End of Life Care Guidelines for People Living With Motor Neurone Disease in Dorset

Diagnosis of MND

Referred to Specialist Palliative Care

- Weldmar Hospice, Dorchester
- Forest Holme, Poole
- Macmillan Unit, Christchurch
- Hospital palliative care teams – RBH, PGH, DCH

End of life indicators:

- Marked decline in physical status/rapidly progressing symptoms – Rapid weight loss, decline in cognitive impairment
- Recurring infection
- Aspiration pneumonia
- Declining respiratory function including reduced FVC/ Increased NIV dependency/Increasing shortness of breath

End of life care discussions

- Sensitive communication with patient & their families/carers regarding EoL wishes / plan / concerns / place of death
- With the use of communication aids if appropriate
- Discussion with LPOA Health &

Diagnosis of dying

Care in last days of life

Care after death

Consider referral to:

- MNDA
- Psychosocial and spiritual support carer's assessment .
- SALT.- info in appropriate format.
- SS/MNDA carer's support groups • Family Support Hospice Team Service/Children's support provision of MNDA children's packs.
- DN teams.
- Benefits(DS1500,AA,PIP,carers allowance)

Advance Care Planning:

- Utilise my Advance Care Plan- My wishes and What is Important to me- Dorset CCG Feb 2018 and End of Life Guide: MNDA 2017.
- Complete AAND/DNAR
- Document TEP or pts wishes for treatments
- Consider ADRT/ LPOA
- Wills & funeral plan / Tissue donation

Other actions:

- Identification of a keyworker
- Detailed assessment of needs
- Symptom management (see MND pathways / NICE guideline NG42 Feb 2016)
- Discuss at MDT
- Add to Palliative Care Register / GSF
- Special Message to OOHr's

- Update Special Message to OOHr's
- Assessment for Fast Track CHC funding/PoC
- District Nurse Team referral
- Mental Capacity/Best Interests/LPOA if registered
- Ensure anticipatory medications in place to the home
- Discussion re withdrawal of artificial feeding/ventilation – ethical decision making/review ceiling of treatment
- Review needs and preferences for place of death
- GSF update
- Rationalise medications
- Ensure spiritual needs are addressed if appropriate

- Communicate individualised EOL plan to all MDT/OOHrs
- Carer support
- Primary care teams

Bereavement care

- Supporting information
- Bereavement support teams provision by Specialist Palliative Care Teams

This pathway has been drawn up with the service providers involved.
Revised by Dorset MND working party. May 2020. Review June 2022.

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Local contact details:

Bournemouth/Christchurch

Macmillan Unit:	Community specialist palliative care team	01202 705470
	Hospital specialist palliative care team	01202 726021
	In patient unit (available for 24 hour advice)	01202 705470

Poole

Forest Holme	Community Palliative Care team	01202 448115
	Hospital palliative care team	01202 448102
	In patient unit (available for 24 hour advice)	01202 448115

Bournemouth/Christchurch/Poole – SPOA = Professional Line for Care issues. DN Teams 03000 334000

Christchurch CIRT Palliative Support Workers 01202 646090

East Dorset St Leonards Generalist Palliative Care (Ferndown, Wimborne, West Moors, Verwood) 01202 584209

West Dorset

Weldmar Hospicecare:

Community palliative care team	01305 215350
Hospital palliative care team (DCH)	01305 255752
In patient unit (Dorchester) (available for 24 hour advice)	01305 215300

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Further information available:

https://www.dorsetforyou.gov.uk/end-of-life-care

https://www.poole.nhs.uk/pdf/Botb%20ACP%20NEW%20tool.pdf

https://www.mndassociation.org/support-and-information/information-resources/information-for-people-with-or-affected-by-mnd/end-of-life-a-guide-for-people-with-motor-neurone-disease/

https://www.mndassociation.org/app/uploads/2019/01/Finding-your-way-with-bereavement.pdf

https://www.mndassociation.org/app/uploads/2017/05/10d-nhs-continuing-healthcare.pdf

https://www.mndassociation.org/app/uploads/px012-a-professional-guide-to-end-of-life-care-in-mnd-v1-0-jan16-web.pdf

https://www.mndassociation.org/app/uploads/2012/04/px016-motor-neurone-disease-a-guide-for-gps-and-primary-care-teams.pdf

https://www.mndassociation.org/professionals/publications/mnd-just-in-case-kit/

https://www.mndassociation.org/app/uploads/2017/05/14a-advance-decision-to-refuse-treatment.pdf

https://www.mndassociation.org/app/uploads/2017/05/Support-and-information-for-children-and-young-people-leaflet.pdf

https://www.mndassociation.org/app/uploads/2017/05/eol07-discussions-with-family-and-children.pdf

https://journals.sagepub.com/doi/full/10.1177/1178224218813914

https://www.mndassociation.org/app/uploads/2019/06/Information-sheet-P4A-2019.pdf

https://www.mndassociation.org/app/uploads/2019/09/P7-CHC-for-MND1.pdf

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This pathway has been drawn up using the following evidence/guidelines:

www.nice.org.uk/guidance/ng42

www.nice.org.uk/guidance/ng42/chapter/Recommendations#planning-for-end-of-life

www.nice.org.uk/guidance/qs13

www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf

https://www.nice.org.uk/guidance/ng31

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