

Genetic Testing - Motor Neuron Disease (MND)

Reference Number: RDF1789-23

Date of Response: 18/09/23

Further to your Freedom of Information Act request, please find the Trust's response(s) below:

Please be aware that the Royal Devon University Healthcare NHS Foundation Trust (Royal Devon) has existed since 1st April 2022 following the integration of the Northern Devon Healthcare NHS Trust (known as Northern Services) and the Royal Devon and Exeter NHS Foundation Trust (known as Eastern Services).

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).

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.

- 1. On behalf of which organisation and department are you answering this request?*

Answer: Royal Devon University Healthcare NHS Foundation Trust, Peninsula Clinical Genetics service.

Service

- 2. Do you offer genetic testing services to people with MND?*

Answer: Yes.

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

Answer: Yes, through Clinical Genetics only.

Resources for people with MND and family members

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

Answer: Mainly Motor Neurone Disease Association www.mndassociation.org; some from Alzheimer's Society www.alzheimers.org.uk if for specific type e.g. FTD.

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

Answer: Mainly MNDA, some from Alzheimer's Society if for specific type e.g. FTD.

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

Answer: The Clinical Genetics service provide bespoke 'Dear Relative' letters for patients and families as required.

Resources and training for staff

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

Answer: All clinical genetics staff are kept updated to any changes in the National Genomic Test Directory, that would impact on R58 (the test indicator that includes diagnostic testing for MND). Mainstream clinicians who are not familiar with consenting for WGS based tests can access training and support through the Genomics Education Programme resources <https://www.genomicseducation.hee.nhs.uk/supporting-the-nhs-genomic-medicine-service/> or by contacting their local genetics service.

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

Answer: Predictive genetic testing is only available through clinical genetics services, where it is undertaken with trained genetic counsellors and consultants.