GMC Guidance on shared decision making in End of Life Care

Wirral Hospice Conference
28th February 2018
Jan Cooper, Regional Liaison Adviser

Working with doctors Working for patients
Our standards
Snapshot of presentation

- Key components of GMC EOLC guidance
- Specific guidance on shared decision making
- Exploration of effective communication and how values impact on the shared decision making process
- Shared decision making in CPR decisions
Treatment and care towards the end of life:
good practice in decision making

General Medical Council

Working with doctors Working for patients
Patients are ‘approaching the end of life’ when they are likely to die within the next 12 months.

When death is imminent or those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.
Underlying principles

- Equality and human rights
- Presumption in favour of prolonging life
- Presumption of capacity
- Maximising capacity to make decisions
- Overall benefit
Decision making in partnership is key.
Red pill/Blue Pill (Atwal Gawande)
Decision making in partnership - Principles

- Listen
- Discuss
- Share information
- Maximise decision making
- Respect
The most challenging decisions

- Withdrawing or not starting a treatment when it has the potential to prolong the patient’s life. This may involve:
  - antibiotics for life threatening infection
  - CPR
  - renal dialysis
  - clinically assisted nutrition and hydration
  - mechanical ventilation.
Decision making model for those with capacity

Assess
Clinically appropriate
Identify Overall benefits
Consult and Explain
Decision point
Patients who lack capacity

Clarity re decisions to be made

Advance statements, decisions or directives?

Legal proxy or lasting power of attorney?

Decide on overall benefit in consultation
Capacity flowchart

Flowchart for decision making when patients may lack capacity

STEP 1: Maximising capacity. Start from the presumption that your patient has capacity to make the decision. To maximise their capacity: Decide the options in a time and place that helps them to understand and remember what you say; ask whether having a friend or relative with them might help them to remember information, or otherwise help to make the decision. Offer written or audio information if it will help and speak to the patient’s relatives, friends and others in the healthcare team, about how best to communicate with the patient.

QUESTION 1: Having worked through these steps are you still in doubt about your patient’s capacity to make the decision?

No

Yes

Your patient has capacity

STEP 2: Assess your patient’s capacity to make the decision. Give your patient the information that they need to make the decision. QUESTION 2: Is your patient able to understand, retain and weigh up the information and communicate their wishes?

No

Yes

Your patient has capacity

Are you still unsure about your patient’s capacity to make a decision?

Yes

No

Seek legal advice with a view to staging a court to determine capacity

STEP 3A: Decision-making when a patient lacks capacity: Advance decisions. Check whether your patient has previously said what they’d like to happen in these circumstances. Check with the healthcare team and those close to the patient. QUESTION 3A: Is there a valid and applicable advance refusal of treatment?

No

Yes

In England and Wales, a valid and applicable advance refusal of treatment is legally binding. Advance requests are not legally binding but must be given weight and if the treatment options are fairly balanced (in terms of benefits, burdens and risks) then an advance request will usually be the deciding factor. You still need to consider other issues, and aim to reach an agreement with those close to the patient.

STEP 3B: Decision-making when a patient lacks capacity: Proxy decision-maker. In Scotland a lasting power of attorney or a court-appointed guardian may have the legal authority to make healthcare decisions on the patient’s behalf. In England or Wales, this could be someone with lasting power of attorney, or a court-appointed deputy. Or an independent Mental Capacity Advocate (an IMCA) may have been appointed to represent the patient. Proxy decision-making is not currently available in Northern Ireland for these circumstances. QUESTION 3B: Has someone else been given legal authority to make this decision for the patient?

No

Yes

Written and verbal advance refusals of treatment that are not legally binding should be taken into account as indication of your patient’s wishes when you are assessing whether a particular treatment would be of overall benefit to them.

STEP 4: Reaching a consensus. You should allow enough time.

No

Yes
Overall benefit

13. The decisions you or others make on the patient’s behalf must be based on whether treatment would be of overall benefit to the patient and which option (including the option not to treat) would be least restrictive of the patient’s future choices.
Overall benefit

- Healthcare professional's views
- Family's views
- Patient's views
- Advance care plans
- Independent Mental Capacity Advocate's views
- Other relevant factors
41. The benefits, burdens and risks associated with a treatment are not always limited to clinical considerations, and you should be careful to take account of the other factors relevant to the circumstances of each patient.
In circumstances in which there is no legal proxy with authority to make a particular decision for the patient, and the doctor is responsible for making the decision, the doctor **MUST** consult with members of the healthcare team and those close to the patient (as far as it is practical and appropriate to do so) before reaching a decision.

GMC End of life care guidance paragraph 16
Disagreements

Not required to provide clinically inappropriate treatment but discussion is key
Second opinion
Round table discussion
Local mediation
Court
So how can we do this?

Effective Communication is key
What does good communication look like – video
Key to this communication are.....
Values – our guidance

- Referred to 14 times
  - Shared decision making
  - Consent
  - After death care
  - Best interest decisions
  - Teamwork
Values

You must take into account of the feelings, beliefs or values that may be influencing the patient’s preferences and decisions.

You must not rely on your personal values when making best interests decisions.
Values and shared decision making

https://www.youtube.com/watch?v=U5-yBjKKicA
“Asked about his anxieties/worries and what trade offs he was willing to make”
“Supported his goals and helped him weigh his choices”
“These conversations are the best way to ensure your healthcare matches your values”
Another patients view.....
The doctors taught me to say “No”
If we had a choice...patients do
Living is more than just staying alive
Shared decisions about CPR

Working with doctors Working for patients
Success rates

- In hospital
  15-20%

- Out of hospital
  5-10%

- Advanced disease
  Estimated 1-2%
## CPR survival rates: on screen

<table>
<thead>
<tr>
<th></th>
<th>ER</th>
<th>CHICAGO HOPE</th>
<th>GREY'S ANATOMY</th>
<th>CASUAL+Y</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>68%</td>
<td>64%</td>
<td>46%</td>
<td>42%</td>
</tr>
</tbody>
</table>

Statistics from White Coat, Black Art by Dr Brian Goldman

http://www.cbc.ca/whitecoat/2013/10/18/cpr-survival-tv-hospitals-vs-real-life-hospitals/ Published online 18 October, 2013
Informing the patient

134. If a patient is at foreseeable risk of cardiac or respiratory arrest and you judge that CPR should not be attempted, because it will not be successful in restarting the patient’s heart and breathing and restoring circulation, you must carefully consider whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made. You should not make assumptions about a patient’s wishes, but should explore in a sensitive way how willing they might be to know about a DNACPR decision. While some patients may want to be told, others may find discussion about interventions that would not be clinically appropriate burdensome and of little or no value. You should not withhold information simply because conveying it is difficult or uncomfortable for you or the healthcare team.

135. If you conclude that the patient does not wish to know about or discuss a DNACPR decision, you should seek their agreement to share with those close to them, with carers and with others, the information they may need to know in order to support the patient’s treatment and care.

136. If a patient lacks capacity, you should inform any legal proxy and others close to the patient about the DNACPR decision and the reasons for it.
Resolving disagreements

If after discussion with those close to the patient and the doctors view that attempting CPR would not be of overall benefit to the patient, the doctor is not obliged to attempt CPR against his/her clinical judgement. However, you must explain the reasons for your view and any other options that may be available to those close to the patient, such as seeking a second opinion and/or a ruling from the court.

http://www.gmc-uk.org/guidance/28734.asp
What can help?

- Early conversations
- Plan ahead
- Explain medical terminology clearly
- Involve family and friends
- Document wishes
End of life care campaign

DNACPR
Discussing resuscitation decisions
February 2016

“My patient has just been admitted having collapsed at home. Their condition has rapidly declined and they are at risk of cardiac arrest. We now need to decide whether CPR should be attempted in those circumstances or a Do Not Attempt CPR order should be made.”

How to approach such sensitive situations is one of the most frequent emotive issues which can lead to disagreements with the patient. People often don’t have a very low level of success in making such decisions. Unrealistic television portrayals of seemingly simple and easy decisions making a DNACPR decision. What we should be doing is meeting these responsibilities.

Here we go through some of the above scenario, highlighting the overarching importance of involving patients and their families in the decision making process.

CAPACITY AND CONSENT IN END OF LIFE CARE

Mental capacity decision making tool
Use our online tool to explore the steps first to assess a patient’s capacity and to a decision about what is important.

Maximising your patient’s capacity
Resources to help you when treating patients who require additional support in order to make treatment decisions.

What to do when patients lack capacity
Resources to help you decide what course of action to take when your patient lacks capacity to make a healthcare decision.

Handling difficult conversations: thoughts from Dr Catherine Millington Sanders

Talking about end of life care: clinically assisted nutrition and hydration

What is important to a patient and those close to them when making decisions about clinically assisted nutrition and hydration?

How should you approach conversations and decisions about this aspect of care?

How can you ensure your patient understands their situation and what choices are available?

Watch this short film exploring views from doctors, patients and those close to them about clinically assisted nutrition and hydration in end of life care.

If you have found this film useful in reflecting on your experiences and practice, read more in our blog by Dr Rebecca Gammell where she shares her experiences of making nutrition and hydration decisions with patients.

Thank you to all who were involved in the creation of this film. You can find out more about how we developed this film and who was involved here.

You can read our guidance on clinically assisted nutrition and hydration in paragraphs 112 - 127 of Treatment and care towards the end of life: good practice in decision making.
End of life care resources

Flow chart for decision making when patients may lack capacity

End of life care: resources

In the sections below you can find links to a range of resources that provide help and advice about different aspects of end of life care.

Resources for doctors

Dying Matters
- Training films for anyone involved in discussions about end of life care.
- Resources aimed at supporting GPs to have conversations about end of life care.

Gold Standards Framework
- Support training programmes, which are available as virtual learning resources for doctors providing end of life care.

Palliative Care
- Support doctors providing end of life care.

HSIQ Transform programme to support end of life care planning.

General Practitioners
- Resources for GPs.
How can we help?
Jan Cooper
West Midlands
Regional Liaison Adviser

0161 240 6858
07788216010
JCooper1@gmc-uk.org