

## Publications and resources list

### 1. Sean White – Nutritional management of people living with MND

- ESPEN guideline clinical nutrition in neurology - <https://pubmed.ncbi.nlm.nih.gov/29274834/>
- NICE MND: assessment and management - <https://www.nice.org.uk/guidance/ng42>
- EFNS guidelines on the clinical management of amyotrophic lateral sclerosis (MALS) – revised report of an EFNS task force - <https://pubmed.ncbi.nlm.nih.gov/21914052/>
- OptiCALS Randomised Controlled Trial - <https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/opticals-randomised-controlled-trial/>

A question raised at the webinar '*what are your thoughts on an anti-inflammatory diet?* Please see the following references to this question:

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4712627/>
- [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4712627/?fbclid=IwAR2EpPXsX1nqJgYoQEbbGdxiya59SfLYnBdpgki8yzWf-f28D7MAbH\\_o](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4712627/?fbclid=IwAR2EpPXsX1nqJgYoQEbbGdxiya59SfLYnBdpgki8yzWf-f28D7MAbH_o)

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- Burgos Ret al 2018. ESPEN guideline clinical nutrition in neurology. Clin Nutr. 2018 Feb;37(1):354-396. doi: 10.1016/j.clnu.2017.09.003.
- NICE Guideline [NG42]. Motor neurone disease: assessment and management. Last updated: 23 July 2019.
- Coates et al 2021. Patient, carer and healthcare professional perspectives on increasing calorie intake in Amyotrophic Lateral Sclerosis. Chronic Illness. 2021;0(0). doi:10.1177/17423953211069090
- Zarotti N et al and HighCALS Study Group 2019. Health care professionals' views on psychological factors affecting nutritional behaviour in people with motor neuron disease: A thematic analysis. Br J Health Psychol. 2019 Nov;24(4):953-969. doi: 10.1111/bjhp.12388.
- Steyn FJ et al 2018. Hypermetabolism in ALS is associated with greater functional decline and shorter survival. J Neurol Neurosurg Psychiatry. 2018 Oct;89(10):1016-1023. doi: 10.1136/jnnp-2017-317887.
- Genton Let al 2011. Nutritional state, energy intakes and energy expenditure of amyotrophic lateral sclerosis (ALS) patients. Clin Nutr. 2011 Oct;30(5):553-9. doi: 10.1016/j.clnu.2011.06.004.
- Janse van Mantgem et al 2020. Prognostic value of weight loss in patients with amyotrophic lateral sclerosis: a population-based study. J Neurol Neurosurg Psychiatry. 2020 Aug;91(8):867-875. doi: 10.1136/jnnp-2020-322909.
- Ning et al 2019. Systematic review of the prognostic role of body mass index in amyotrophic lateral sclerosis. Amyotroph Lateral Scler Frontotemporal Degener. 2019 Aug;20(5-6):356-367. doi: 10.1080/21678421.2019.1587631.
- Shimizu T et al 2019. Prognostic significance of body weight variation after diagnosis in ALS: a single-centre prospective cohort study. J Neurol. 2019 Jun;266(6):1412-1420. doi: 10.1007/s00415-019-09276-2.
- White et al; the HighCALS group 2021. The nutritional management of people living with amyotrophic lateral sclerosis: A national survey of dietitians. J Hum Nutr Diet. 2021 Dec;34(6):1064-1071. doi: 10.1111/jhn.12900.
- Essat et al; HighCALS group 2019. Interventions to promote oral nutritional behaviours in people living with neurodegenerative disorders of the motor system: A systematic review. Clin Nutr. 2020 Aug;39(8):2547-2556. doi: 10.1016/j.clnu.2019.11.015.
- Essat et al; HighCALS group 2022. Understanding the current nutritional management for people with amyotrophic lateral sclerosis - A mapping review. Clin Nutr ESPEN. 2022 Jun;49:328-340. doi: 10.1016/j.clnesp.2022.03.026.
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- Wills et al 2019. Nutritional counseling with or without mobile health technology: a randomized open-label standard-of-care-controlled trial in ALS. BMC Neurol. 2019 May 29;19(1):104. doi: 10.1186/s12883-019-1330-6.
- Ludolph et al 2020; LIPCAL-ALS Study Group. Effect of High-Caloric Nutrition on Survival in Amyotrophic Lateral Sclerosis. Ann Neurol. 2020 Feb;87(2):206-216. doi: 10.1002/ana.25661.
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- 2. Erin Probert - Eating and Drinking with Acknowledged Risks - Clinical considerations when supporting people living with MND**
- RCSLT Eating and drinking with acknowledged risks: Multidisciplinary team guidance for the shared decision-making process (adults) <https://www.rcslt.org/wp-content/uploads/2021/09/Eating-and-drinking-with-acknowledged-risks-guidance.pdf>
  - EDAR – Eating and/or Drinking Acknowledged Risks
  - Biozoon – innovation products for persons suffering from dysphagia <https://www.biozoon.uk>
  - Mouth Care Matters – Improving Oral Health <http://www.mouthcarematters.hee.nhs.uk/>
  - RHN Documentation Capacity assessment and decision [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

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- Right Care Progressive Neurological Conditions Tool Kit: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf>.
- Royal College of Physicians. Supporting people who have eating and drinking difficulties. Guide to practical care and clinical assistance, particularly towards the end of life. Report of a working party. London: RCP, 2021
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- Right Care Progressive Neurological Conditions Tool Kit: <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf>.

### 3. Christina Federico and Emma Wood - Exploring best practice – nutritional approach for people living with MND

- Gastrostomy tube – is it for me? A web-based patient decision aid for people with MND considering a gastrostomy tube. <https://gastrostomychoice.co.uk>
- Breathing and ventilation <https://www.mndassociation.org/support-and-information/living-with-mnd/breathing-and-ventilation/>
- Eating with Dignity – real food real people <https://www.eatingwithdignity.org>
- Knowledge Oral Health - <https://www.kohc.co.uk>
- BDA – Ready steady blend <https://www.bda.uk.com/resource/ready-steady-blend.html>
- Nestle HealthScience – Dysphagia diet recipe ideas (cooking with confidence ISSSI Levels 4-6) <https://www.nestlehealthscience.co.uk/health-management/dysphagia/recipe-ideas>
- ALSUntangled reviews alternative and off label treatments, with the goal of helping people with ALS make more informed decisions about them <https://www.alsuntangled.com>
- ALSuntangled Ketogenic Diets <https://www.alsuntangled.com/review/ketogenic-diets/>

#### References

- Ready Steady Blend - <https://www.bda.uk.com/resource/ready-steady-blend-now-it-s-your-turn.html>
- <https://www.eatingwithdignity.org/>
- RightCare Progressive Neurological Conditions Toolkit <https://www.england.nhs.uk/rightcare/wp-content/uploads/sites/40/2019/08/progressive-neuro-toolkit.pdf> [Accessed 14/1/23]
- Motor neurone disease: assessment and management. NICE guideline [NG42] <https://www.nice.org.uk/guidance/ng42> [Accessed 14/01/23]

#### MND Association Care resources:

- Eating and drinking guide <https://www.mndassociation.org/app/uploads/2022/06/Eating-and-drinking-guide.pdf>
- 7A Swallowing difficulties <https://www.mndassociation.org/app/uploads/2015/07/7A-Swallowing-difficulties-1.pdf>
- Care booklet includes mouth care and managing fatigue <https://www.mndassociation.org/app/uploads/2022/06/Personal-Care-with-MND.pdf>
- Advance care planning and advance decisions <https://www.mndassociation.org/app/uploads/2015/07/EOL9-Advance-care-planning-and-advance-decisions-2018.pdf>
- Tube feeding <https://www.mndassociation.org/app/uploads/2022/06/07B-Tube-feeding.pdf>

#### MND Association Professional resources:

- Dysphagia, nutrition and saliva problems <https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/dysphagia/>
- Dietetics and nutrition infographic [https://www.mndassociation.org/app/uploads/2021/09/77401\\_MNDA\\_Infographic\\_Dietetics\\_And\\_Nutrition\\_v5\\_HR.pdf](https://www.mndassociation.org/app/uploads/2021/09/77401_MNDA_Infographic_Dietetics_And_Nutrition_v5_HR.pdf)
- Managing saliva problems in MND <https://www.mndassociation.org/app/uploads/information-sheet-p3-managing-saliva-problems.pdf>
- Information for dental teams - <https://www.mndassociation.org/app/uploads/MND-dentist-guide.pdf>
- Oral suction in MND <https://www.mndassociation.org/app/uploads/Information-sheet-P9-Oral-suction.pdf>
- Respiratory symptoms in MND information <https://www.mndassociation.org/professionals/management-of-mnd/management-by-symptoms/respiratory-symptoms-in-mnd/>

- End-of-life care in MND <https://www.mndassociation.org/app/uploads/2022/06/Professionals-guide-to-end-of-life-care-px012.pdf>
- Multidisciplinary team working for MND <https://www.mndassociation.org/app/uploads/2012/04/Multidisciplinary-team-working-for-MND.pdf>
- Breathing and ventilation <https://www.mndassociation.org/support-and-information/living-with-mnd/breathing-and-ventilation/>
- Education and development at MND Association - <https://www.mndassociation.org/professionals/professional-education-and-development/>