

TOGETHER

thistle
Foundation

For Thistle Supporters • Summer 2020

Hello and how are you?

We hope that you and your loved ones are staying safe and starting to enjoy the gentle lifting of the restrictions that have created the boundaries of our lives for the past few months.

Thanks to your support during these challenging times, we're able to continue to support people struggling to cope with their long-term health conditions at a time when they're most vulnerable to isolation and loneliness.

“ Our staff and volunteers are now able to carry out all of our 1:1 and group support remotely – online and over the phone – which means we can support people wherever they live.

”

We're also in a position to support those who have had Covid-19 and are now finding themselves stuck with fatigue, weakness, pain and disturbed sleep (known as Post Viral Fatigue). Many are finding it hard to get the right support. Perhaps you heard Ross Grieve from Thistle speaking on BBC Radio Scotland's Drive Time about this last month?

So, on behalf of all our staff, volunteers and people we support, I would like to say a huge heartfelt thank you.

Mark Hoolahan, CEO



THANK YOU!

We have been incredibly touched by the ingenuity and generosity of our community throughout the pandemic.

We're grateful to teachers from the technology departments of Preston Lodge High School, Knox Academy, Musselburgh Grammar, North Berwick High and George Watson's College, who collectively made and donated almost 300 visors to be used by our wonderful personal assistants as they continue to provide support to people living with disabilities and long-term conditions.

Richard Graham from George Watson's told us, "We're really happy to support people when they need it. It's a small thing we can do to help but we think it's made a real difference to our local charities and other organisations. Between the three members of staff, we've made around 500 visors in total so far – all while socially-distancing and between teaching our pupils through online lessons."

We're also incredibly grateful to all the volunteers who have helped our community during this time. More than 50 people offered their help as volunteer drivers, ensuring our keyworkers can continue to provide vital support to people throughout the crisis. We've also had volunteers helping with shopping and picking up prescriptions for those shielding at home.



This is Brian, who has been helping Moira get to her shifts. Thank you to Brian, and to all our volunteers!

A huge thank you also to Edinburgh All-Ability Bike Club for their free bike loans, helping our keyworkers get to work while physically distancing.



Federico with his ABC bike loan



John Hall, CDT teacher at Preston Lodge, delivering the visors

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Living well through lockdown

Some of our wonderful supporters share what's been keeping their spirits high during lockdown.

Eleanor

I'm very lucky as I have a big garden where I'm able to have borders and a veg garden with a greenhouse. This year instead of buying tomato plants, I grew them from seed, and also sowed lots of vegetable seeds. I am so pleased with the way everything has grown – down to the good weather more than my skill! I'm also very lucky that I live next to a hill where I can go for walks and where it's easy to socially distance.

Needless to say, talking to friends on the phone has been helpful too. It has been hard not being able to cuddle my daughter, but the knowledge that she is so well looked after by her Thistle care team is a great comfort. We look forward to getting the daily report, complete with photos, from her team and maybe before too long, we'll be able to be with her again.



“This year instead of buying tomato plants, I grew them from seed, and also sowed lots of vegetable seeds”

“I think I miss the Leith Library more than anything.”

Dawn

The ‘Visit our gallery/museum online’ websites have been marvellous! I would be so bored were it not for the computer and emailing our sons in the USA and Australia. Luckily our daughter, her husband and our granddaughters live downstairs, so there is plenty to chat about and bits and pieces of crafts to do - we're taking two days to make bobbles at the moment! Having our wonderful Leith Library closed, I have actually had to buy a book. I think I miss the Leith Library more than anything.

Gill

What's keeping me going during lockdown? Still being able to go out on my bike, whether it's for exercise, transport, or just for fun.

Sheenagh

I have a purpose in my life. I also have a routine for each day of the week. I think about myself and also of others. I think of something nice to do or something special to do or sometimes make soup and deliver to those in need. I make masks so people can shop safely so in some ways I am creative.



Life(style Management) goes on

Thistle's Lifestyle Management courses are open to anyone living with a long-term condition or facing a challenging life situation. Within the group, participants can access different perspectives and share their experiences, strategies and ideas. Linsay, one of our Wellbeing Coaches, tells us about moving the course online.

"We were four weeks in. The group were getting to know one another and I could see lightbulb moments already happening, where people start to see things differently. One person shared their realisation that "I might never be pain free but I can still live a good life." Another noticed "I've always focused on what I can't do and paid no attention to what I can still do." A third shared "I've been to every group possible but there is something different in this one." It was going well.

Then the pandemic hit. The group had to stop immediately. The easy thing would have been to stop and restart later, when things were back to normal. But we wanted to find a way around this. So, getting to grips with technology, we started our first Zoom Lifestyle Management course!

Nicola, who co-facilitated the group alongside Linsay



We were able to keep the group together to support each other, helping participants to do more of what was working for them and offering up new strategies to try if things weren't working.

Towards the end of the course we do a 'what have you most appreciated about each other' exercise. With over half the course delivered online, it was wonderful to hear the responses and see that the distance hadn't diminished the connection participants made:

"I remember when you shared the anxiety you felt. I don't generally like to share things, but I thought if you can share I can share. It took me out of the isolation."

"I thought you were incredible and relatable despite what you say you struggle with. Your strength has held me up and if you are able to talk about things, I can talk about things too!"

In the final session we explore the importance of maintaining a future focus, imagining one year from now. One participant said in one year she'd have the courage to get on a plane and visit her brother in Canada – something she's been unable to do since becoming ill as she's lost confidence in herself.

Another participant shared she's dreaming again about things she'd long given up on. In a year, she'd be back on stage doing comedy, laughing about her experience living with chronic pain.

Moving the course online was unexpected and not without its challenges, but I'm so glad we did. Knowing that we can still support people, and seeing the difference the group makes even when we can't physically meet, is fantastic."

Thistle is currently delivering a range of remote supports, including online Lifestyle Management, Veteran's Lifestyle Management and mindfulness courses.

"I'm dreaming again about possibilities for my life – things I'd long given up on"

www.thistle.org.uk/donate

For people coming to terms with the devastating diagnosis of a long term health condition or those who are struggling post-COVID, Thistle's support has never been more needed. If you would like to help us ensure support is available for people throughout the pandemic and beyond, you can donate here: www.thistle.org.uk/donate

How work keeps me going

Malcolm, our Digital Communications Officer, tells us what's been helping him cope with shielding through lockdown.

When we can't meet in person, social media falls into focus a bit more than usual. I found that when I was stuck in hospital as a teenager and I'm finding it again now. Except this time part of my job is helping to run Thistle's social media presence!

Personally, my job hasn't changed too much since most of my role can be done sitting at a computer. My focuses have been video editing and posting updates on our Facebook, Twitter and Instagram.

What has changed is the routine of it all. Having chronic fatigue syndrome, I've always been grateful that one of my three workdays has been from home. Now every day is a work from home day. You'd think that would be easier but it took me a while to readjust. Everything I learned about pacing and routine at Thistle's Lifestyle Management course came in handy again.

Lockdown, while often difficult, could've been much more of a struggle than it has been. Whether it be the video calls with my team, folk sending me videos they've made or seeing the comments on our Facebook page, the regular contact with the Thistle community has really helped.



“Everything I learned about pacing and routine at Thistle's Lifestyle Management course came in handy again.”

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