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Palliative Care in Motor Neurone Disease

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Outline

- Case
- Symptom control
- Advance care planning
- Anticipatory clinical planning

Case

- Brian is a 54 year old man with motor neurone disease
- He fully understands his diagnosis & prognosis
- His speech is rapidly deteriorating with no reversible cause. He is worried he may soon be unable to communicate his wishes
- His swallow is getting weaker
- He is very clear that he wants to die at home and does not want to be admitted to hospital
- He does not want to receive cardiopulmonary resuscitation, artificial ventilation of any sort, or a PEG

What would be the key things to consider when you first meet him?

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Physical

As he gets weaker:

- How will he communicate?
- How will he swallow?
- Will he choke?
- Will he have problems with saliva?
- Will he get pain?
- How will his breathing change?

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Social

- How does & will he manage at home?
- Is he safe?
- How are his family managing?

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Psychological

- Is he / will he be frightened?
- Who does he talk to?
- What gives him strength?

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Future Care Planning

- Has he thought about the future?
- Does he understand the impact of his diagnosis on his future?
- Does he have wishes about his future care, including end of life?
- Will he be able to communicate those wishes as his speech deteriorates?

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Physical

Communication

- Needs considering ideally before the patient loses the ability to speak
- Will pen & paper work?
- Technology?

Swallowing

- How will he maintain nutrition if he can't swallow? He has declined a PEG
- Intake vs. need
- Nutritional supplements
- Adaptations of e.g. cutlery
- SALT assessment
- Is it OK to let him eat and drink a normal diet? Whose responsibility / fault is it if he chokes?

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Physical

Saliva

Need to assess the problem – volume & viscosity

- If drooling consider swallowing advice, diet, posture, oral care, suctioning
- Consider anti-muscarinic e.g hyoscine – can be sedating
- Could also consider glycopyrronium or Botulinum toxin

- If saliva is thick & sticky – review medications, fluid intake.
- Consider saline nebulisers, carbocysteine

Physical

Pain

Advanced MND is not a painful condition, but can result in pain:

- muscle cramps / spasticity / stiffness – quinine (for cramps), baclofen
- mechanical stress on joints – paracetamol, NSAIDs

- skin
- immobility
- oedema
- constipation
- neuropathic pain

Patients will need full assessment to work out likely cause of pain so as to best treat it

Physical

Breathing difficulties

- He has declined any artificial ventilation

- Always consider reversible causes
- May be more prone to chest infections as breathing weakens
- Treat breathlessness symptomatically

- Non medical
  - Open window, fan, cool air

- Medical
  - Opioids
  - Benzodiazepine

Social

- Consider whether patient managing at home
- Need to understand how his MND is likely to progress and therefore how his care needs will progress
- Aim to avoid preventable hospital admissions due to social problems that could have been anticipated

Psychological

- Is he frightened?
- Is he anxious?
- Who does he talk to?
- What gives him strength

Future care planning

= advance care planning

- Has he thought about the future?
- Does he understand the impact of his diagnosis on his future?
- Does he have wishes about his future care, including end of life?
- Will he be able to communicate those wishes as his speech deteriorates? If not, what are the alternatives?

- Process of discussion about choices a patient may wish to make should they lose the capacity to make these decisions in the future
- While a patient has capacity, they make their own decisions

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Advance care planning

Northumbria Healthcare NHS Foundation Trust

Advance statement

Wishes & preferences, but not legally binding

- *Where would I like to be cared for?*
- *Do I have religious beliefs which are important to me?*
- *Is there anything I would not want to happen?*
- *Do I need to talk to my family about my wishes?*

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Advance Decisions to Refuse Treatment

- Set out specific treatments patient wishes to refuse
- Legally binding if circumstances set out match those that have arisen
- Adults with capacity can refuse a treatment, even if you think it is an unwise decision
- If refusing life supporting treatments, must include *"I am refusing this treatment even if my life is at risk as a result"*

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NHS

NHS North of Tyne

Advance Care Planning

ADVANCE STATEMENT

This Advance Statement document should be completed by you, the patient, in discussion with your registered nurse or Medical Practitioner / Doctor.

YOUR NAME: ..... DOB: ..... NHS No: .....

Completion of this Advance Statement is voluntary.
It allows you to state your wishes, preferences, values, beliefs and feelings about your care in the future if you are unable to communicate your wishes for yourself in the future.

Although this advance statement is not legally binding, those involved in your care are legally required to take it into account when making decisions in your best interests.

Before you write your Advance Statement you may like to think about and discuss the following:

- Where I would like to be cared for in the future if I become unable to make my own decisions.
- What types of services will be available to assist me with my care?
- Do I have any religious or other beliefs / values which are important to me?
- Is there anything I would not want to happen?
- Do I need to talk to my family about my wishes?

If circumstances alter which make you change your mind about your care, speak to your Doctor or nurse so that you can complete a new Advance Statement.

Have you had any particular thoughts about your care and where it should take place in the future?

If your condition deteriorates where would you most like to be cared for?

What is important to you in the way you are cared for and what would you like to happen?

What would you NOT want to happen?

Do you have an Advance Decision to Refuse Treatment (ADRT) YES / NO

Do you have any requests or arrangements?

If there is anyone else you would like to involve if it ever becomes difficult to make decisions, please give their name below.

NAME:	RELATIONSHIP:	TELEPHONE NUMBER:	LASTING POWER OF ATTORNEY: (please tick)	
			Health & Welfare	Financial

The content of this record reflects my present wishes. Should I lose the ability to make decisions, then I give permission for this information to be shared with other relevant health & social care professionals.

Patient Signature: ..... Date: .....

I have decided to review this plan on: .....

This plan was discussed with: ..... Designation: .....

I have distributed copies of this document to: .....

Advance decision to refuse treatment (ADRT)

v7 (Adapted from *Advance Decisions to Refuse Treatment: a Guide for Health and Social Care Staff*, 2008)

NHS North East

My name	If I became unconscious, these are distinguishing features that could identify me:
Address	Date of birth: NHS no (if known): Hospital no (if known):
	Telephone Number

What is this document for?

This advance decision to refuse treatment has been written by me to specify **in advance** which treatments I don't want in the future.

These are my decisions about my healthcare, **in the event that I have lost mental capacity and cannot consent to or refuse treatment.**

This advance decision replaces any previous decision I have made.

Advice to the carer reading this document: Please check

- **Please do not assume that I have lost mental capacity before any actions are taken.** I might need help and time to communicate when the time comes to need to make a decision.
- If I have lost mental capacity for a particular decision **check that my advance decision is valid, and applicable to the circumstances that exist at the time.**
- If the professionals are satisfied that this advance decision is valid and applicable this decision **becomes legally binding and must be followed, including checking that it is has not been varied or revoked by me either verbally or in writing since it was made.** Please share this information with people who are involved in my treatment and need to know about it.
- Please also check if I have made an advance statement about my preferences, wishes, beliefs, values and feeling that might be relevant to this advance decision.

This advance decision does not refuse the offer or provision of basic care, support and comfort

Important note to the person making this advance decision:

If you wish to refuse a treatment that is (or may be) life-sustaining you must state in the boxes ***"I am refusing this treatment even if my life is at risk as a result."***
Any advance decision that states that you are refusing life-sustaining treatment **must be signed and witnessed on page 3.**

My name	

My advance decision to refuse treatment

I wish to refuse the following specific treatments:	In these circumstances:

Anticipatory Clinical Planning

- Slightly different to advance care planning

- Complications of a disease can often be anticipated ahead of time
- How would you (as the nurse / doctor etc.) like / expect the medical, nursing or patient team to manage this complication?
- This should (as far as possible) be considered ahead of time and discussed with the patient

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One Saturday night…

- Brian is waiting for his son to come back from USA (where he lives) so they can do advance care planning together
- His swallow suddenly worsens, he panics and the paramedics are called
- He is not able to talk, write or communicate his wishes
- From your previous discussions you & he knew this deterioration was predictable, unlikely to be reversible and he has been consistently adamant that he would not want admission to hospital, even if his life was at risk as a result of this decision

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On Monday morning would you rather:

A. Know that Brian's clear wishes had been respected, that he had stayed at home and the paramedics had called the OOH GP for advice and support so he could stay at home

OR

B. Discover that Brian had been admitted to hospital because the paramedics felt there was no alternative

How could you have helped Brian achieve option A?

- Early discussions with Brian as to his wishes
  - What would he accept / not accept
  - What can you anticipate happening?

- Emergency Healthcare Plans can describe a mix of what the patient wants combined with what you can anticipate

How could you have helped Brian achieve option A?

- Brian has consistently said he would not want hospital admission
- Can anticipate that Brian may have sudden deterioration in his speech and swallow
- This would mean he can't take his medication orally and not be able to speak / communicate his wishes verbally
- What would / could you do if this happened?

- Discuss this ahead of time with Brian & document in EHCP
- Make sure appropriate medication in place at home

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For children and young people, who has parental responsibility?

GP and practice details:

Lead nurse: **Place of work:** Tel:

Lead consultant: **Place of work:** Tel:

Emergency out of hours **Person or service** **Tel:**

Other key professionals:

Place of work: Tel:

Place of work: Tel:

Place of work: Tel:

Place of work: Tel:

Underlying diagnosis(es): **For children:** **wt in kg** **Date**

Motor neurone disease - advanced

Key treatments and concerns you need to know about in an emergency
(eg. main drugs, oxygen, ventilation, active medical issues)

Brian has motor neurone disease. We have discussed his thoughts around hospital admissions many times and he has been consistently clear that he does not want admission to hospital under any circumstances.

EMERGENCY HEALTH CARE PLAN (EHCP) v14

Anticipated emergency(ies)	What to do
1. Breathlessness	Brian - if you get breathless: 1. Open a window for fresh air 2. Use your hand held fan 3. Remember your breathing exercises 4. Try a dose of lorazepam (1/2 tablet under your tongue) 5. Wait 30 minutes and keep doing your breathing exercises 6. If this hasn't helped, then try taking 2.5 ml morphine liquid 7. Wait 30 minutes 8. If the breathing is no better, take another 1/2 tablet of lorazepam 9. Wait 30 minutes 10. If the breathing is still no better, then phone for the district nurses who will come to assess you and could phone GP if needed
2. Disease progression / dying	Brian knows that his disease is slowly progressing and that his condition may suddenly deteriorate. If this happens he is very clear that he wants to stay at home for end of life care and not be admitted to hospital.
3. Inability to swallow	If Brian's swallow deteriorates, he may become unable to take his medication by mouth. He therefore has injectable medication in the house. These have been prescribed for PRN (as required) use, but not regular use as Brian does not need them regularly at the moment. If he is unable to swallow, he will need assessing by a GP as he may need to start regular injectable subcutaneous medication via a syringe driver and this would need prescribing.

If a DNACPR decision has been agreed, complete the regional DNACPR document

Background information about these decisions

EMERGENCY HEALTH CARE PLA

Summary

- Patients with advanced MND have *many* needs that need to be addressed
- MND can cause large symptom burden
- Lots of discussion with patient & family over a period of time is required to enable future care planning as MND is relatively predictable

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Thank you