

How to share your experiences of employment with the APPG for MS

Please use your chosen method to share your experiences on the list of topics below. We're sure there is a lot you could talk about, so please cover as many as you'd like, from one to all of them! There's no pressure or expectation as to how long your response should be.

1. What is your experience and reflections of employment since your MS diagnosis?

This might include your experiences of:

Finding work:

- Identifying and applying for jobs
- Support given by Jobcentre Plus's and/or Disability Employment Advisers
- Sharing your MS

Being at work:

- Managing your MS in work and the support you have/haven't received (reasonable adjustments, Access to Work, Occupational Health)
- Flexible working and/or working from home
- Sharing and discussing your MS with your employer and colleagues
- Career development and progression
- Self-employment
- The impact of Covid-19 and how safe workplaces feel

Leaving work:

- The decision to leave work due to your health and the level of support you received
- The process of leaving work and any transitional period you may have had
- The role of your healthcare professional in supporting you to leave work
- The adequacy of government support to transition out of work, and once you have left work.

Support:

- Following your diagnosis
- The role of your support network e.g. family, friends, other people with MS, charities
- The role of your healthcare professional in supporting you at work
- In-work financial support including Statutory Sick Pay and Universal Credit

2. What is one key thing you'd like to tell the Government about what it is like to live with MS and work?
3. Is there anything else you'd like to tell us about employment and living with MS that you haven't had a chance to share? It can be anything, about your future, or things you'd like to see introduced, or big ideas you have on how things could be improved!

How you can share your experiences

By video:

- Please make a video no longer than 3 minutes. You can send multiple if they are covering different topics.
- Please film yourself horizontally and make sure you can be seen in the shot well.
- Please introduce yourself, including your name and where in the country you live. If you are happy to share, it would be great to include the type of MS you have and when you were diagnosed before you start to share your work experiences.
- Send to daisy.giuliano@mssociety.org.uk or via WhatsApp 07765 898778
- If the file is too large to send, please use [wetransfer.com](https://www.wetransfer.com) which is a quick and free way to send large files. Daisy can provide help with this if you'd like.

By WhatsApp voice note:

- Please send a voice note no longer than 3 minutes. You can send multiple if they are covering different topics.
- Please speak as clearly as possible into the microphone and we'd recommend planning roughly what you want to say before you press record!
- Please introduce yourself, including your name and where in the country you live. If you are happy to share, it would be great to include the type of MS you have and when you were diagnosed before you start to share your work experiences.
- Please send to Daisy via WhatsApp on 07765 898778

By email:

Please send written responses to daisy.giuliano@mssociety.org.uk

By photo diary:

- Please send all photos together, along with a short email that tells us your name and where you live. If you are happy to share, it

would be great to include the type of MS you have and when you were diagnosed.

- Please include any captions to your images to help explain a bit further about what they represent.
- Please email to daisy.giuliano@mssociety.org.uk

By interviewing others:

- If you know other people with MS, you could record a conversation between you, or interview one another. If there is a group of you, you could have a Zoom call and record it and send the recording.
- If you feel you have answers to the list of topics which both you and your employer/manager would like to talk about together, you could record a conversation between the two of you, discussing both perspectives of supporting you at work.
- It's totally up to you as to how you film it, but please remember to keep the camera horizontal and make sure everyone can be seen on camera.
- Please send recordings to daisy.giuliano@mssociety.org.uk or via WhatsApp on **07765 898778**.
- If the file is too large to send, please use [wetransfer.com](https://www.wetransfer.com) which is a quick and free way to send large files. Daisy can provide help with this if you'd like.
- We can offer support to a group conversation and would be happy to do so. Please get in touch with Daisy at daisy.giuliano@mssociety.org.uk or call/text **07765 898778** to arrange this.

If you're not sure about any of the above, we can arrange to speak in a way that suits you and take notes of our conversation to be shared with the APPG. Please contact daisy.giuliano@mssociety.org.uk or call **07765 898778** and Daisy will arrange this with you.