therapist can help you maintain your health and independence so you can carry on doing activities that are important to you.

They may be able to help by:

- providing help and training on new ways to carry out daily activities such as bathing, dressing, eating, working and learning
- offering advice on adapting your home or workplace to meet your needs
- assessing and recommending equipment and advising on aids to help around the home or workplace
- giving you advice on getting out and about
- promoting your sense of wellbeing by helping you find ways to continue with hobbies and interests, such as gardening or sports

You can usually contact an occupational therapist through your GP, your social services or social work department, or health and social care trust.

You can also access occupational therapy privately, though this will cost money.

Find out more: see our information sheet *Occupational therapy*.

How can social services help me?

Your local social services or social work department should arrange support if you need help to live independently because of your age, health condition or disability.

If you fit into any of these categories they must assess you to see what services you need and what's available in your area. A care manager or social worker will carry out a needs or care assessment. This will usually take place in your home, and will take into account your personal needs and your social and cultural background.

“Three years ago, I decided to get a dog. Having grown up with dogs, I thought it would be good company for me.

Cookie, my Jack Russell, watches me all the time. If I can't do my jacket up, he will sit patiently, looking like he would help me if he could.

Even if I don't feel like it, I have to take him for a walk, so I can't lie around and do nothing – he gets me out of bed in the morning.”

Kay, who can often be found painting in her shed

From this they will develop a care plan with you and give you a copy of it. This might be provided by your local social services or social work department, or department of health and social services, or by private agencies and voluntary organisations. Different local authorities have their own ways of deciding who gets access to which services.

The types of services available will change according to where you live, but might include help in your home with things like housework, day care, equipment or changes to your home. They may also be able to help with things like leisure and meeting people.

Who pays for social care?

Your needs assessment is free of charge. Who pays for any services that social services recommend depends on your finances and whether you qualify to receive the services where you live.

Contact your local social services or social work department for more information. You can also call our helpline on **0808 800 0303**.

Staying safe

If you live alone, you may have concerns about being able to manage day to day in the safest way possible. You may want to think about:

- preventing falls or other injuries
- reducing your vulnerability. For example, avoiding scam or nuisance phone calls or rogue doorstep traders

An occupational therapist can advise you on safety in and around your home. They may suggest:

- using non-slip mats in the bath or shower
- rearranging furniture to make moving around your house safer
- checking that electrical leads don't cross walkways
- fixing loose carpets and floorboards
- installing grab rails alongside stairways and in places that you find hard to move around
- using equipment or disability aids to make some activities easier and safer
- installing a 'key safe', where a wall code is fitted to the house. This means that keys don't need to be left under doormats and multiple keys don't need to be handed out. People such as carers can also access the property in an emergency

Scams

While there are many genuine tradespeople and officials, it's wise to be on your guard when you answer your door. Doorstep scammers can be pushy.

- If someone comes to your door, ask for their identity card and check it carefully. Keep your utilities services phone numbers handy so you can easily call and check an official's identity.

- Don't be afraid to ask a salesperson to leave. If they refuse, call the police.
- Don't agree to sign a contract or hand over any money until you have talked to someone you trust.

Unwanted phone calls

If you want to block cold callers, you can register with the Telephone Preference Service (TPS). This is a free service, where you join an official, central register to record your preference not to receive unsolicited sales and marketing calls. When you're registered, all organisations are legally required not to contact you, unless you have given them permission.

It's important to note that the system is not 100% effective and you may still receive some unsolicited sales and marketing calls.

You can also register your mobile phone number with the TPS. To find out more and register, call **0845 070 0707** or visit **www.tpsonline.org.uk**.

Age UK have lots of information about home safety and security. Visit **www.age.uk** or call **0800 169 6565**.

Personal alarms

If you live alone, an Age UK personal alarm can give you peace of mind, because you can get help quickly in an emergency.

It works by pressing the button on a pendant or wristband, which will connect you to Age UK's 24-hour emergency response centre. They will contact your nominated friends or family to come and check on you, or if it is really urgent, the emergency services.

Be aware this alarm costs money. For more information visit **www.ageuk.org.uk** or you can call **0800 011 3846** for a no-obligation demonstration.

Message in a bottle scheme

This is a scheme run by some local health services. You place your basic personal and medical details on a form and keep it in the fridge in a green bottle. You then attach a sticker to the fridge and to the inside of your front door. Emergency services are trained to look for this and it can save them valuable time if they need to enter a property in an emergency situation.

Lions Clubs International run the scheme in partnership with some local NHS services. You can find out more information by calling them on **0845 833 9502**.

Will I need to make changes to my home?

This may depend on how well you feel you are managing at home. Some people need to adapt their home to make living with Parkinson's easier. There is a wide range of aids and equipment available which may help with particular problems. For example, you could improve access to your front door with a ramp, refit a bathroom to make it easier to manage or put in a stair lift.

However, equipment and aids aren't always the answer and they can be very expensive. We recommend you get advice from an occupational therapist before buying anything.

If you are looking for information on equipment for daily living, charities such as the Disabled Living Foundation may help. See page 8 for contact details.

Welfare benefits and finances

Welfare benefits

It's important to make sure you are getting the financial support you are entitled to. Remember that, even if you are still working, you may be entitled to certain benefits if you live alone.

You can check you are getting all the benefits you're entitled to by asking your Parkinson's local adviser, or speaking to our helpline's dedicated adviser for benefits and employment on **0808 800 0303**. We also have a range of information sheets about benefits. See parkinsons.org.uk/publications.

Financial issues

Some people with Parkinson's may find it difficult to leave the house at times. This can cause problems if you need to get cash from a bank or get your benefits. It might be possible to arrange with the bank or benefits provider to have someone trusted collect this on your behalf.

You may also find it useful to do the same with service providers (such as utilities companies), if you have problems using the phone.

You may have questions about managing your money when living alone. You can get free advice on debt from StepChange Debt Charity. The Money Advice Service can also give free advice on things such as mortgages, borrowing money and insurance. See page 8 for contact details.

Planning for the future

It may be that you're not sure whether you want to think too far ahead. But you may find it helpful to learn more about your options so you can be prepared when things come up.

For example, you may need to consider who will look after your finances if you are no longer able to, or whether you need any extra support and how this will affect where you live.

Talking to someone you know and trust about future decisions can be helpful. This might be a person with an understanding of Parkinson's, such as your GP, specialist, Parkinson's nurse (if you have one), or one of our helpline advisers or Parkinson's local advisers.

Find out more: see our *Thinking about advanced Parkinson's* booklet.

More information and support

AbilityNet

This is a voluntary organisation that aims to make computer technology accessible to people with disabilities. They have a free advice and information service, a website and links with centres across the UK.

0800 269 545 or 01926 312 847

www.abilitynet.org.uk

Blue Cross

This charity has produced a fact sheet called Finding the right pet for you, which offers tips for buying a pet.

0300 790 9903

www.bluecross.org.uk

Borrow My Doggy

Allows people to borrow dogs from local owners for walks, play days, sleepovers and family holidays. An annual subscription charge applies.

www.borrowmydoggy.com

British Association for Counselling and Psychotherapy

01455 883300

www.bacp.co.uk

The Cinnamon Trust

Helps people who are over 60 or terminally ill to stay with their pets for as long as possible.

01736 757 900

www.cinnamon.org.uk

Disability Action (Northern Ireland)

This has a range of assistive technology products that people can try and in some cases loan (for a short period) before they go ahead and buy the product.

028 9029 7880

www.disabilityaction.org

Disabled Living Foundation

This is a registered charity that provides practical advice and information on equipment to help disabled people be more independent. It has a helpline for general information, a range of information sheets on equipment and a demonstration centre where you can get help from advisers and try things out before you buy.

0300 999 0004

www.dlf.org.uk

Money Advice Service

Give free and impartial money advice by phone, email and face-to-face.

0300 500 5000

www.moneyadviceservice.org.uk

Pets as Therapy

01844 345 445

www.petsastherapy.org

Relate

Relate provides counselling for people with sexual or relationship difficulties.

0300 100 1234

enquiries@relate.org.uk

www.relate.org.uk

RSPCA

0300 123 4555

www.rspca.org.uk

Scottish SPCA

0300 099 9999

www.scottishspca.org

StepChange Debt Charity

0800 138 1111

www.stepchange.org

Turn2us

A charity who have an online benefits calculator and can help you find all the financial support you are entitled to.

0808 802 2000

www.turn2us.org.uk

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They can also make contact with other health and social care professionals to make sure your needs are met.

The role of the Parkinson's nurse varies. Each will offer different services, aiming to meet local needs. Some nurses are based in the community, whereas others are based in hospital settings.

Many Parkinson's nurses are independent prescribers. This means they can prescribe and make adjustments to medication, so someone with Parkinson's doesn't always need to see their specialist for changes to or queries about their Parkinson's drugs.

Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services.

You can find out more at **parkinsons.org.uk/nurses**

Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**. We run a peer support service if you'd like to talk on the phone with someone affected by Parkinson's who has faced similar issues to you. The service is free and confidential – ring the helpline to talk to someone about being matched with a volunteer.

Our helpline can also put you in touch with one of our Parkinson's local advisers, who give one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

We also have a self-management programme for people with Parkinson's, partners and carers. It is an opportunity to reflect on life with the condition, learn about self-management and think about the future. To find out if there is a group near you visit **parkinsons.org.uk/selfmanagement**

Our website **parkinsons.org.uk** has a lot of information about Parkinson's and everyday life with the condition. You can also find details of your local support team and your nearest local group meeting at **parkinsons.org.uk/localtoyou**

You can also visit **parkinsons.org.uk/forum** to speak with other people in a similar situation on our online discussion forum.

Thank you

Thank you very much to everyone who contributed to or reviewed this information sheet:

Richard Brown, Professor of Neuropsychology and Clinical Neuroscience, King's College London

Gillian Carey, Parkinson's Disease Nurse Specialist, University of Surrey and St Peter's Hospital Chertsey

Susan Martin, Parkinson's Local Adviser

Roisin Coultier, Parkinson's Local Adviser

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

Can you help?

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's.

If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **parkinsons.org.uk/donate**. Thank you.

Our information

All of our most up-to-date information is available at **parkinsons.org.uk/information-support**. If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **parkinsons.org.uk/ordering-resources** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **publications@parkinsons.org.uk**

Living alone with Parkinson's (2016)

If you have comments or suggestions about this information sheet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to **Editorial and Creative Services, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ**. Or you can email us at **publications@parkinsons.org.uk**. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this information sheet from?

- GP, specialist or Parkinson's nurse Information and support worker
- Parkinson's UK local group or event Ordered from us directly
- Our website Other

How useful have you found the information sheet? (1 is not useful, 4 is very useful) 1 2 3 4

Have you found the publication easy to read/use? Yes No

Has this resource given you information that might help you manage life with Parkinson's better?

- NA It hasn't helped It has helped a little It has helped a lot

What aspects did you find most helpful?

Were you looking for any information that wasn't covered?

Do you have any other comments?

If you would like to become a member of Parkinson's UK, or are interested in joining our information review group, please complete the details below and we'll be in touch.

- Membership Information review group (who give us feedback on new and updated resources)

Name.....

Address.....

Telephone..... Email.....

What is your ethnic background? Asian/Asian British Black/Black British White

Mixed/multiple ethnic backgrounds Other (please specify)

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

Together we can bring forward the day when no one fears Parkinson's.

Parkinson's UK

Free confidential helpline **0808 800 0303**

Monday to Friday 9am–7pm, Saturday 10am–2pm. Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices).

For more information see **www.ngts.org.uk**

hello@parkinsons.org.uk

parkinsons.org.uk



Last updated March 2016. We review our information within three years.
Please check our website for the most up-to-date versions of all our information.
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