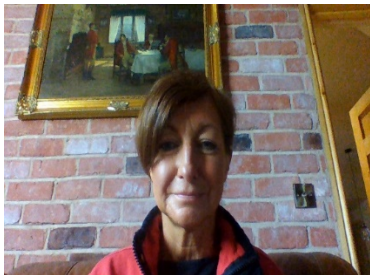




## **MS Support Volunteer Newsletter from Deborah and Barbara**



Dear All,

Welcome back to our MS Support Volunteer Newsletter.

We hope this communication finds you safe and well and managing to cope in these unprecedented times.

We felt it was important to touch base with you all, as one of our key teams in the MS Society. We hope to resume sending this newsletter on a regular basis to keep you up to date, and equally to hear back from you about how you are doing and if there is anything more we can do to support you.

We have over 500 of you across the UK offering this key role in your local groups; on the front line in supporting the MS community at a local level by offering emotional support, giving information, signposting to services and organisations, and often supporting with local and national grants.

### **Supporting our community**

You told us you are still taking calls and responding in the usual ways to support people affected by MS locally. And you are proactively contacting members (both people with MS and carers) by phone where you know they are isolated, vulnerable and alone. One of the key benefits of being

local volunteers is that you have been able to find out about the organisations in your area that can support with deliveries of shopping and medications, or help with finances, and to pass these details on.

But you have also been extremely inventive in developing different ways to support those who do not have online access - by using social media, Zoom, WhatsApp groups and Facebook groups. One of the really exciting results of this is that you have been reaching new people affected by MS. People who perhaps couldn't come to group events, due to work commitments or inability to travel, have now joined Zoom or social media events and connected with our groups. It seems likely that, even when face-to-face services can resume, groups will also continue to use Zoom to encourage new contacts to join.

Importantly, you have remained aware of those without access to computers and/or social media and have sent letters or newsletters to reassure them that your support is still there.

## **Supporting you**

Barbara and I have been running some snappily titled 'COVID-19 MS Support Volunteer Forums' via Zoom. These have replaced the face-to-face meetings you may have been used to being invited to at this time of year. They have been informal, at times lots of fun, and an opportunity for us to meet some amazing volunteers who are keeping this service going.

We have run five sessions over the past few weeks and have had an amazing response, with over 30 of you (UK wide) joining us for three hours of chat; talking about your roles and how things are feeling and changing for you in this current time. We were joined by a colleague from the Helpline for an "ask me anything" session, and finished with a session where you shared ideas, offered each other peer support and let us know how you were feeling.

At the end of the meetings, we shared links to key MS Society website pages, which are updated as COVID-19 guidance changes. For anyone who was unable to attend, these can be found at [volunteers.mssociety.org.uk/node/3753/coronavirus-covid-19](https://volunteers.mssociety.org.uk/node/3753/coronavirus-covid-19).

These meetings have been really well received, with resounding positive feedback from those who attended that they have been helpful and a great opportunity to get top tips about how some of the challenges can be overcome, and ideas for offering support in inventive ways. So do all look out for more of these opportunities when they come up.

Some feedback from the attendees (and, no, we didn't pay them...):

- "Was a great session; learned loads. I have shared information of KiT and Helpline services with all our group coordinating team this morning. And await feedback from the team on how we can move forward with supporting our nearby group, too."
- "Thank you for your information. I really enjoyed the day."
- "Many thanks to you both for your time and good advice yesterday afternoon. My thanks also go to Harshil for sharing his experiences and giving us valuable information. I found the time we had together well worthwhile. I was able to get one or two things 'off my chest', as it were, and hopefully I didn't bend people's ears too much!"
- "Thank you both. The meeting was very interesting and it was good to see how other groups are doing too. I got a lot out of yesterday."
- "Thank you very much for a very enjoyable and useful forum yesterday afternoon."

### **What's next?**

Our plans are to continue offering the MS Support Volunteer induction via Zoom. Barbara will continue with her Support and Wellbeing sessions and offer some virtual workshops on subjects to support the role (see next page...).

If you would like to find out more, or have any suggestions, please just get in touch with Barbara or me. We are always happy to chat.

We would also love to hear about what you are doing in your support role and whether things have changed for you during COVID-19, so do let us know, and we can all share thoughts and ideas in future newsletters.

Thank you for volunteering with us. Without you we couldn't reach and support the number of people affected by MS that we do.

Best wishes, and we look forward to hearing from you.

**Deborah** ([deborah.redman@mssociety.org.uk](mailto:deborah.redman@mssociety.org.uk)) and  
**Barbara** ([barbara.sujecka@mssociety.org.uk](mailto:barbara.sujecka@mssociety.org.uk))

## **Barbara's Workshops**

### **New MS Support and Wellbeing Workshops**

I'm delighted to be able to introduce you to some new workshops that you can join online. Come along and share experiences, brush up on skills or maybe learn something new! There will be a maximum of 10 people in each workshop so there is plenty of opportunity to talk.

#### **How to show emotional support in an email - 1 hour**

As a Support Volunteer, you all have the skills to support someone emotionally on the phone or face-to-face. But how do you make an email response supportive and warm?

Come along to a workshop where you can pick up some tips from the MS Society Helpline on how to show empathy in an email.

- o Tuesday 4 August: 2-3pm
- o Thursday 6 August: 11am-12

#### **How to support someone who is talking about suicidal feelings - 1.5 hours**

It can be very unsettling when someone mentions that they are feeling suicidal. What do I say? What if I say the wrong thing? What if I make things worse?

This workshop is designed to offer a place where you can talk, confidentially, to your peers about how you feel about talking to someone who is suicidal. I will also take you through some useful tools to add to your skill set and hopefully make you more confident in supporting someone who has mentioned suicide.

- o Wednesday 29 July: 10.30am-12
- o Thursday 30 July: 2-3.30pm

You can find details of all the workshops here - [volunteers.mssociety.org.uk/events](https://volunteers.mssociety.org.uk/events). We expect them to book up fast. If they are full, just send me an email and I can organise some more...

**Barbara** ([barbara.sujecka@mssociety.org.uk](mailto:barbara.sujecka@mssociety.org.uk))

## Oceans of Hope

*For those of you missing a summer holiday this year, here's Annette, a Support Volunteer, describing her amazing adventure last year....*

On Friday 10 August, 2019, my husband Kevin drove me to Bewl Water in Kent, where I met up with 22 others with MS to do the Oceans of Hope Challenge. We were allocated rooms and I was sharing a room with a lady called Karen, who I had never met or spoken to before, which was daunting in itself. We all enjoyed a meal before heading off to bed to rest up for the following day.

After a decent full English breakfast we got kitted up with buoyancy aids before going down to the water. The more able walked down but many of us took advantage of traveling down by car. We were allocated boats; I was in a gig called Bewl Rose with five others and an experienced skipper. We sailed around the reservoir for some time then arranged to meet up on the other side with Mariners of Bewl (MOB). Ian, who I knew from Frensham Pond Sailability, made a point of coming over in the safety boat he was travelling in to say hello.

Once we moored at MOB, I had trouble getting off the boat and ended up sitting on the jetty. Several volunteers helped me to my feet, including Pippa and Stefan, who supported me in the walk to the picnic we enjoyed with the MOB. I have to confess that I took the offer of a lift in a car back to our base as I was nervous of getting in and out of the boat again. That evening we had a tasty BBQ.

The following morning, after breakfast, we went sailing again. This time I was in a Stratos with an experienced skipper and two others with MS, and they dug out a hoist especially for me!

I found the weekend very challenging, but I am planning to do Oceans of Hope Croatia – watch this space! I go sailing alone in a Hansa 2.3 at Frensham Pond whenever I have a free Saturday and they hoist me in and out there. **Annette**

Here is a photo of me being hoisted out of a Laser Stratos, proving that anyone can sail if they want to!



## **Short Breaks at your service!**

Even though we're still 'locked down' in lots of ways, we're all patiently waiting to get back to some kind of normal. Taking a break will be on the list as something we all want to get back to. Living with the day-to-day demands of MS, or of caring, can mean that it takes a little bit of extra support and planning to organise a break.

We're here, ready, willing and able to give you that extra support, for when the time is right to pack our cases once again.

Maybe it's accessible accommodation, care and support services, or equipment you'd need for a successful break. Or perhaps to find a way from A to B by plane, train, or WAV (Wheelchair Accessible Vehicle), or help to source some respite care.

We know that it might not be right now, but a little forward planning may help when we can finally see what's around the corner, and the world is once more our oyster!

So, if you don't know what's available, where to start, or how to plan, why not give us a call and talk through your ideas?

You can reach the Short Breaks Service through the MS Helpline on 0808 800 8000, by email at [helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk) or on Facebook - [facebook.com/MSSociety/](https://www.facebook.com/MSSociety/).

The MS Helpline is open between 9am and 7pm, Monday to Friday. These times do not include bank holidays.