



Facing the future, together

Hello everyone,

Welcome to the fourth issue of SPARK, our second edition during the time of coronavirus. It's been a very tough few months for most of us. As lockdown begins to lift, we know that there is still a lot of uncertainty about what the "new normal" will look like, and how everyone in our community can feel confident to navigate it. It's more important than ever for us to stay connected.

I'm delighted to say that everyone in the Scotland staff team has returned from furlough. It's great to be at full strength again. One of the important positives to come from the recent situation has been how brilliantly our volunteers have stepped up to make sure that important things continued to happen during lockdown.



We have heard from our community in lots of ways during the pandemic, including in a [detailed survey into the impact of lockdown we conducted with Lancaster University researchers](#). More than 1 in 3 people with Parkinson's said symptoms including slowness, stiffness or fatigue had got worse during lockdown, at the same time that NHS services, medication, social care and opportunities to be active and social became harder to access. Those providing unpaid care to support someone with Parkinson's were spending more time on care, with over 4 in 10 reporting a worsening of their mental health and 1 in 3 deteriorating physical health. Thank you to everyone who took part in this work, which we are using to inform what we do as a charity as well as what we are saying to Scottish Government, the NHS and others.

As ever, we want to make sure that everyone who needs our support can access it. Many of our [local groups](#) are staying active at a distance during lockdown. And please keep directing people to [our website](#), [helpline and local advisers](#) for information and advice when they need it.

With warm wishes,



Annie
Annie Macleod, Scotland Director

Latest information on Covid-19 and lockdown restrictions

We are constantly updating our website with the [latest coronavirus advice and information](#) for people with Parkinson's, carers, families and friends.

For more detailed information, please visit the [Scottish government website](#).

Face coverings

These are now compulsory in shops and on public transport in Scotland, and are recommended in other enclosed spaces. You don't have to wear one outdoors.

The [Scottish government guidance](#) includes a guide to making a face covering, and outlines exemptions to the rules.

These include disabled people who experience difficulty, pain or severe distress or anxiety when wearing a face covering, or cannot put on or wear a face covering consistently.

If you can't wear a mask, you may feel more comfortable having a card or image on your phone to explain that you are exempt. [Disability Equality Scotland has free cards and images you can download](#).



Visiting hospitals and care homes

Some people with Parkinson's have needed to be in hospitals and care homes during coronavirus. Visitors have not been allowed, except in exceptional circumstances, such as at the end of life. This has made hospital and care home stays much harder for individuals and their partners, families and friends.

These limitations are now starting to lift. The Scottish government has issued guidance that people in hospital (except those with coronavirus) can now have one named visitor, who can visit at times arranged with clinical staff.

The visitor must follow hand-washing guidance and wear a face covering. [Read the Scottish Government leaflet on hospital visiting.](#)

And from 24 July, residents in care homes where no resident has displayed any Covid symptoms for at least 28 days can have multiple outdoor visitors, and one named indoor visitor. There will also be more opportunities to join activities with other residents.

Shielding to be paused from 31 July

Some people with Parkinson's have received letters from the Chief Medical Officer telling them that they are part of the shielded group who need to practice strict self-isolation measures to protect themselves from coronavirus. Most people with Parkinson's have **not** been asked to shield.

Shielding in Scotland will be paused from 31 July. This means that people who have been shielding will be able to do the same things as everyone else, although they are advised to be careful about hand hygiene and maintaining physical distancing. Most support for people who were shielding will

continue after 31 July, but if you are receiving free grocery boxes they will be stopped.

The number of people with coronavirus in Scotland is now much lower than when the country went into lockdown. This means that there is much less chance of catching coronavirus.

If you are shielding, the Scottish government will write to you to tell you what you need to do. [See the latest Scottish government advice on shielding.](#)

Worried about work?

As restrictions lift and workplaces start to open again, people with Parkinson's and unpaid carers may have concerns about staying safe at work. Our [new web page](#) covers some common issues - and our [helpline and local advisers](#) can help too.



Get the most out of an online or phone appointment

Because of coronavirus, your next appointment with your Parkinson's nurse, consultant or GP will probably be by video or phone.

We know that this new way of working can be daunting when you're used to seeing professionals face-to-face.

To help you get the most out of a video or phone consultation, see our [useful guide to online and phone appointments](#).

We also need to hear from people who have had video or online appointments, so we can make sure that the needs of people with Parkinson's are considered when online, phone or face to face appointments are offered. Please [email Mary](#) if you'd be willing to tell us what you thought, and how it compares with a face-to-face consultation.

Request a wellbeing call from our adviser team

These times have been tough and people have lots of questions and concerns. Did you know that you can [book a wellbeing call from one of our trained advisers](#)?

We'll meet again

The safety and health of everyone in our community is our priority. And right now, the Scottish and UK governments are recommending that we continue to reduce our social contact with others from outside our households to minimise the risk of catching and spreading the virus.

We've decided that now is not the time to restart any of our face-to-face charity activities. That includes everything we do, from Parkinson's cafes to home visits from local advisers, face to face meetings and events. It's the safe thing to do.

We'll continue to monitor the guidance and keep reviewing the situation, and expect to update you by 31 August.

The charity is planning across the UK for the next steps. In Scotland, we've already started a conversation with our local group volunteers about what needs to happen for people to feel safe and confident to meet face to face, and what we can do to keep folk connected in the meantime.

Over 40 volunteers took part in our [initial discussion](#).

But we want to hear your thoughts, too!

Please [email us](#) to tell us what you think about restarting face to face contact, and staying connected while we can't.



Some attendees at our Glenrothes Parkinson's cafe

New course for unpaid carers in Highland

When someone has Parkinson's it affects people around them too - and for partners, family members and friends who provide unpaid care it helps to have information about the condition and support that's available and to connect with other people.

Our Area Development Manager, Cathy Orr has been working with [Connecting Carers](#)

to develop a 6 week online course for carers in Highland, exploring different aspects of life with Parkinson's from communication to medication and movement.

Starting on 6 August, it will run every Thursday from 10am - 12noon. It will be hosted online on the simple to use Zoom platform.

Please [email Cathy](#) to find out more.

Parkinson's Active Project Update

Amanda McKay has got off to a flying start with our 3 year [Parkinsons Active project](#) which aims to make it as easy as possible for people with Parkinson's to stay active in their community. Initially, we'll be working in Highland, Aberdeenshire and Orkney.

Parkinson's UK has worked with physios to develop regular online Parkinson's exercise sessions that are open to all. You can access these classes via a special [exercise playlist on the Parkinson's UK YouTube channel](#).



Amanda surveyed people with Parkinson's to understand more about how they use online exercise resources, and the barriers that might make this less attractive for some. Overall, people were positive about online exercise, especially reducing travel, but face-to-face sessions are hugely missed.

Our website also has lots of helpful information on [staying active at home](#) and [other exercise links](#), and we regularly post content about exercise and physical activity on our [Scotland Facebook page](#).

And please [email Amanda](#) if you would like more information about Parkinson's exercise and to give your feedback.

Reaching everyone who needs us

Recent events have focussed the charity's mind on the gaps in the services Parkinson's UK provides. We published a [statement](#) in response to the issues raised by the global Blacks Lives Matter protests.

In Scotland as well as across the whole UK, we have been thinking about how we can make sure that our support and services are truly open to everyone affected by Parkinson's, and that we are reaching everyone who needs us -

including people from minority ethnic backgrounds, those on low incomes, people who live in care homes and those who are not online.

Our Scotland Advisory Group and Scotland Development Team are interested to hear your ideas about increasing our reach. Please [email us](#) to tell us what you think.

Nominate someone for our 2020 Volunteer Awards

Our 300-strong army of volunteers in Scotland are at the centre of everything we do - from supporting others affected by Parkinson's, to helping us to raise awareness, raising vital funds, campaigning or helping the charity to decide what research to fund.

If you know a Parkinson's UK volunteer who's made a real difference to any area of our work over the last 2 years - or longer - please help us say thank you by nominating them for a [Parkinson's UK Volunteer Award](#) before 31 August.



Influencing Scottish government

Most attention has been focussed on measures relating to coronavirus, and we have met with officials to talk about what is happening with shielding. We also met with the Minister for Public Health, Joe FitzPatrick MSP, to raise concerns from people with Parkinson's in June.

The [Neurological Alliance of Scotland](#) published a [report on the experiences of people with neurological conditions in lockdown](#). We contributed the views of people with Parkinson's. The newly published [Lancaster survey results](#) from over 2,000 people across the UK provide an even more detailed picture.

What should we be campaigning on now?

Coronavirus has impacted everyone. Since the outbreak started we have been supporting the Parkinson's community with guidance and information - and we have been lobbying Scottish Government and NHS Scotland about the issues that matter to people with Parkinson's and their families.

Please help us to understand what matters to you now. Please [complete this very quick poll](#) to tell us what your campaigning priorities are at this time.

2020 fundraising events cancelled - but you can still support us

Coronavirus has had a huge impact on our planned fundraising activities in Scotland - and events planned for later in 2020 have now been cancelled. These include our Walks for Parkinson's at Brodie Castle and Loch Leven, Pedal for Parkinson's, and our Ladies' Lunch and Afternoon Tea.

We're really disappointed. But rest assured, we're doing all we can to get back up and running for 2021.

The health and wellbeing of our volunteers and supporters comes first, and the risks of coronavirus, and uncertainty over the lifting of lockdown restrictions mean it's the right thing to do.

Thank you to all of you who have chosen to undertake individual and socially distanced fundraising challenges to support us while our mass participation events are on hold.

You can still [support our Emergency Appeal](#) or [take part in your own virtual challenge](#).

Contact us

You'll find all the Scotland Team's contact details [here](#). If you don't know who to contact, then please email us at scotland@parkinsons.org.uk. You can also contact us privately by sending us a message via [Facebook](#).

About us

We're the Parkinson's charity that drives better care, treatments and quality of life. Together we can bring forward the day when no one fears Parkinson's.

Contact Parkinson's UK Scotland at Suite 1-14, King James VI Business Centre, Riverview Business Park, Friarton Road, Perth PH2 8DY. Parkinson's UK is registered at 215 Vauxhall Bridge Road, London, SW1V 1EJ and is the operating name of the Parkinson's Disease Society of the United Kingdom. A registered charity in England and Wales (258197), and in Scotland (SC037554).

[Read our privacy policy](#)