

Nutrition Care Pathway for People Living With Motor Neurone Disease in Dorset

All patients with an MND diagnosis should have access to a Registered Dietitian for nutritional assessment (MUST - Malnutrition Universal Screening Tool) and dietary advice particularly if 5%+ weight loss is identified. Conversations about artificial feeding should take place as early after diagnosis as is appropriate to the patient's psychological state involving the MND/MDT

Dysphagia/weight loss

Consultant (Neurologist/Palliative) to refer to SALT and Dietitian if not already involved

All members of the MND/MDT should be involved with decision making. Conversations with patient/spouse, next of kin, carer about what is involved in feeding tube insertion and artificial feeding, including explanation that oral diet can continue and that artificial feeding may become inappropriate at some point. Resources: 7B tube feeding & Information sheet No: 11 & www.mytube.mymnd.org.uk

Patient declines feeding tube

Consider completing Advance Decision to Refuse Treatment (pack available from MND Association). Inform GP and others.

Ongoing oral intake as appropriate and ongoing support from Dietitian and SALT

Patient would like to be assessed

FVC < 60%

Consider Consultant referral to respiratory specialist

Respiratory assessment

FVC > 60%

Assessment by MDT e.g. Dietitian; Nutrition Nurse Specialist/Practitioner & Consultant Gastroenterologist (Consider who is delivering care)

MDT assessment

Admit to neurology or other acute hospital bed for insertion of appropriate feeding tube

Education of patient/carers by Nutrition Nurse Specialist/Practitioner Dietitian & Nutricia Nurse. Refer to HEN team.

Pt/carers **NOT** willing, confident/competent

Remain in acute hospital awaiting Package of Care for home/nursing. Transfer to local Palliative Care Hospice

Pt/carers willing, confident and competent to manage tube/feeding

Discharge home

Ensure GP and patient aware that if complications arise to present to ED (NPSA guidelines)

2-5 working days post procedure

Review by SALT/dietitian as out-patient/at home/on phone as per NPSA guidelines

Ongoing care of tube by community staff/Home Enteral Nutrition Team

Reference: <https://www.nice.org.uk/guidance/ng42/chapter/Recommendations#nutrition-and-gastrostomy>
<https://www.mndassociation.org/wp-content/uploads/Eating-and-drinking-with-MND-final-web-PDF-2017.pdf>

This pathway has been drawn up with all commissioners and service providers involved.

Revised by MDT MND working party; version 4, 2018 review 2020

Nutrition Care Pathway for People Living With Motor Neurone Disease in Dorset

Local contact details:

Bournemouth/Christchurch

Gastroenterologist

Clinical Nutrition Specialist (Advanced Nurse) Practitioner:
Dietitian:

Speech & Language Therapist:

Community Team

Speech & Language Therapist

Nutricia Homeward Nurse

Dietitian (Home Enteral Nutrition Team) (HEN)

RBCH Direct line 01202303626

Dr Simon McLaughlin

01202 704732 bleep 2561

01202 704732 bleep 2272

01202 704437

01202 443712

0800 8409695 (day time)

08457 623636 (out-of-hours)

01202 711531

Poole:

Gastroenterologist:

Dietitian and S<

Clinical Nutrition Specialist (Advanced Nurse) Practitioner
0151

Community team

Speech & Language Therapist:

Nutricia Homeward Nurse:

PGH Direct line 01202 665511

Dr N Sharer

01202 442687

01202 442106 bleep

01202 305719

0800 8409695 (day time)

08457 623636 (out-of-hours)

East Dorset Community Teams

Community Dietitians:

Dietitian (Home Enteral Nutrition Team) (HEN)

01202 733323

01202 711531

West Dorset:

Gastroenterologist

Nutrition Nurse Specialist

Community Team

Dietitian (Home Enteral Nutrition Team) (HEN)

Speech and Language Therapist

Nutricia Homeward Nurse

DCH Direct line 01305 251150

Dr James Shutt

01305 255394 bleep 515

01305 254895

01305 255165

0800 8409696 (day time)

08457 623636 (out-of-hours)

01258 394084

01305 762584

Blandford

Jurassic

Abbreviations

FVC Forced Vital capacity

GP General Practitioner

HEN Home Enteral Feeding Team

MDT Multidisciplinary team

MND Motor neurone disease

MNDA Motor Neurone Disease Association

MUST Malnutrition Universal Screening Tool

NPSA National Patient Safety Agency/NHS England

SALT Speech & Language Therapist

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