

# British Lung Foundation

The British Lung Foundation (BLF) has a network of volunteer-led local support groups across the UK for people with lung conditions, 90 per cent of whom have multiple health conditions. Around 100 groups offer sessions with healthcare professionals and wellbeing advice, as well as weekly opportunities to come together for exercise and other activities. Further detail about the BLF Support Groups was originally set out in a [case study](#) in the 2019 Multiple Conditions Guidebook and discussed during a follow-up [webinar](#).

**In Autumn 2020 we heard from the BLF's Head of Support Groups, Petra McCauley, about how COVID-19 had affected the groups and their participants.**

## **How did the COVID-19 pandemic affect the support you offer?**

As a charity focused on respiratory illness, we knew from an early stage the pandemic would have significant implications for our beneficiaries. We asked our team of medical advisers to get together and brainstorm likely scenarios. Face-to-face support was not an option in the short term given the majority of people we work with are considered extremely vulnerable to the virus. So, everything had to stop. This included all the existing support groups as well as the rollout project for developing new groups.

## **What impact did you see on people with multiple conditions?**

Understandably, with COVID-19 being classed as a respiratory condition we had, and continue to have, a lot of very anxious and confused people on our helpline and in our groups. However, people's concerns have changed over time. In the beginning we had a lot of queries about shielding, what to do when important clinical reviews or appointments were cancelled, how to access GPs and medication, and safety in the workplace. It was difficult for everyone involved because you want to be able to help clarify and reassure people but often there was no clear answer. More recently we have had a lot of people with concerns about face masks and eligibility for flu jabs.

Now we see anxiety levels rising again as the numbers of cases increases. And a lot of people are clearly suffering from the social isolation that comes with needing to stay at home more, especially in the winter months.

## **Did you manage to provide alternative forms of support?**

As a team, once we knew the implications for face-to-face support we quickly started to try and bring the existing groups up-to-speed technology-wise. Obviously some of our volunteers knew what they doing. They already used things like FaceTime and Skype to communicate with family and friends but not many had used Zoom. I certainly never envisaged organising a Zoom meeting with breakout rooms.

We started holding quarterly events for the volunteer group leaders. In these sessions we have a balance of the latest information on COVID-19 and how to manage different respiratory health conditions, what's happening in the wider work of the charity, maybe a speaker but then time to go into breakout rooms for a discussion, which may be about something specific or just a general catch-up.

Our project officers also talked volunteers through the technicalities – like how Zoom works, how people can access it through a phone line, and how to stay safe online. They would then go to the first few meetings to help out before leaving volunteers to run with it.

We were due to have our annual national conference for our group leaders during Volunteers Week in June but we transferred this to an online conference.

Many of the groups have gone on to provide regular opportunities for their members to come together online. Online exercise classes have worked well. And the people in the groups have been really inventive. One person did a long sponsored walk around her garden as a fitness challenge and fundraiser.

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#### Did you see any positives from the shift to working online?

We have seen an increase in the numbers of people attending events online as well as new connections being made. For example, at our annual conference we were expecting about 60 volunteers to attend in person but over 90 joined virtually representing 60 support groups. It was fantastic to watch. It was a real social occasion rather than a formal business event. We have seen volunteers from Scotland linking up with others in Norwich and people being free to join whichever group they want as they are not geographically constrained anymore.

For us as a team it has also brought a lot of positives. We are a small team in a national organisation but we are finding that with the shift to online working we are able to reach out to people more than ever before. Now we know what nearly all our volunteers look like whereas before much of the communication was done by email or over the phone. We can also pop in and join events easily so it is much easier to support groups with speakers and share information. It has also really built rapport between staff and volunteers. We have all been learning together so there has been a level playing field. Some volunteers were really worried about running events online but they have seen things go wrong when we have had technical glitches and it has helped reassure them and build confidence.

One thing we did not expect was how uplifting it would be to help people get online. People are really delighted and surprised at themselves when they manage to do it. And they really enjoy the breakout rooms and opportunity to chat to others. We have been trying to encourage our volunteers to get to know each other for years and it is now really happening.

#### What challenges did you face?

I do not think any of us realised how exhausting it is to work online all the time. We are learning now about the right length of time for sessions and groups. They have to be shorter than face-to-face events because of the intensity but this seems common with what other organisations are experiencing too.

However digital access, the lack of it, is the biggest issue. There's an element of this that is around helping people develop the necessary skills and overcome their distrust of the digital world to be able to join in virtually. We can and do help with this. We are always there to help our volunteers join our online meetings. It is important we are there, and we like to help, but it is labour intensive. But there's another element to it, where people are excluded on financial grounds. This is a much bigger problem than we as one organisation can tackle.



#### What do you think the future holds for your work?

With the pandemic ongoing there are lots of things that are still continually changing. We are thinking about how we manage that going forward. Back in March, for example, we were very hands on with volunteers and members. Then everyone was very enthusiastic and engaged. But once we came out of lockdown, we lost people as they returned to a more normal life. We are trying to find ways to motivate people to keep going and see how we can remain responsive to a fluid situation.

In the future we hope to continue with regional and national networking meetings virtually. We have found it is the best way to meet people across the country. However we would like to still have two opportunities a year for people to meet face-to-face. For us a blended approach seems the best way to go. Now that we understand the differences in online and face-to-face events we plan to keep making improvements. We have found that it works better online to be a little less prescriptive and more free flowing than at face-to-face events, and also to allow for a greater element of creativity. We have also realised that we have more capacity as a team for online events and they are less time consuming to organise and facilitate than we originally thought. Previously when volunteers have asked if we could do monthly get togethers we were nervous about capacity. But now, and especially over the winter months, we are going to try and do that.

## Spotlight on inequalities

Lung disease is a major factor in widening health inequalities. Chronic Obstructive Pulmonary Disease (COPD) and asthma are more prevalent in more deprived communities. And there are significantly higher rates of asthma in BAME communities.

Currently there are no specific BLF Support Groups for people from BAME communities but the team are currently looking at how they can address this. They are hoping that with increased use of digital that they can diversify the people they meet, for example by taking up opportunities to join existing networks and connect with more varied community groups.

The impact of inequality on digital access is something that the team have experienced first-hand. A number of group leaders were already technologically savvy before the lockdown but then they completely dropped off the radar. For Petra and the team this was a bit of a puzzle, but they discovered that they had been using computers at their local library and with lockdown they lost this access.



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## Peggy’s story

**Many people living with a lung condition are affected by complex health issues. Daily life can be a struggle. With the heightened risks and restrictions from COVID-19 this has been even more true. We spoke to Peggy Allison, a British Lung Foundation volunteer who is the secretary of the local support group in Chorley and South Ribble.**

Peggy is 76 and has multiple health issues including asthma, COPD, type 2 diabetes and heart problems. Whilst Peggy has mobility issues and needs ongoing care and support from her husband at home, she is normally kept busy keeping up with her family, including seven grandchildren and two great-grandchildren. She has been a scout leader for 46 years and enjoys helping others with health problems through the BLF support group.

*“I can talk to them through the window but that’s it. I cannot wait for the day I can hug all my grandchildren and great-grandchildren again.”*

- Peggy

When Peggy heard the news of COVID-19 she quickly shared her decision to isolate with her family. During lockdown her husband would still go and get the shopping every few weeks, but otherwise they did not go out. As secretary of the local BLF Support Group Peggy has kept in touch with the other members through monthly emails. In these emails she shares their news with the group. “I want to encourage others in the group to try and find a hobby and keep their minds as active as they can. I share with them what we have been doing. For me I am always knitting but I also enjoy playing card games on the computer. My husband tends to the allotment which the group always benefit from so I like to let them know what is happening there.”

Family is very important to Peggy and whilst her son and daughter live nearby it is hard to not be able to see them properly. “I can talk to them through the window but that’s it. I cannot wait for the day I can hug all my grandchildren and great-grandchildren again.” For now, though, Peggy is still largely avoiding any contact with others. “I have been for an eye test and to the GP surgery car park for a flu jab but that is it. I really do not want to risk going into the surgery.” For now Peggy and her husband are finding their hobbies and interests are keeping them busy and trying to help others in a similar situation to do the same.