

Planning for end of life

Offer the opportunity to discuss preferences and concerns about care at the end of life at trigger points:

- diagnosis
- a significant change in respiratory function
- or if interventions such as gastrostomy or non-invasive ventilation are needed.

Be prepared to discuss end of life issues whenever people wish to do so. Time discussions sensitively and take the person's current communication ability, cognitive status and mental capacity into account.

Support with EOL



Consider possible trigger points for discussion:

Think about discussing advance care planning with people at an earlier opportunity if you expect their communication ability, cognitive status or mental capacity to get worse.

Offer people the opportunity to talk about, and review any existing, ADRT, DNACPR orders and Lasting Power of Attorney when interventions such as gastrostomy and non-invasive ventilation are planned.



Provide support and advice on advance care planning for end of life:

Topics may include:

- what could happen at the end of life e.g. how death may occur
- anticipatory medicines in the home
- advance care planning, including Advance Decisions to Refuse Treatment (ADRT), Do Not Attempt Resuscitation (DNACPR) orders, and Lasting Power of Attorney
- how to ensure advance care plans will be available when needed
- when to involve specialist palliative care
- areas that people might wish to plan for, e.g.
 - preferred place of death
 - what they do not want to happen
 - who will represent their decisions, if necessary
 - what should happen if they develop an intercurrent illness.



Towards end of life:

Provide additional support e.g. additional social or nursing care to enable informal carers and family to reduce their carer responsibilities and spend time with the person with MND.

Ensure there is prompt access to the following:

- a method of communication that meets the person's needs
- specialist palliative care
- necessary equipment, e.g. syringe drivers, suction machines, hospital bed
- anticipatory medicines to treat breathlessness, and antimuscarinic medicines to treat problematic saliva and respiratory secretions.

Offer bereavement support to family members and/or carers.