End of Life Care Pocket Guide

The ReSPECT Process during the Covid-19 Crisis

The ReSPECT Process facilitates conversations between patients and health care professionals, allowing them to express what matters to them in a future medical emergency.

There will be fewer opportunities to have conversations in such trying and difficult times, but having these conversations so that frail, elderly or other patients with serious conditions have personalised care plans is an important part of care during COVID-19.

These conversations should not only cover the likelihood of benefitting from CPR, but also what is important to them, and what their ceiling of care is – would they want to be admitted to hospital? Would they want to receive IV antibiotics? Would they want to be admitted to ICU? Patients must make informed choices, and must be given relevant information about treatments that are available and the likelihood of making them better.

Advanced Care Plans and Difficult Conversations

Prepare yourself and the environment as best you can:

- What is the key purpose of this conversation?
- If possible, find a comfortable and private place to have this conversation. During Covid-19 you may have to have conversations over the phone or via e-consultation
- How will you end the conversation – what advice or referral for support can you offer the person? Which professional (doctor, nurse, registrar for death) do you anticipate they will speak to next?
- Support yourself – who can you talk with to debrief?

During the Conversation:

- Start the conversation with ‘signposting’
- Show empathy and compassion throughout. Show understanding without claiming you can possibly fully understand.
- Find out some of what the person you are talking to knows, expects, and feels
- At this point and not before, find out if they are with someone, or have someone to talk to afterwards
- Bring the person (further) towards an understanding of the situation – how things are, what has happened or is likely to happen
- Use clear terms: either die, dying, death OR ‘gentler’ terms that are nevertheless unambiguous
- If they cry - acknowledge with soft tone of voice, express sympathy: I’m sorry. If they apologise for crying, reassure them it’s OK, understandable. If you can, avoid giving further information until they’re slightly calmer
- Move towards ending the conversation – ‘screening’ understanding and unanswered questions
- Offer words of comfort and give information on what happens next

Potential Questions to Prompt Discussion:

- At this time in your life, what is important to you?
- What elements of care are important to you and what WOULD you like to happen in future?
- What would you NOT want to happen? Is there anything that you worry about or fear happening?
- Who would speak for you - your nominated proxy spokesperson or Lasting Power of Attorney?

For more information please see: https://www.eolc.co.uk/professional/lincolnshire-specific-resources-and-documents/

Adult Safeguarding

Even during a pandemic, clinicians should be aware of and follow the Mental Capacity Act 2005 principles:

1. The patient must be assumed to have capacity
2. The patient must be given all possible support to make decisions
3. The patient can make unwise decisions [subject to restrictions for infection control which apply to everyone]
4. Any decision taken about a person without capacity must be in their best interest [Subject to considerations of justice in the use of limited resources]
5. Any decision taken about a person without capacity should be the least restrictive

Recognising the Dying Phase

It's important that the patient is known to have advanced disease or frailty and that reversible causes of deterioration have been excluded. Usually the dying phase can be recognised from the following features:

- Unconscious/ sleeping much of the time
- Little interest in food/fluids
- Unable to swallow tablets
- Largely bed-bound

The assessment that a patient is in the last days of life should be made in discussion with the patient and relatives as appropriate

Priorities for Care of the Dying Person

When it is thought that a person may die within the next few days or hours:

- This possibility is recognised and communicated clearly and sensitively, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

At this stage, only drugs that are required for comfort and symptom control should be prescribed:

a) Stop non-essential medication e.g.
    - cholesterol-lowering agents such as statins
    - anti-hypertensive drugs
    - levothyroxine

b) Prescribe medication via a suitable route (e.g. subcutaneous injection or syringe driver/pump if available) for:
    - pain
    - nausea and vomiting
    - sedation
    - secretions
    - breathlessness

c) Essential drugs that cannot be given by the usual route should be changed to an alternative (e.g. anticonvulsants converted to subcutaneous midazolam, steroids to dexamethasone sub-cutaneously)