

12 September 2023

Motor Neuron Disease

We are requesting details on what information and training resources are used by your trust to support patients, family members and staff around genetic testing in motor neuron disease (both genetic testing of people with motor neuron disease and predictive testing of family members). The information we request is listed below this email. We are interested in information on publicly available or locally produced resources. We appreciate your responses to all questions, even where the answer is 'none' or 'not relevant'.

In addition, please send us copies or a link to any resources you are able to share.

Basic information

On behalf of which organisation and department are you answering this request?

Belfast Trust Neurology Service

Service

Do you offer genetic testing services to people with MND?

Yes – if they wish this and consent to testing

Do you offer predictive genetic testing services to at-risk relatives of people with MND?

Occasionally counselled asymptomatic individuals in MND clinic. Normal practice was to suggest that such individuals ask their GP to refer them to the Clinical Genetics Service, for advice, counselling and testing if they wished and it was deemed appropriate.

Resources for people with MND and family members

What leaflets and websites do you provide (or signpost) to people with MND on genetic testing?

12 September 2023

We signpost to relevant pages on the MND Association UK website. If a patient doesn't have internet access, we give relevant print outs of MNDA website pages

What leaflets and websites do you provide (or signpost) to at-risk relatives of people with MND on predictive testing?

We signpost to relevant pages on the MND Association UK website, also the ALS.org US site, or MDA site. At-risk relatives are not often seen in clinics.

What letters, leaflets or websites do you provide to people having MND genetic testing or predictive testing to facilitate family communication?

A bespoke clinic letter based on the clinical interaction with the individual person with MND, to that patient, saying that they may wish to share the letter with their family.

Resources and training for staff

What educational resources or training do you have to support staff with MND genetic testing?

No specific resource is provided via the Trust. We rely on consultant experience in MND care and genetic research. Professor Karen Morrison has presented nationally on 'My Approach to Genetic Testing in MND' several times over the years, and has shared her approach to genetic testing in MND with other Belfast Trust Neurologists, and the MND Specialist Nurses.

She has also spoken to the Clinical Genetics Service staff in Belfast about this. Professor Morrison has fed into guidelines on genetic testing developed by the MNDA UK over many years, and via the national UK MND CSG.

What educational resources or training do you have to support staff with MND predictive testing?

No specific educational resources provided for this.