

PARKINSON'S^{UK}
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PARKINSON'S AND CORONAVIRUS

Your questions answered





We've put together this information on Parkinson's and coronavirus to support you and help you cope during the crisis. We've tried to give you answers to some of the most common questions people have been asking.

Inside you'll find information about staying safe, healthy, active and connected, including practical information and tips. And you can find out about different ways to get support.

We know lots of people with Parkinson's and their families, friends and carers can't easily access online information, or aren't online at all – that's why we've made this information available in print for you. If you know other people who aren't online and might need a copy, please let them know they can contact us to order one.

We're here for you with information and support throughout the coronavirus crisis. You can call our helpline on **0808 800 0303** or email us at **hello@parkinsons.org.uk**. If you are able to get online, or know someone who can help you, we have lots of information about coronavirus and more at **parkinsons.org.uk**, which is updated regularly.

We hope you find this information helpful.

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PARKINSON'S AND CORONAVIRUS -THE FACTS

During this challenging time, our priority remains to support everyone who is affected by Parkinson's. Here we've covered what you need to know about Parkinson's and coronavirus.

Q What is coronavirus?

A. Coronavirus (or COVID-19) is an illness that affects the lungs and airways. It causes flu-like symptoms and can be spread very easily from person to person. Its main symptoms include:

- a high temperature – over 37.8 degrees
- a new, continuous cough

Q What does coronavirus mean for me if I have Parkinson's?

A. Some groups of people have an increased risk of complications if they get coronavirus. These groups include everyone over 70, people who are pregnant, and people with certain health conditions, including Parkinson's. However, people with Parkinson's don't have a greater risk of catching coronavirus than anyone else. The advice for people with Parkinson's is the same for most other people – to stay at home. This includes washing your hands frequently with soap and water.

Q Why do people with Parkinson's have an increased risk of complications from coronavirus?

A. If you have advanced Parkinson's, or have lived with

Parkinson's for a long time, you are more likely to have breathing and respiratory difficulties. Coronavirus affects the lungs and airways.

This is why people with Parkinson's are described as being at greater risk of severe illness or complications if they get coronavirus.

Should I be in self-isolation?

A. Self-isolation means stopping all face-to-face contact for a short period of time to protect others and prevent the spread of coronavirus. If you have symptoms of coronavirus and live alone, you must self-isolate for seven days. If you live with others, and either you or they have symptoms, the person with the symptoms must self-isolate for at least seven days. Everyone else in your household must self-isolate for at least 14 days.

What is shielding? Should I be doing it?

A. Shielding is a measure to protect extremely vulnerable people who are at a very high risk of severe illness from coronavirus. It means being extra careful to minimise contact with others, by staying at home and limiting non-essential contact with members of your household.

While people with Parkinson's do not fall into the extremely vulnerable group, you might have other health issues or conditions that put you at extremely high risk. If this is the case, you should have received a letter from the NHS advising you to shield yourself.

I'm worried about going into hospital. What considerations should I make?

A. During this uncertain time, it's understandable that you might be feeling anxious or unsure about going to hospital. If you need to go to hospital, your hospital will take appropriate measures to ensure your safety.

If you're worried, it can be helpful to prepare an overnight bag in advance. Make sure you include the following items:

- Your medication.
- A full list of your medications and supplements.
- A daily medication schedule.
- A list of your dietary needs.
- Toiletries.
- Nightwear.
- Slippers.
- Clean underwear.
- A phone charger.
- Your Parkinson's alert card.

You might also want to read our ***Going into hospital when you have Parkinson's***

booklet, which you can order through our helpline on **0808 800 0303**.

I live with someone who has Parkinson's. What can I do to help?

A. We understand that this is a particularly anxious time for many people with Parkinson's, and also for people living with them. If you're caring for someone with Parkinson's, you should continue following government and NHS advice, by staying at home and practising good hygiene. This will protect them and reduce their risk of coronavirus.

How might coronavirus affect Parkinson's medication?

A. If you do become unwell with coronavirus, it's important to keep taking the medication prescribed for your Parkinson's.

You should not suddenly stop taking your prescribed medication for Parkinson's, as that can cause additional problems. However, missing a small number of doses if you're very unwell will not cause you harm.

Always follow the advice given to you by your health professional, who may adjust your tablets or dose, depending on your condition.



STAYING CONNECTED WITH OTHERS

At the moment many of us are facing challenges with loneliness and how to stay connected with others.



Professor Richard Brown

Here, Professor Richard Brown, Professor of Neuropsychology and Clinical Neuroscience, talks about loneliness, and we explore how others have coped.

Loneliness is a concern for lots of people at the moment. Loneliness lowers our mood and makes us feel unhappy. Over longer periods of time it can affect both our physical and mental health. And it's something that we all need to be paying careful attention to – not just for ourselves, but for other people we know who may be feeling lonely at this time.

If you're finding living alone difficult, then something to consider is the support

people in local communities are offering.

In many areas, from urban to rural, people have set up community groups and volunteer schemes – from dropping off a pint of milk, to giving someone a friendly phone call.

It's worth checking what opportunities there are like this in your area. Maybe you'll have received a leaflet or flyer through the post from someone locally, or read about a scheme in the local newspaper. Perhaps your local Parkinson's group or faith community has reached out to you, or a neighbour who you've not spoken to before



has been in touch asking if you need anything.

You might feel uncomfortable reaching out or talking to someone you don't know. But even though it may feel difficult, learning to live in the current situation can involve changing our habits. Even if it's not something that we would normally do, it can help to pick up the phone and contact that person who has offered help to ask for support, or accept that support.

If you find it hard to contact someone for support, planning in advance how to start the conversation can help. Prepare a short script or a few words of what you could say at the beginning. This can help relieve any anxiety.

Tips from the Parkinson's community on staying connected

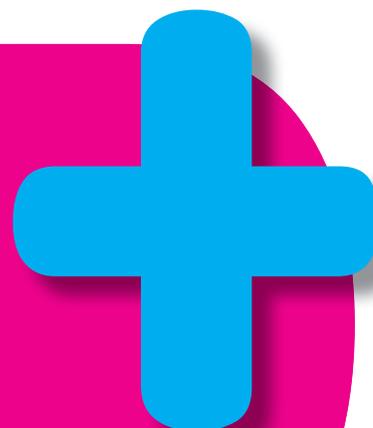
- Try to get out as much as you can while sticking to guidelines. Just being outside and seeing other people can be a good way of feeling less isolated.
- Make the effort to smile and say hello to people. Keep your distance but wave or strike up a conversation if you want to.
- Make time to ring your friends. Now is the perfect time to reconnect with someone you've not chatted to for a while. Put time aside to call someone different each day.
- Say hello to your neighbours over your garden wall or fence.
- A good way of meeting your neighbours is to go out at 8pm on Thursday evenings to clap, or bang a tin tray or saucepan with a wooden spoon. (Not only for the NHS, but for all key workers including postal staff, refuse collectors, delivery drivers and the emergency services).
- Accept help or support from others like faith groups.

Helpful contact numbers

If you're feeling lonely, there are people who can offer support.

- **Parkinson's UK helpline**
Our free confidential service offering emotional support to anyone affected by Parkinson's.
0808 800 0303
- **Silver Line**
Offers weekly telephone calls from a friendly and supportive volunteer for people aged 60 and over.
0800 470 80 90
- **NHS Volunteer Responders**
A volunteer scheme where people can call you for a friendly chat (England only).
0808 196 3646

HOSPITAL APPOINTMENTS AND MEDICATION



You might be worried about how your hospital appointments and medication will be affected at the moment. Here, we answer your questions.

Q I'm due a medication review but my appointment has been cancelled. What do I do?

If your appointment has been cancelled, think about how you are feeling right now. Some appointments for medication reviews are routine check-ups and if you are feeling well your medication would not be changed.

Are you feeling anxious? Remember that anxiety can be a symptom of Parkinson's and can affect other symptoms. You can read more about managing your mental health on page 20.

If you still have concerns or questions, you should contact your specialist or Parkinson's nurse over the phone, or speak to your GP for advice.

Q I feel worried about the availability of drugs. Are stocks in good supply?

Parkinson's UK are in regular contact with the Department of Health and pharmaceutical companies and so far, we're pleased to hear Parkinson's medications are in good supply. It's important to keep ordering your prescriptions and taking your medication as you usually would.

We do know there may be some localised supply issues with certain medicines. If you are having difficulties getting your medication, please call our helpline on **0808 800 0303**.

Q I have an appointment with my healthcare professional in the next few weeks, will this be cancelled?

Your Parkinson's healthcare team may contact you to

change your appointment to a telephone appointment. This will vary across the country.

Some specialists, Parkinson's nurses and therapists are being moved to different job roles because of coronavirus or may not be working due to illness or because they are self-isolating. Some appointments will be cancelled then and your healthcare team should let you know in advance by phone or letter.

Q I'm due to have an appointment to start or review deep brain stimulation (DBS) soon. Will it still go ahead?

If you are having a routine appointment to review how DBS is working for you, or to check your battery charge, this may happen over the phone.

It is likely that all new DBS surgery will be cancelled at the moment. Your Parkinson's

team will advise you whether your surgery is going ahead or not. If you have any concerns, contact your Parkinson's nurse or your DBS specialist directly where possible.

Q I have an appointment about, or issues with, apomorphine pens or a pump or a Duodopa pump. What should I do?

Your Parkinson's healthcare team should contact you to let

you know if an appointment has been changed to a telephone appointment or been cancelled.

It's likely that all new surgeries to fit medication pumps will be cancelled at the moment. Your Parkinson's team will advise you whether your surgery is going ahead or not.

If you experience any problems with apomorphine, you should call the APO-go helpline on **0844 880 1327**.

Q My Parkinson's nurse has been moved to a different role. What should I do if I need to talk to someone?

If your usual Parkinson's nurse service has changed, there may be an alternative way of contacting your nurse for support, or they may have provided an emergency contact.

You can also speak to a Parkinson's nurse on our helpline on **0808 800 0303**.



Do not attend an appointment in person unless you have spoken directly to your healthcare team and confirmed this.

If you still have concerns or questions about your Parkinson's:

- You could call your specialist or Parkinson's nurse, or speak to your GP for advice. Many healthcare professionals are still available on the phone.
- You can ring the Parkinson's UK helpline on **0808 800 0303** to speak to one of our trained advisers or a Parkinson's nurse. They can provide information and advice about living with Parkinson's, including advice on medical issues and symptoms.

In response to the coronavirus pandemic, the government has made changes to the benefits system and employment support.

WORK, RIGHTS AND BENEFITS

As of March 2020, the government has made several changes to benefits. What you are entitled to and the amount you can claim will depend on your employment status and which benefits you already receive.

One of the main changes is that face-to-face assessments or appointments for all benefits have been suspended until at least 19 June. This includes any new claims.

If you already receive means-tested benefits and apply for Universal Credit, this could stop your current benefits. For more information and advice, contact Citizen's Advice on **03444 111 444** or our helpline.

Q I'm over pension age and claiming benefits. Will my payments be affected?

A. Your payments will not be affected. You also do not need to apply for Universal Credit. This applies to:

- State Pension
- Attendance Allowance
- Pension Credit
- Housing Benefit
- Council Tax Reduction
- help with NHS costs

Q I'm receiving Carer's Allowance. Will this be affected?

A. You will continue receiving Carer's Allowance, even if you temporarily stop caring for someone with Parkinson's because you:

- have, or might have, coronavirus
- are self-isolating to avoid coronavirus

Q My employer says I must still go to work. Do I have to?

A. If you feel that you shouldn't be going to work, or are worried about the risk of infection, it's important to know your rights.

The government has issued guidelines on coronavirus and employment. So if you've asked your employer if you can work from home, or claim sick pay, and they've turned down your request, you can get advice from the Acas helpline on **0300 123 1100** or our helpline.

Under equality legislation, people with Parkinson's are entitled to have reasonable adjustments made by their employer if their work is being affected by coronavirus.

Our helpline can provide information and advice about employment and benefits. Call **0808 800 0303** to get in touch.

HOW TO STAY ACTIVE AND EXERCISE AT HOME

Staying active and exercising is still important for our physical and mental wellbeing. It's especially good for you if you have Parkinson's.

Here, we've put together some of the best exercises to help you stay active at home when you have Parkinson's. If you like, you can pull this information out and keep it separately.



Can I do all of the exercises?

If you're fit and healthy and your Parkinson's symptoms are mild, aim for the standing exercises. Start gently before easing into a more vigorous pace.

If you've had Parkinson's a long time, or your symptoms are more complex, do the seated exercises to keep you limber and active.

If you have any underlying health conditions (eg heart problems, breathing problems, diabetes, joint problems), you should contact your GP before starting any new exercises.

How do I get started?

Before you begin any specific exercise, make sure your living space is safe and comfortable for the activity.

- » Move loose rugs and unnecessary furniture to clear enough space.
- » Make sure your room is at a comfortable temperature – don't exercise in a room that's too hot. Open a window if you need to.

- » Check that your shoes and any equipment you're using are in a good condition and right for the activity.
- » Remember to keep any important medication or inhalers close by.
- » Have a phone or mobile nearby in case of an emergency.
- » Don't forget to drink water. You can lose around one and a half litres of fluid for every hour of vigorous exercise, so drink water before, during and after a session.

It's also important to prepare your body by doing a warm-up. If you're able to, a good way to start is by marching on the spot. This will make you breathe faster and more deeply, make your body feel warmer, and make you break into a mild sweat. Hold on to a steady chair if you need to.

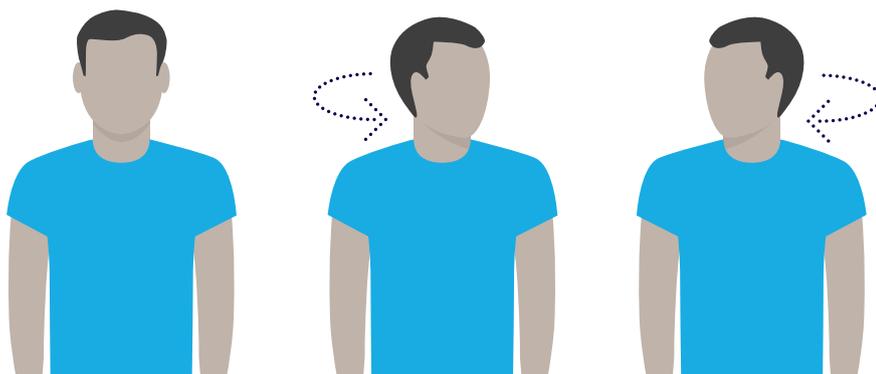
You can also do seated marching to get warmed up. Make sure to get your arms moving as well as your legs.

STRETCHES

Start your day off with these to help you loosen up. Anyone with Parkinson's can give them a go.

SEATED NECK ROTATIONS

These will help you keep your neck moving and stop it from stiffening.



- » Sit in a firm chair, shoulders pushed downward, and looking straight ahead.
- » Slowly turn your head towards your left shoulder. Hold for five seconds before returning to the starting position.
- » Repeat on the right.
- » Do three rotations on each side.

SEATED ARM STRETCHES

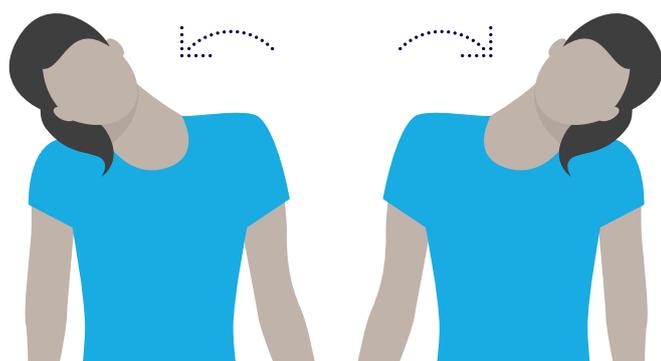
These will help you stretch your arms as well as your chest and back.

- » Start with your arms by your side.
- » Raise your arms above your head, with elbows straight and hands about shoulder-width apart.
- » Hold this position for five seconds before you relax by bringing your arms down.
- » Repeat three times.



SEATED NECK BENDS

Another good one for loosening tight neck muscles.



- » Start in the same position as the 'seated neck rotations' exercise.
- » Slowly tilt your head to the right, keeping both shoulders pushed down. Hold the position for five seconds before returning to the starting position.
- » Repeat on the opposite side.
- » Do three bends on each side.

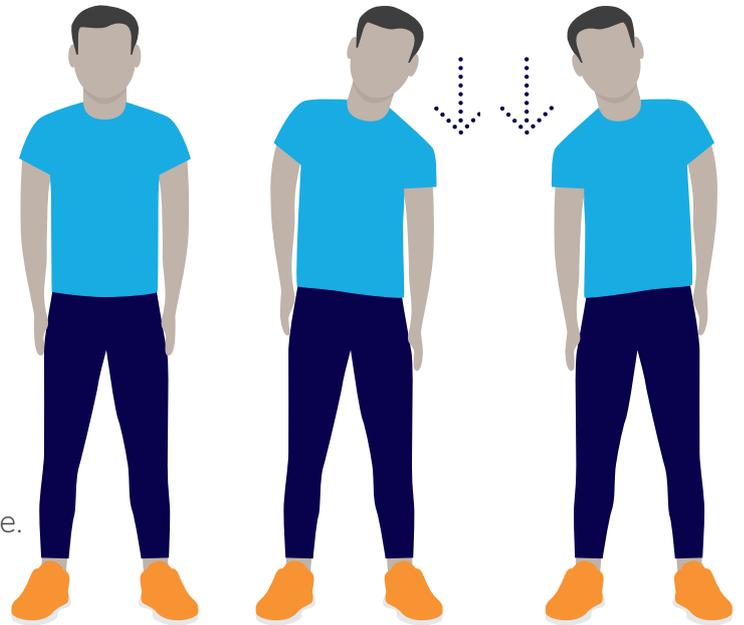
STANDING STRETCHES

For these, if you're a little unsure of your balance, hold on to a firm surface or stand next to the wall if necessary. If you can't do them safely when standing, you can do the same exercise while sitting on a firm chair.

SIDEWAYS BENDS

These are good for loosening the muscles on the side of your body.

- » Stand upright with your feet hip-width apart and arms by your sides.
- » Slide your left arm down your side as far as is comfortable, until you feel a stretch on the opposite side. Hold the stretch for five seconds before you bring your body upright again.
- » Repeat with your right arm down your right side.
- » Do three reaches down each side.



BODY ARCHES

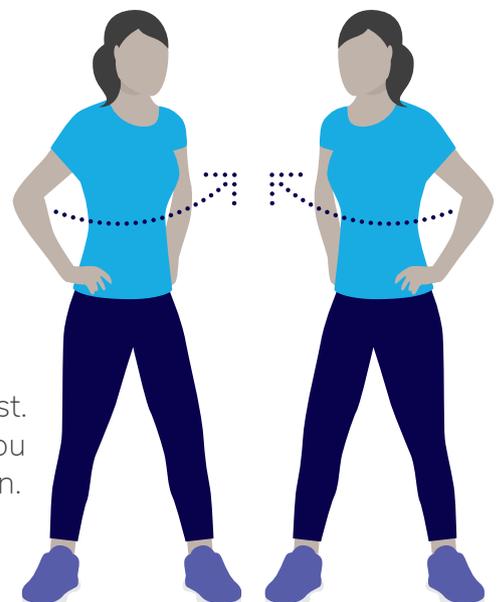
These are a really nice way to stretch the spine and come out of a stooped sitting position.

- » Start in the same position as the 'sideways bends', but place your hands (or one hand) on to the small of your back (where your spine curves inwards).
- » Slowly arch your spine backwards, pull your shoulders back and lift your head – do NOT tip it backwards.
- » Hold for five seconds while taking a deep breath in, then breathe out as you return to the starting position.
- » Do three arches.

BODY TWISTS

These will keep your middle moving, working your abdominal as well as your back muscles.

- » Start in the same position as the 'sideways bends' exercise, but place your hands on your hips, or fold your arms across your chest.
- » Slowly turn your head and shoulders as far round to the left as you can. Hold for five seconds before returning to the starting position.
- » Repeat on the right.
- » Do three rotations on each side.



SOFA EXERCISES

For these you will need a stopwatch, or a clock with a second hand, as you do each exercise for 30 seconds. Rest for one minute between each exercise. Once you feel confident doing them, repeat the whole set of exercises with rests in between.

SOFA DIPS

These will help build strength in your arms and torso.

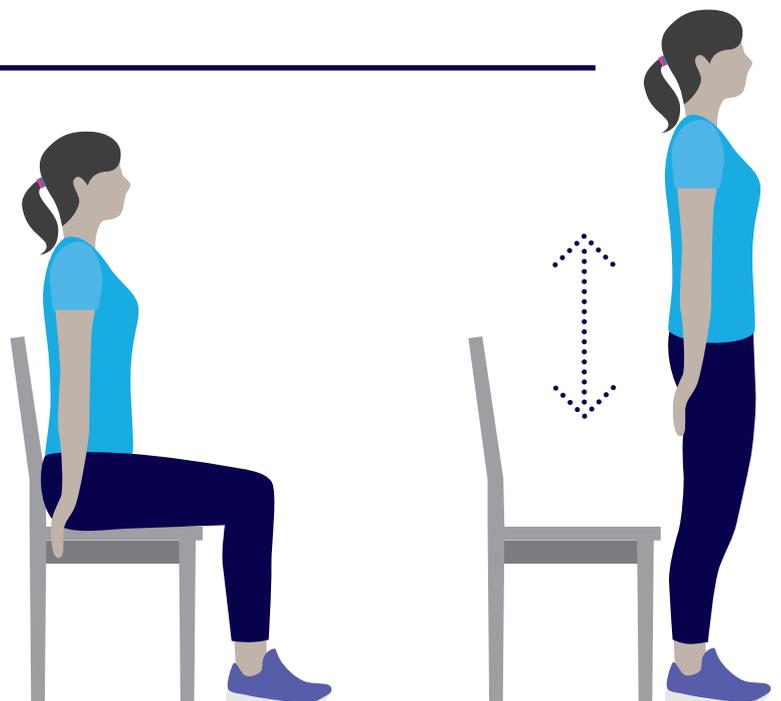


- » Sit on the edge of the sofa and grip the edge next to your thighs. Your legs should be semi-straight, and your feet placed hip-width apart with the heels touching the ground. Look straight ahead with your chin up.
- » Press your palms down on the sofa to lift your body up, then move forwards far enough that your bottom is off the edge of the chair.
- » Lower yourself using your arms.
- » Slowly push yourself up and back to the start position and repeat.

SOFA/CHAIR SQUATS

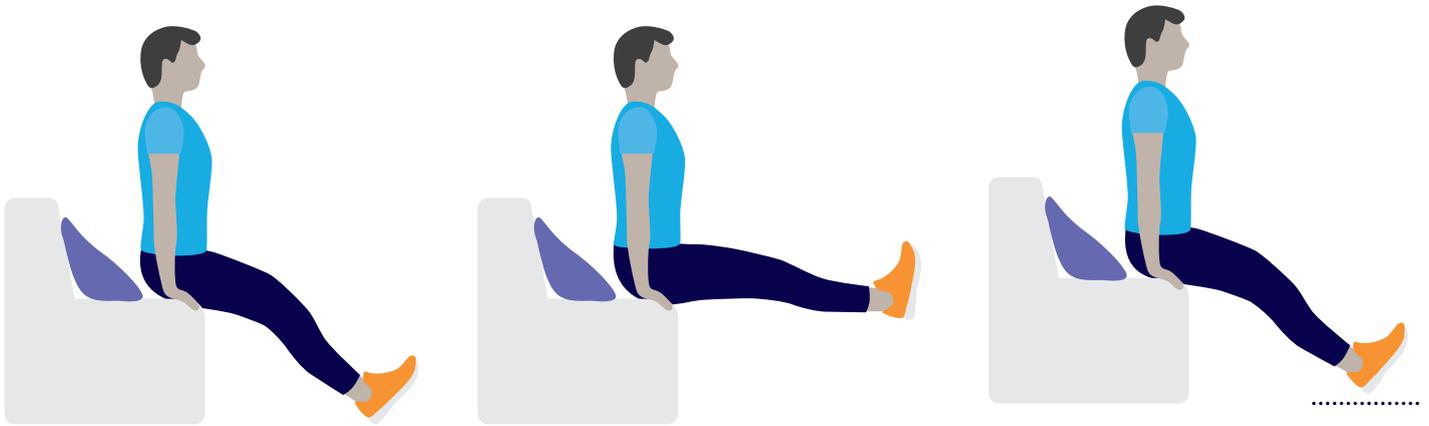
A great exercise for leg strength and mobility.

- » Sit upright, and move towards the front of the sofa with your bottom still fully on the seat.
- » Push up into a standing position, using an aid for balance if necessary.
- » Slowly lean forwards, to sit back down in a controlled manner.



LEG RAISES

These will also improve leg strength and stability when on your feet.



- » Sit towards the front of the sofa. Place your hands either side of you, and your feet together on the floor.
- » Lift your legs from your knee as high as possible until they are parallel with your hips. Do one leg at a time if this is easier.
- » Slowly lower your legs until your feet are five centimetres (two inches) from the floor and repeat. To make it easier, allow your feet to touch the floor.

SOFA CLIMBERS

These will get your heart pumping and are great for flexibility.



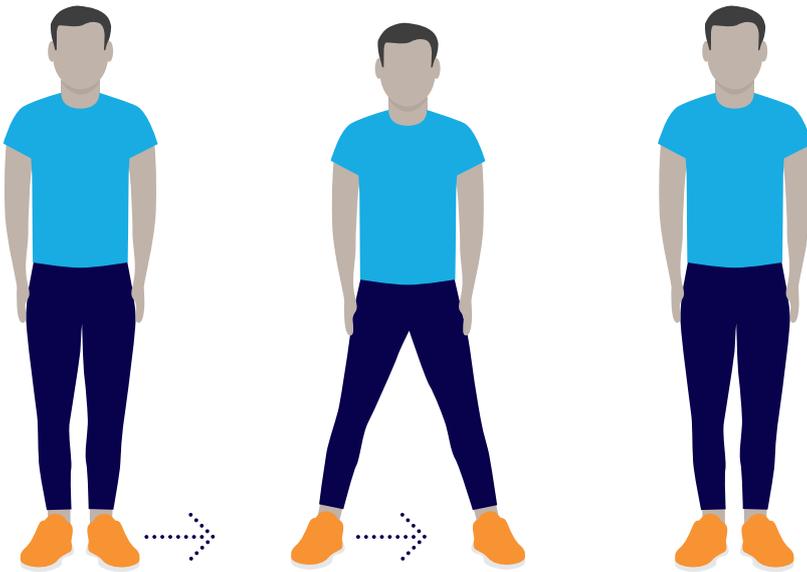
- » Place your hands on the sofa, then straighten your legs straight behind so that you're at an angle against the sofa.
- » Slowly lift your knee towards your chest in a straight line, then lower it back down. Alternate between legs.
- » To work your oblique muscles (the muscles on the side of your abdomen), lift your leg towards your opposite elbow in a slow and controlled manner.

BALANCE EXERCISES

These exercises will work the muscles that support you as you move, keeping you steady on your feet.

SIDEWAYS WALKING

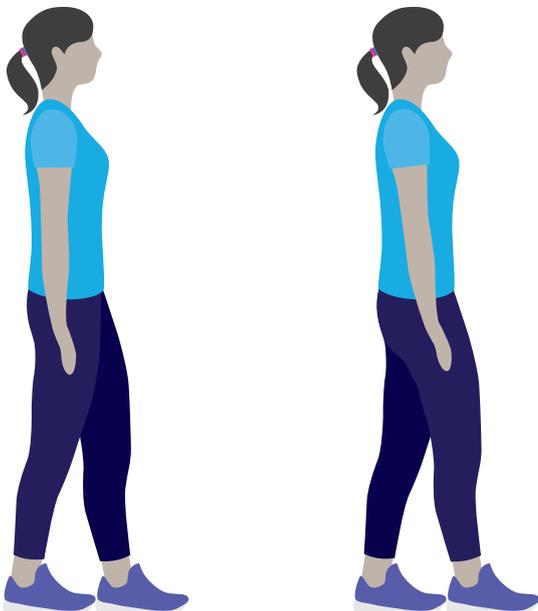
This is great for working the outer hip and thigh muscles and for widening your steps.



- » Stand with your feet together. Take a large step sideways, moving one foot out to the side, and then bring your other foot in.
- » Avoid dropping your hips as you step.
- » If you have space, perform five steps from one side of the room to the other.
- » Repeat this 10 times.

HEEL-TO-TOE WALK

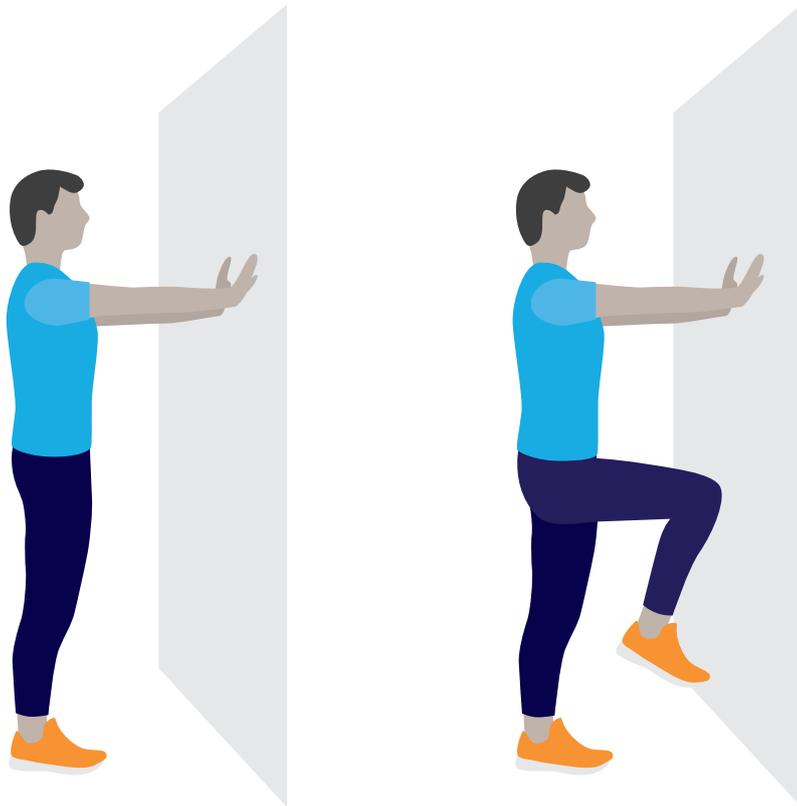
This exercise is challenging – make sure you do it using a wall or chair at the beginning.



- » Stand upright and place your right foot on the floor directly in front of your left toes. Hold the back of a sturdy chair for stability or use a wall for balance until you get the position right.
- » When ready, let go of the supporting surface and then step forward, placing your left foot on the floor directly in front of your right toes.
- » Make sure you keep looking forward at all times, and use the supporting surface to keep you steady if necessary.
- » Try to perform at least five steps. As you progress, move away from the wall, or place your hands on your hips.

ONE LEG STAND

Doing this exercise will help you when you end up standing for a slightly longer period on just one foot. This might include climbing stairs, stepping on or off curbs, or over puddles.

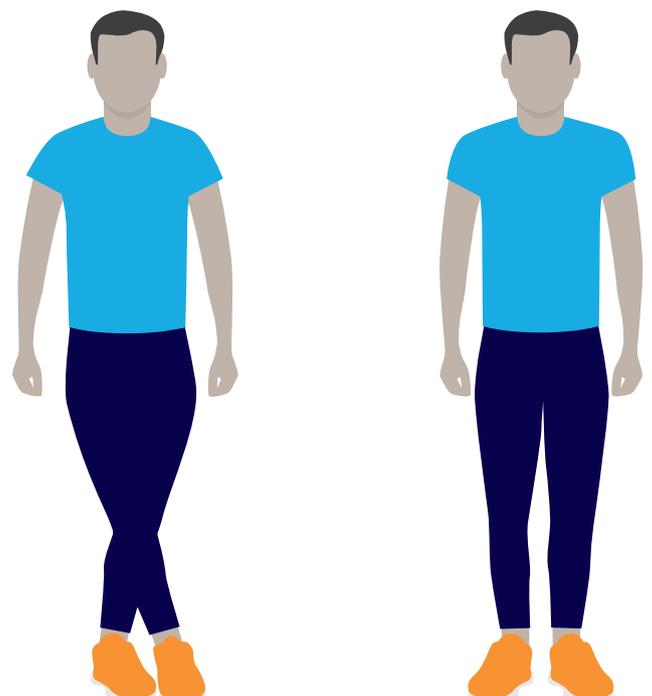


- » Stand facing the wall, with arms outstretched and your fingertips touching the wall.
- » Lift your left leg, keeping your hips level and a slight bend in your opposite leg.
- » Gently place your foot back on the floor. Hold the lift for five to 10 seconds and perform three on each side.
- » To make this harder, move away from the wall and extend your arms in front of you.

GRAPEVINE

This exercise combines coordination and steadiness.

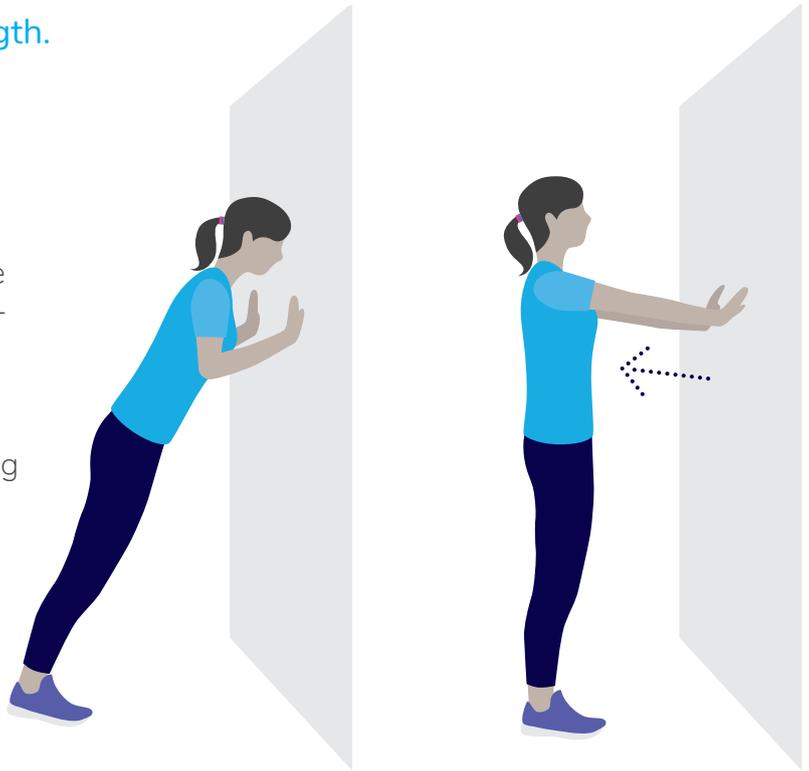
- » Start by crossing your right foot over your left.
- » Bring your left foot to join it. Attempt five cross steps on each side.
- » If necessary, put your fingers against a wall for stability. The smaller the step, the more you work on your balance.



WALL PUSH-UPS

These build arm and upper body strength.

- » Stand in front of a wall, just over an arm's length away, with your feet shoulder-width apart.
- » Bring your hands up to shoulder height. Leaning forward on extended arms, place your hands flat on the wall, also shoulder-width apart.
- » Breathe in and bend your elbows, lowering the body toward the wall. During this movement, focus on tightening your muscles around your middle and buttocks to maintain a strong, straight body position.
- » Pause for one second and then, as you breathe out, push off the wall with your arms, keeping the hands on the wall.
- » Keep your feet flat on the floor. If your heels come up off the floor, move slightly closer to the wall.



DAILY TOP TIPS

Here are our top tips for being active at home. Finding something that's fun and fits in with your life can help strengthen muscles, increase happiness levels and improve balance and posture. Using movement and physical activity is a great way of breaking up your day and keeping fit.



Do heel raises while doing the dishes.



Hang the washing out rather than using a tumble dryer.



Stand up to take phone calls or text.



Dance while getting dressed, making a drink or meal.



Do side lunges while brushing your teeth.



Use tins or bottles as weights to do bicep curls or shoulder presses.



A lot of people are going online at the moment to do their everyday tasks. But if you're new to the internet, you might be finding some aspects of it confusing, overwhelming or tricky to navigate. Here are our tips for getting online.

Getting started

Before going online, it's worth considering what you need from the internet, and which type of computer or device might be best for your information and accessibility needs.

This will either be a desktop computer, laptop or touchscreen device, such as a mobile phone or tablet computer.

How can I benefit from the internet?

Getting online is useful for many things. These include:

- Searching for information and support on Parkinson's and coronavirus, and the latest news.
- Setting up an email account.
- Managing everyday tasks, such as online shopping and paying bills, which can be helpful if you have limited mobility or live in a remote area.
- Keeping in touch with friends and family, and sharing your experiences with others who are living with Parkinson's through social media websites (including Facebook and Twitter) and support communities, such as the Parkinson's UK online discussion forum (parkinsons.org.uk/forum)

- Making video calls to keep in touch with people face-to-face. You can make free calls over the internet using platforms such as Skype or Google Hangouts.
- Booking or changing GP appointments with your GP or healthcare professional. Your GP surgery may also offer online consultations. Contact your GP surgery for more details.

Ask for help from others

If you're interested in finding out more about how to use the internet, or have been finding certain tasks difficult to do online, it might help to ask a friend or family member to support you or give you tips.

Trusted websites

There's a lot of information about Parkinson's and coronavirus on the internet – but not all of it is reliable or up-to-date. We recommend the following sites:

- Parkinson's UK website parkinsons.org.uk
- Government guidelines www.gov.uk/coronavirus

MANAGING YOUR MENTAL HEALTH

Many people are feeling more worried, anxious or low at the moment. We spoke to experts about how best to manage your mental health.

Clinical psychologists Andrew Paget and Jennifer Foley share their tips for looking after your mental wellbeing.



Andrew Paget and Jennifer Foley

TIP Plan a routine

Think about your normal routine and stick to it as much as possible. For example, try to get up, dressed and eat at the same time each day. A daily planner can help you do this. Keeping to a routine maintains a sense of normality. It can also help you keep busy and distract you from thinking too much about other things.

TIP Keep in touch with people any way you can

It's important to stay connected with family and friends. Read more on page 6.

TIP Be aware of where you are getting your information from and how much you are checking news

We can now get continuous news and information from lots of different places. You might find some things you read or hear about worrying, overwhelming or in some

cases misleading, so it's important to be mindful of this. If the news is making you feel anxious, consider limiting what you watch, read or listen to. Or decide only to check in with the news once a day, for example.

TIP Stay active

Keeping active is important for mental and physical wellbeing (read more on page 11). Spending time on a range of activities can keep you stimulated in different ways. Concentrating on activities can also be a helpful distraction.

TIP Look after your mental health

It's natural to feel worried at the moment. Talk to people about how you're feeling. By sharing your concerns, you may feel reassured that you're not alone. If you feel very anxious or think you are depressed, you should contact your GP or Parkinson's nurse.

We put your questions about mental wellbeing to Professor Richard Brown, Professor of Neuropsychology and Clinical Neuroscience.

Q I have anxiety and am finding it difficult to manage at the moment. Do you have any tips?

A. When you find yourself stuck in a cycle of worry, stop, write your concern down and then find something else to focus on. Writing the worry down can help calm your mind and you can come back to it later.

A good idea is to plan one or two 'worry times' during the day when you sit down, close your eyes and make yourself worry about the things you've written down. This may seem strange, but it helps manage the worry at other times. Often it can be difficult to deliberately worry and you may find your concerns don't seem as troublesome when you come back to them later. It is a skill to be able to do this, but the more you practise, the easier it will become. This exercise can be particularly helpful if you worry when trying to sleep.

A lot of worry is based on 'what ifs' that there are no answers for. It can be helpful to look for solutions instead then. For example, if you're worried about a loved one who you can't see at the moment, you could give them a call.

Q I'm a carer for someone with Parkinson's. I want to stay upbeat, but I'm finding this situation difficult. What can I do?

A. It is helpful to recognise this is a difficult and exceptional time. So keep positive when you can, but don't feel forced to do it all the time. It can also be useful to think about things you can do that are positive rather than just having a positive attitude. For example, you could do some gardening, or have a conversation with a friend on the phone. It may be that the person you care for shares your concerns, so being open with each other is important.



Q I have anxiety and depression and am finding it hard to manage my mood swings. What can I do?

A. It's important to recognise when you start to feel low and take steps to stop you feeling worse. For example, you could call a friend and have a short chat, or put on a piece of music you enjoy. If you feel your symptoms are becoming more difficult to manage, speak to your specialist, Parkinson's nurse or GP for advice. Many healthcare professionals are still available on the phone.

Our helpline can support anyone with Parkinson's, their family or friends. Call **0808 800 0303** to get in touch.

YOUR CARE QUESTIONS ANSWERED



Ian Adams

Ian Adams, Parkinson's UK Care Adviser, answers some of the common questions he's being asked about care.

Q I am worried that my homecare worker won't be able to visit me because they are ill or self-isolating. What would happen then?

A. If your homecare worker is unable to visit you, your agency should contact you to let you know and also whether they are able to send someone else for you. If they are unable to provide you with a carer, you should contact the UK Home Care Association on **020 8661 8188** or your local social services department for alternative help.

Q My wife is my carer. What happens if she gets coronavirus and can't care for me?

A. If this happens and you need care, you should contact your local social services department. You should explain that you are

self-isolating, so any carers coming into your home can take the right precautions. If you have to receive care in this situation, the legislation says you should not be financially worse off as a result of having to arrange replacement care.

Q My neighbour sometimes helps care for me. Can they keep doing that for me?

A. Yes, they can – providing care to someone is one of the permitted reasons someone can leave their house. If someone is coming into your home, they should wash their hands when they arrive and again when they leave. If possible, you should try and keep a distance of around two metres (six feet) between you and the person helping you. If they bring you shopping or a prescription, make sure you wash your hands after handling the goods.

Q I'm a carer and I'm exhausted. Is there anywhere I can get help from?

A. It's important to look after your physical and mental health especially at a time when you may be taking on extra tasks for the person you care for. If you're physically unable to carry out aspects of care, contact your local social services department who can organise help. Your local carers association can help you to do this (contact the Carers Trust on **0300 772 9600** to get details of groups in your area). The Carers Trust and Carers UK (**0808 808 7777**) can also provide you with emotional support.

Q I receive direct payments to employ personal assistants. How can I get the right protective equipment for them and what happens if they have to self-isolate?

A. Guidance around personal protective equipment can be complex. You should contact your local social services department who will be able to advise you. If your personal assistant is unable to care for you, your local social services department or care brokerage scheme can arrange replacement care for you.

“ Providing care to someone is one of the permitted reasons someone can leave their house. ”

Q My relative is due to be discharged from hospital, but I'm worried they won't have a care package in place. Is there anything I can do?

A. You should speak to the hospital discharge team who have a duty to arrange any care needed. You may also wish to contact care agencies or care homes yourself, especially if you will be self-funding.

In some areas of the UK, the coronavirus crisis means that the discharge may be faster than usual and care assessments are delayed, with the NHS funding the care in the meantime. It is vital that you discuss with the hospital the right sort of care without delay.

For support or further details, contact our helpline on **0808 800 0303**.

Q My relative is in a residential home. What are care homes doing to reduce the risk of residents getting coronavirus?

A. You should contact the care home and find out what precautions they are taking. Staff are wearing more personal protective equipment than they usually would and many homes have stopped family visits. The government has recently issued guidance to care homes to protect residents. For example, if cases are reported, the home must make specific arrangements for the residents affected, such as allocating specific staff to residents so others are not put at risk.

If you have any questions or concerns about care, our helpline (**0808 800 0303**) can provide information and advice on all aspects of health and social care, and emotional support.

CARING DURING CRISIS

Jane cares for her husband, who has lived with Parkinson's for 40 years. Here, she shares her experiences of being a carer when everyone must stay at home.



The first few weeks at home were particularly hard. I can't escape Parkinson's anywhere in the house – I can always hear my husband's dyskinesia, I'm constantly on alert for falls, and still have to attend to his basic needs.

I worry every time I have to go out for food and go later in the day when it's quieter. The fear of contracting coronavirus and being unable to care for my husband or worse, passing it to him, is a constant, scary experience.

During the day, I listen to Classic FM. It's calming and a welcome break from the news. If I'm feeling stressed, I dance around my kitchen to my husband's community radio show. I count that as part of my exercise regime along with some yoga stretches when I wake up. A gentle walk also helps but I'm conscious of the increased numbers of people about.

I have been tackling household tasks and spring-cleaning to occupy my time. Baking is

proving therapeutic, reading helps me unwind and the world's smallest jigsaw is still awaiting completion!

My garden has been my salvation. I talk to the plants, butterflies and my cat in the sunshine and they understand how I'm feeling especially after my husband and I have argued – we've had two humdingers with the word 'divorce' mentioned. My yearning for physical and social contact, and attending usual activities for respite outside the home is tangible and frustrating.

The weekly meditation sessions I usually go to have obviously been cancelled, but I listen to sessions on CD. Just talking on the phone to friends is good for my wellbeing and it's lovely to have a quick chat and laugh with our neighbours when we 'clap for carers' each Thursday evening.

Having struggled initially, life has settled down and this situation has become the norm. It is the little things that matter at the moment.



BUYING FOOD AND ESSENTIAL ITEMS

Shopping during the coronavirus lockdown has been a big adjustment for many, especially for those with Parkinson's. Here we share some tips and information on getting food and other essential items.

Should I be shopping?

The current advice says that you can go shopping for essential items, including food and medicine, only when necessary. If you're aged over 70, or have an underlying health condition, you should ask for support from a friend, family member or neighbour. This is the same if you have coronavirus, or are self-isolating or shielding (see page 4).

Local support

- Many local areas have volunteer or community support hubs, who can support you with food and other shopping needs. You can find your nearest hub by contacting your local council, or by going online at <https://covidmutualaid.org>
- The NHS Volunteer Responder scheme can provide local support in England including food shopping and collecting medication. You can call the service on **0808 196 3646**.
- You can also contact our helpline on **0808 800 0303** to talk to someone about what help is available to you locally.

Supermarkets

- Many supermarkets, including Sainsbury's, Tesco and Iceland, have introduced dedicated shopping hours to support older and vulnerable people with their food shopping.
- Tesco, Sainsbury's, Asda and Morrisons are offering priority online delivery slots to older and vulnerable customers.
- Parkinson's UK has a team of people set up to support you locally. Call our helpline number on **0808 800 0303** to find out more.
- Ask a family member, friend or neighbour if they can help you order items online.

HELPFUL INFORMATION

Government helplines and websites have the most up-to-date information and advice about coronavirus.

* England

0800 024 1222
GOV.UK

* Northern Ireland

0300 200 7898
www.nidirect.gov.uk

* Scotland

0800 028 2816
www.nhsinform.scot/coronavirus

* Wales

gov.wales/coronavirus

NHS 111 (and NHS 24 in Scotland) can help if you have an urgent medical problem and you're not sure what to do. Dial **111**.

In Wales, NHS 111 is currently available in the following health board areas: Hywel Dda, Powys, Aneurin Bevan and Swansea Bay – including Bridgend. If you are outside these areas, you should call **0845 46 47**.

If you aren't able to get online, ask a family member or friend if they are able to help.

Get in touch

If you're feeling isolated, worried or struggling to cope, our team of Parkinson's advisers are here for you.

You can chat to a member of our team or request that they give you a call back to talk about any issues you're facing, and to give you the information and support you need.

Call us on **0808 800 0303** or email **hello@parkinsons.org.uk** with the best number to contact you on.

Thank you

Thank you to everyone who contributed to or reviewed this information, including experts and people affected by Parkinson's.

All of the photographs in this publication feature people affected by Parkinson's, health professionals or Parkinson's UK staff. Thank you to everyone for letting us use their photograph.



This resource has been produced in line with government guidelines on social distancing. We've made every effort to ensure the information in this resource is correct at the time of publishing (May 2020), but content may be subject to change.

When we refer to 'government' in this publication, we are referring to the UK Government. Legislation and policy may be different in Northern Ireland, Scotland and Wales. If you have queries about your specific area, you should call our helpline team on **0808 800 0303** who will be able to advise you.



Getting through this, together

The need for our support is greater than ever. We're rapidly expanding our print, telephone and online support to reach everyone who needs us.

We're encouraging people to join us, standing side by side with the Parkinson's community. Anyone can play their part.

Together, we'll deliver what people need, wherever they are, when they need it most.

To find out more, you can call our team on **0800 138 6593**. Or visit [parkinsons.org.uk](https://www.parkinsons.org.uk)

We are Parkinson's UK.
We are powered by
people. We're here to
find a cure and improve
lives, together.

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London SW1V 1EJ

Free confidential helpline **0808 800 0303**
Monday to Friday 9am–7pm, Saturday 10am–2pm
(interpreting available)
NGT relay **18001 0808 800 0303**
(for textphone users only)
hello@parkinsons.org.uk
parkinsons.org.uk