Communication stages in advanced incurable disease

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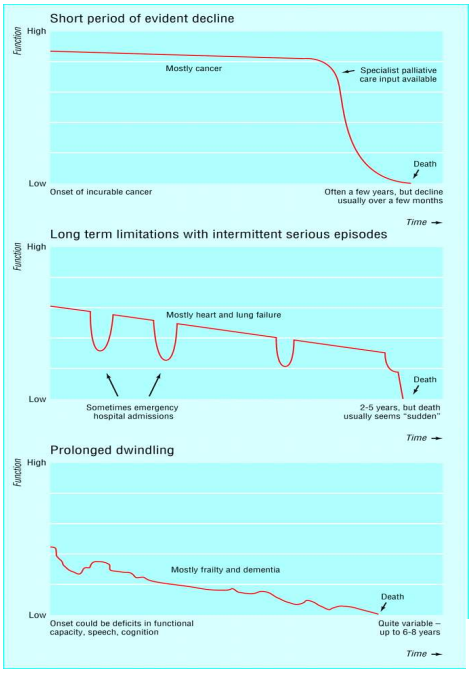
Using a scenario, the workshop will look at difficult discussions with the patient at various stages of the illness. We will address the following issues:

1. Explaining to the patient that the disease is progressive and incurable
2. Anticipatory care and activity prioritisation
3. DNACPR

Trajectories and triggers



The surprise question
"Would you be surprised if this patient were to die in the next few days/weeks/months?"

Choice
The patient with advanced disease makes an informed choice for comfort care only

Clinical indicators
Specific indicators of advanced disease

Palliative Care Register

Physical symptoms
Social issues
Psychological adjustment
Spiritual health

Planning ahead
DNACPR
Regular review
Specialist services

Framework for Cardiopulmonary Resuscitation (CPR) Decisions

NHS SCOTLAND

Can a cardiac or respiratory arrest be anticipated?

For example:

- Progressive cardiac or respiratory compromise.
- Previous life-threatening event or condition in which cardiac arrest is likely.
- Patient dying from irreversible condition e.g. advanced cancer.
- Patient whose death would not be unexpected.

NO →

Do not burden the patient or relevant others with a CPR decision

- Continue to communicate and assess any concerns of the patient and relevant others. This may involve discussion about CPR and its outcome.
- Review only when circumstances change.
- In the event of cardiopulmonary arrest, carry out CPR unless it would clearly be unsuccessful.
- For patients with strong views about CPR, advice may be given about creating an advance healthcare directive.

YES ↓

Are you as certain as you can be that CPR **would realistically** have a medically successful outcome?

YES →

Advance Decision on CPR is possible

- Sensitive exploration of the patient's wishes regarding resuscitation should be undertaken by the most experienced staff available.
- **If the patient has capacity** for this decision, discuss options of CPR and DNACPR with patient. Involve relevant others* if appropriate (with patient's permission).
- **If the patient does not have capacity** to understand the implications of this decision, the medical team should make this decision based on available information regarding patient's previous wishes (from relevant others*, advance healthcare directive, other healthcare professionals or members of the multidisciplinary team). Relevant others* should never be asked to make the decision unless they are the legally appointed welfare attorney/welfare guardian/ person appointed under an intervention order. Healthcare staff must be aware of the principles of assessing capacity and the patient must be cared for in line with the terms of the Adults with Incapacity (Scotland) Act 2000 (see policy).
- Document the decision and any discussion around that process.
- Continue to communicate and assess concerns of the patient and relevant others*.
- Review at individualised clinically appropriate intervals to assess any change in circumstances.
- In the event of a cardiopulmonary arrest, act in accordance with the documented decision.

NO ↓

Are you as certain as you can be that CPR **would realistically NOT** have a medically successful outcome?

YES →

CPR inappropriate

- As CPR would fail it cannot be offered as a treatment option. A DNACPR form should be completed and used to communicate this information to those involved in the patient's care.
- Document the reasons for the decision and any discussion around that process.
- Do not burden the patient or relevant others* with a CPR decision.
- Continue to communicate and assess any concerns of the patient and relevant others (which may include discussion about why CPR is inappropriate).
- Patients at home or going home should be offered the DNACPR form if appropriate through sensitive discussion by experienced healthcare staff.
- Review when clinical responsibility for the patient changes.
- Review at individualised clinically appropriate intervals to assess any change in circumstances.
- Where the patient is clearly dying in days allow natural death with good palliative care and support for patient and relevant others.

NO ↓

SEEK ADVICE

*Relevant others refers to the patient's partner, relatives, carers, guardian etc

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

Full name of patient: .....

Patient CHI: ..... Date of Birth: .....

Address: .....

..... Postcode: .....

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This decision applies only to CPR treatment where the patient is in Cardiopulmonary arrest.

Patients must continue to be assessed and managed with whatever treatments are appropriate for their health and comfort irrespective of their DNACPR status (this may include emergency assessment if appropriate in the event of unexpected deterioration).

A decision has been taken (please indicate below) that the above patient is **not** for attempted Cardiopulmonary Resuscitation (CPR). Any discussion around this decision (with patients, relatives, team members etc) must clearly be documented in patient's notes.

Please tick one of the three boxes below

☐ **CPR is unlikely to be successful due to:**** .....

.....

(NB: It is essential that the patient/relevant other is made aware of this decision if this DNACPR form is to go home with the patient. Every effort should be made to do this in other situations but, where CPR will fail, the decision can be documented without discussion.)

○ This **has** been discussed with patient/relevant other:
(name.....)
(Tick whenever discussion has occurred and record details of discussion in patient's notes).

☐ **The likely outcome of successful CPR would not be of overall benefit to the patient.**
(The patient's informed views and wishes are of paramount importance for this decision).

One of the following circles must be ticked;

○ Decided with the patient who has capacity for the decision.

○ Decided with the patient's legally appointed welfare guardian/welfare attorney/person appointed under an intervention order:
(name.....)

○ Patient lacks capacity for the decision and no legal welfare guardian/welfare attorney/person appointed under an intervention order can be identified. Decision made on basis of overall benefit to the patient in discussion with:
(name(s).....)

☐ **CPR is not in accord with a valid advance healthcare directive/decision (living will) which is applicable to the current circumstances.**

*See full policy guidelines. **Record underlying condition(s) e.g. end stage heart failure; end stage Chronic Obstructive Pulmonary Disease; large intracerebral haemorrhage with coning; etc.

(For hospital inpatients Junior Doctors with **full GMC licence to practise** can sign but the decision must be fully discussed and agreed with the **Responsible Senior Clinician** who should then sign at the next available opportunity.)

FOR HOSPITAL INPATIENTS **Junior Doctor's Signature:**	**Date:**
Print full name:	
Responsible Senior Clinician's Signature: *(Dr or Nurse)*	**Date:**
Print full name:	**Review time frame:**

The **Responsible Senior Clinician** = most senior clinician assuming clinical responsibility for the patient during that care period who has the appropriate capability and knowledge (e.g. GP, Consultant, Staff Grade doctor, Associate Specialist, Nurse, Out of Hours Clinician).

This original DNACPR Form should follow the patient (e.g. On admission to, discharge from or transfer between hospitals). Please note that if the DNACPR Form is to be at home with the patient this must be discussed with them and the relevant others to ensure they are aware of its positive role in ensuring the patient receives appropriate care at home.

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)*

Explaining to the patient that the disease is progressive and incurable

YOUR PATIENT

Your patient is a 63 year old man with a long history of COPD. Over the past year he has got worse and has had three admissions to hospital with exacerbations of his disease. On each occasion he has responded well to antibiotics and bronchodilator therapy but he has not needed ventilation. He continues to smoke despite strong advice to the contrary. His exercise tolerance is poor and he has to stop and rest a couple of times on his way from the car park to your surgery. He is married and lives in a modest terrace house on two floors. He enjoys pottering in his small garden, and building model ships. You have observed his declining condition but you don't know how much he is aware that his condition is deteriorating irreversibly.

Write down three questions you could ask to prompt conversation about his current condition.

1 _____

_____

_____

2 _____

_____

_____

3 _____

_____

_____

Now write down some statements to develop the theme, communicating to the patient that his disease is progressive, incurable, and terminal.

1 _____

_____

_____

2 _____

_____

_____

3 _____

_____

_____

YOUR PATIENT

Your patient has motor neurone disease with bulbar palsy. He is bed-bound and needs help with personal care. He is worried about choking to death.

What would you tell him about choking? Suggest a statement to prompt discussion about his wishes in the event of a rapid decline in his condition.

_____

_____

_____

_____

_____

_____

_____

_____

YOUR PATIENT

Your patient with end stage cardiac failure has decided not to have further hospitalisation.

You need to complete a DNACPR form and leave it in the house. Suggest some forms of words to communicate that to the patient.

1 _____

_____

_____

2 _____

_____

_____

YOUR PATIENT

Your patient has multiple liver and peritoneal metastases from pancreatic cancer. She is bed-bound and very frail, with jaundice and signs of developing pneumonia.

You decide to plan her care using the LCP. What would you do about completing a DNACPR form to leave in the house?

_____

_____

_____