Northumbria Healthcare NHS
NHS Foundation Trust

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Advance Care Planning

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From JRCPTB palliative medicine curriculum:

2.21 Delivering Shared Care
To be able to deliver palliative care whatever the environment (hospital, hospice, nursing homes, day-care and the patient's home)
Planning for emergencies in the home
Planning for end-of-life care

3.1 The Patient as the Central Focus of Care
To develop the ability to prioritise the patient's agenda encompassing his/her beliefs, concerns, expectations and needs
Develop a self-management plan with the patient

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Why would you want to plan decisions & care ahead of time?

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Case 1

- 54 year old man with motor neurone disease that you see on domiciliary visits
- He fully understands his diagnosis and prognosis
- His speech is deteriorating and he is worried there will come a point when he is no longer able to communicate his wishes
- He is very clear that he wants to die at home and does not want to be admitted to hospital
- He is clear he does not want to receive cardiopulmonary resuscitation, artificial ventilation of any sort, or a PEG

How could you help him facilitate his wish?

Advance Care Planning

- Is a process of discussion about choices a patient may wish to make should they lose the capacity to make these decisions for themselves in the future
- If a patient has capacity, they can make their own decisions
- How does a patient share their wishes if they have lost their capacity?

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Advance Care Planning

1. Do nothing – best interests decision at the time
2. Advance Statement
3. Advance Decisions to Refuse Treatment
4. Appoint a Lasting Power of Attorney for health

- In England and Wales, this is supported by the Mental Capacity Act 2005

Which option to pick?

- Best interest decision
  - Involve the person as much as possible
  - Ask family what the patient's views and wishes were
  - Do the family know what the patient would have wanted *rather than* what the family think should happen

- Lasting Power of Attorney. There are 2 types:
  - health and welfare
  - property and financial affairs
- In England & Wales patient nominates LPA, complete forms, registers LPA (can take up to 10 weeks) and pays £110
- Different process in Scotland & Northern Ireland

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Which option to pick?

- Advance Statements set out wishes & preferences, but are not legally bringing

- Advance Decisions to Refuse Treatment set out specific treatments the patient wishes to refuse
  - Legally binding if the circumstances set out in the ADRT match those that have arisen

Advance statements

- 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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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

- All adults with capacity can refuse a treatment, even if you think it is an unwise decision
- This can be documented in ADRT
- If refusing life supporting treatments, must include the written phrase *“I am refusing this treatment even if my life is at risk as a result”*

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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:

Case 1

- What would you recommend for the patient with motor neurone disease?

Anticipatory Clinical Planning

- Slightly different to advance care planning

- Complications of a disease can often be anticipated ahead of time
- How would you 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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Case 2

- An 80 year old lady has metastatic colorectal cancer and is known to intermittently develop sub-acute bowel obstruction
- She does not want to go into hospital
- How can you help support her wishes?

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Case 2

- Discussion with patient as to her wishes
  - What would she accept / not accept
- Medical discussion
  - Given that she is declining a hospital admission, what treatment can be done at home should her symptoms recur?
  - What would I want to communicate to an out of hours' GP / district nurse who has never met this patient before?
  - How can I share this information?

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Copies of this document cannot be guaranteed to indicate current advice- the original document must be used

Name of individual:		NHS no:	
Address:		Date of birth:	
Postcode:		Hospital no:	
Next of kin 1:	Phone:	Relationship:	
Next of kin 2:	Phone:	Relationship:	
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:	
P	Place of work:	Tel:	
	Place of work:	Tel:	

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

Metastatic colorectal cancer
Subacute bowel obstruction

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

XXXX may develop a complete bowel obstruction, with large volume vomits, bowel colic and no passage of stool or flatus. If this happens she would like to be managed out of hospital, she would need her syringe driver changing from metoclopramide to cyclizine, and would need review by a member of the palliative care team.

Whilst in XXXX the district nurses from XX will change the syringe driver daily. If you have any problems between 9am-10pm please ring Rapid Response on the number above. Monday-Friday 9-5 you can contact Dr Y or Macmillan nurse Z from the palliative care team. There is always out of hours palliative care advice on the number listed above.

Important information for healthcare professionals (if necessary use p3 for additional information)

XXXX currently has a metoclopramide syringe driver in place to help with her nausea, if she develops crampy abdominal pain then this needs to be stopped and changed to cyclizine. Buscopan could also be added for symptom relief - to help with the bowel colic.
XXXX does not want top be readmitted to hospital and would like her symptoms managing in the community - preferably in YYYY, XXXX does not want to be resuscitated.

EMERGENCY HEALTH CARE PLAN (EHCP) v14

Anticipated emergency(ies)	What to do
Bowel colic	1st line: Stop metoclopramide syringe driver and start a syringe driver with 150mg/24 hours of cyclizine 2nd line: If ongoing bowel colic add in hyoscine butylbromide 60mg/24 hours. (Can also have top ups of hyoscine butylbromide hourly to a total maximum of 120mg)
Pain	XXXX is on a morphine syringe driver with 5mg/24 hours and can take 1.25mg sub-cut when required. I would recommend avoiding the oral route for analgesia as it may not be absorbed due to vomiting. If XXXX has increasing pain and is needing more top up doses then please increase her morphine syringe driver.
Vomiting	If on a metoclopramide syringe driver use metoclopramide 10mg sub-cut prn, if a few doses are needed please ask GP to increase syringe driver (can go up to 60mg in 1st instance) If on a cyclizine syringe driver use top up doses of haloperidol sub-cut (1.5mg, can be repeated hourly - maximum of 3mg/24 hours) If on cyclizine and hyoscine butylbromide then use an extra dose of haloperidol or hyoscine butylbromide. Please ring palliative care team 7 days a week for advice.

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

Background information about these decisions

EMERGENCY HEALTH CARE PLA

Hot off the press….. ReSPECT

- Recommended Summary Plan for Emergency Care and Treatment
- A process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices
- Complementary to a wider process of advance / anticipatory care planning.
- Plan is created through conversations between a person and their health professionals

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Hot off the press….. ReSPECT

- Plan is recorded on a form which can be used across all care settings
  - includes personal priorities for care & agreed clinical recommendations about care and treatment that could help to achieve the outcome that they would want, that would not help, or that they would not want
- Not yet rolled out nationally. DO not use until rolled out in your locality. Watch this space…

http://www.respectprocess.org.uk/

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Thank you