

**All Party Parliamentary Group for MS: Review into Employment Support for People with MS
Call for written evidence**

About the Review

The APPG on MS, with support from the MS Society, has launched a review into the employment support needs of people with MS to understand what support has been particularly effective, and what more needs to be done. The review will cover both out of work support for those wishing to gain employment, and support in the workplace for those currently in work and in need of support.

About the survey

To better understand this issue, we would be grateful for your expert insight and views in response to the questions in this survey. We welcome evidence relating specifically to MS, as well as evidence relating to long term conditions more widely. Long term conditions are health conditions that last a year or longer, impact on a person’s life, and may require ongoing care and support. Please answer as many questions relevant to your organisation/area of expertise as you can, and return the survey to katharine.mcintosh@mssociety.org.uk by **Friday 29th April**.

Please note that the boxes will expand as you write – do not feel constrained by their current size.

Questions

1. What type of organisation are you responding from?

- Think-tank
- Not for profit/charity/voluntary organisation
- Employment support provider
- Employer
- Advice Service
- Professional association/body
- Other [please give details]

2. Please tell us about any experience you have of providing employment-related support to people with long term conditions such as MS.

This response is based on feedback from RCN members with long term conditions such as MS.

3. What features of the support you provide, if any, have been particularly effective?

N/A

4. Have there been any barriers at an individual, organisation, or policy level that have made it difficult for you to support people with long term conditions such as MS? What would help you to provide better support?

- RCN members suggest that lack of understanding of MS and its variation day to day is a significant barrier and that often, employment services are not best placed in all cases to provide advice due to their lack of understanding of the condition.

Out of work employment support

5. What are the barriers at an individual, organisation, and policy level to people with long term conditions such as MS getting back into work, and how could these be overcome? Where relevant, please illustrate with evidence and examples.

- Anecdotal evidence from members and RCN staff involved in representing members with long term conditions, is that understanding of the Equalities Act is patchy, therefore we want to see improved efforts to raise awareness of the Act among senior management and HR staff.
- In addition to compliance with the legal framework, the RCN believes it is important to value and support skilled and experienced nurses with long term conditions to maintain their employment. Redeployment opportunities may be limited, but employers workplace adjustments can and should be made.

6. How adequate and appropriate are Government programmes for out of work employment support (such as the Work Programme, Work Choice, Jobcentre Plus) at supporting people with long term conditions such as MS?

- The DWP Access To Work scheme has proved invaluable in the past and awareness of the scheme could be better promoted to improve access. In one example, Access to Work provided payment and support for a driver for a community nurse who was unable to drive as a result of her condition.
- RCN members working with people with MS report that the removal of dedicated Disability Employment advisors has proved both difficult and frustrating for people with MS.

7. Are there any particular sources of support that you think should be prioritised and promoted to people with long term conditions such as MS?

- Access to competent occupational health advice support for employees with long term conditions is essential to support employees to continue working. This support, alongside support from managers to provide reasonable adjustments and signposting to sources of support such as Access To Work, is integral to achieving this. In addition, the ability for staff to self-refer to such services is key, and enables issues to be picked up at the earliest stage.
- Disabled staff may require time off work to help them manage their disability, such as to attend appointments or consultations or have treatment related to the ongoing management of their disability.
- Disability and ill health are not the same thing. The RCN recommends that disability related absence is captured separately to that related to ill health. The purpose of this is to ensure that disabled staff are not discriminated against in managing absence policies that contain trigger points for capability procedures by reason of their disability, rather than their capability.
- An agreed level of paid disability leave per annum may be negotiated on an individual basis with a disabled staff member as an expected or tolerated level of leave required to manage their disability effectively.
- Improved organisational cultures and attitudes to employees with long term conditions and disabilities, where, within the limits of confidentiality, there is a shared organisation understanding of the value of all employees and their ability to work notwithstanding their disability. Teams play an important role in supporting colleagues with long term conditions and team behaviours, modelled by line managers, are key for preventing bullying at work.
- In addition, RCN members report that vocational rehabilitation is essential.

8. Are there any particular aspects of out of work support provision which are not working or that could be improved? If so, how could they be improved?

N/A

9. How should out of work benefits interact with access to sources of employment support, such as the Work Programme and Work Choice government schemes?

N/A

10. Please describe what you think an ideal employment support programme tailored to help people with long term conditions such as MS get into work would look like, in terms of both content and structure.

[Click here to enter text.](#)

In work employment support

11. What are the key issues preventing people with long term conditions such as MS from accessing the support they need in the workplace?

- Organisational cultures and attitudes to employees with long term conditions and disabilities can prevent people with long term conditions such as MS from accessing the support they need in the workplace. The RCN believes shared organisational understanding of the value of all employees and their ability to work notwithstanding a disability is important for achieving this.
- In addition, teams play an important role in supporting colleagues with long term conditions and team behaviours, modelled by line managers, are key for preventing bullying at work.

12. What types of workplace support/interventions do you think most benefit people with long term conditions such as MS? Why?

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13. What help, if any, do a) small and medium employers, and b) larger employers need to enable them to support employees with long term conditions such as MS effectively?

N/A

14. How can uncertainty for employers caused by the symptoms of long term conditions such as MS be addressed or alleviated?

N/A

15. Is there anything else that could be done to reduce the number of people with long term conditions such as MS leaving their job within a few years of diagnosis?

From the perspective of RCN members who are working with a long term or fluctuating condition such as MS:

- The NHS should act as an exemplar in terms of its employment practices and support staff with long term conditions to continue working.

- The RCN believes all NHS organisations should implement the guidance developed in partnership by the NHS staff council on supporting staff with disabilities, which provides a framework for good employment practice.¹

Recommendations for the future

16. Is there anything Government could do to help organisations that are supporting people with long term conditions such as MS around employment issues to improve the support offered?

N/A

17. Is there anything else you would like to tell us about employment support for people with long term conditions such as MS?

N/A

Thank you for your time

To find out more about the APPG Review into Employment Support for People with MS, please see the [MS Society website](http://www.ms-society.org/).

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<http://www.nhsemployers.org/~media/Employers/Documents/Plan/Guidance%20on%20flexible%20working/Guidance%20relating%20to%20disability.pdf>