

'This is my journey' – people with MND and their carers share their perspectives

We have provided some additional resources to support this webinar and supporting the care you provide to patients.

Evaluation

Please do spend five minutes to complete the evaluation form and provide feedback on the recorded webinar format - for our continued development of these resources

<https://www.smartsurvey.co.uk/s/Patients8/>

MND patients and their carers were asked – 'What does hope mean to you?'

- Article supporting hope at the end of life - Paula Gawthorpe, Nurse Lecturer, School of Health and Social Work, University of Hull
<https://blogs.bmj.com/ebn/2018/05/07/supporting-hope-at-the-end-of-life/>

The patient groups and their carers were asked what are the benefits of having a multi-disciplinary professional team who understand MND?

Useful reading

- Motor neurone disease: assessment and management NICE guideline NG42 Methods, evidence and recommendations February 2016
<https://www.nice.org.uk/guidance/ng42/evidence/full-guideline-pdf-2361774637>
- NICE – National Institute for Health & Care Excellence
<https://www.nice.org.uk>

MND Association resources

- Infographic – NICE Quality Standards for MND
<https://www.mndassociation.org/app/uploads/2022/03/NICE-Quality-Standards.pdf>
- Infographic – Multidisciplinary teams
https://www.mndassociation.org/app/uploads/2021/09/77401_MNDA_Infographic_MDT_v4_HR.pdf

Care resources

- Living with motor neurone disease
<https://www.mndassociation.org/app/uploads/2015/07/Living-with-MND-STANDARD-PDF-Oct-20-1.pdf>
- Caring and MND: support for you
<https://www.mndassociation.org/app/uploads/2022/06/Carers-Guide-Dec-2021-Standard-PDF.pdf>
- Telling people about MND
<https://www.mndassociation.org/app/uploads/2022/06/Telling-people-about-MND.pdf>
- Emotional and psychological support -
<https://www.mndassociation.org/app/uploads/2020/07/Emotional-and-psychological-support.pdf>
- Making the most of life with MND
<https://www.mndassociation.org/app/uploads/2019/01/Making-the-most-of-life-with-MND.pdf>