End of life conversations and planning

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Overview

- Is it important?
- Why is it so hard?
- Can we make it easier?
- What should we discuss?
- Questions

Why are End of Life Discussions Important?

Multiple studies suggest

- improved wellbeing
- improved satisfaction with care
- better agreement on appropriate interventions (including hospitalisation)

Studies also suggest

- reduced hospitalisations
- increased use of hospice and palliative care services
- decreased use of life-sustaining treatments
- better compliance with patients' wishes

So why do we not discuss plans around death?

Poll

What factors inhibit you from discussing end of life matters with patients? (tick as many that apply)

- I might cause distress to the patient
- I am unsure of when is the right time to talk about this
- I don't know what to say
- I am unsure if I have got the facts right (eg prognosis, disease trajectory, etc)
- It might bring up issues for me that I don't want to think about
- Other reasons
- I feel comfortable discussing end of life issues with patients

So why don't we do it?

- Might cause distress
- Unsure of when to talk
- Don't know what to say
- Unsure if got facts right (eg prognosis, disease trajectory, etc)
- It might bring up issues for me that I don't want to think about
- Other reasons

When is the Right Time?

- Suggestions in the chat section please

When is the Right Time?

- Last week / a year ago?
- Now!
- Whilst the patient has capacity!
- Pick up on the cues – the patient is trying to tell you (but may not want to initiate the conversation)!
- Not necessarily at a crisis point

Quote from Pancreatic Cancer UK website

- "Some people want to talk about end of life and they want loads of information, other people don't want to talk about it. My mum didn't. She didn't talk about her end of life at all really."

What to discuss

Advance Care Planning (ACP)

1.Think → 2.Talk → 3. Record → 4.Discuss → 5.Share

1. **Think-** about the future - what is important to you, what you want to happen or not to happen if you became unwell

2. **Talk-** with family and friends, and ask someone to be your proxy spokesperson or Lasting Power of Attorney (LPOA) if you could no longer speak for yourself

3. **Record-** write down your thoughts as your own ACP, including your spokesperson and store this safely

4. **Discuss** your plans with your doctor, nurses or carers, and this might include a further discussion about resuscitation (DNAR or Respect) or refusing further treatment (ADRT)

5. **Share this** information with others who need to know about you, through your health records or other means, and review it regularly.

www.goldstandardsframework.org.uk

Another way of looking at it

- Think
- Talk
- Record
- Discuss
- Share

Who to Talk to

- Talking to family and friends
- Talking to children
- Talking to health professionals

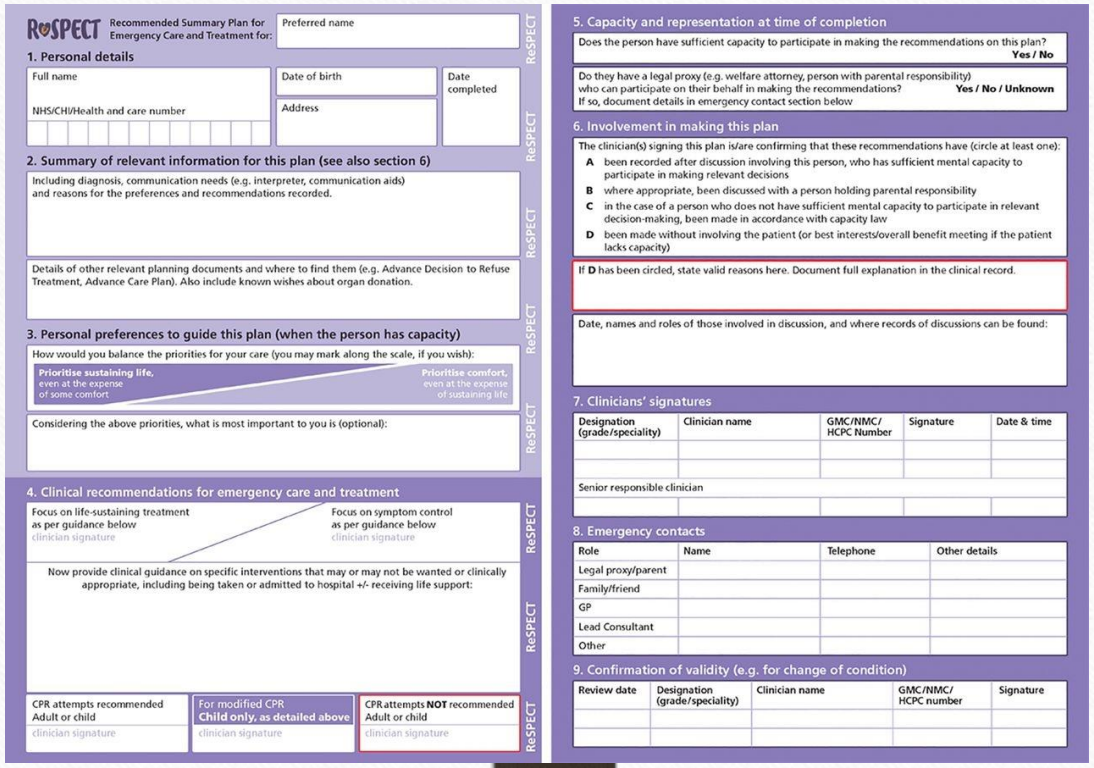
Who is the right person to do this?

- Family
- Professional
  - Doctor
  - Nurse
  - Other
- Specialist
- Non-specialist

Things to discuss

- Where to be cared for
- What interventions / treatments
- Those important to you – family, etc including pets
- Finances
- Wills, etc

ReSPECT Form



ReSPECT Recommended Summary Plan for Emergency Care and Treatment for: Preferred name

1. Personal details

Full name

NHS/CHI/Health and care number

Date of birth

Address

Date completed

2. Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort

Prioritise comfort, even at the expense of sustaining life

Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment as per guidance below
clinician signature

Focus on symptom control as per guidance below
clinician signature

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts recommended Adult or child
clinician signature

For modified CPR **Child only, as detailed above**
clinician signature

CPR attempts **NOT** recommended Adult or child
clinician signature

5. Capacity and representation at time of completion

Does the person have sufficient capacity to participate in making the recommendations on this plan? **Yes / No**

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**
If so, document details in emergency contact section below

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that these recommendations have (circle at least one):

- **A** been recorded after discussion involving this person, who has sufficient mental capacity to participate in making relevant decisions
- **B** where appropriate, been discussed with a person holding parental responsibility
- **C** in the case of a person who does not have sufficient mental capacity to participate in relevant decision-making, been made in accordance with capacity law
- **D** been made without involving the patient (or best interests/overall benefit meeting if the patient lacks capacity)

If **D** has been circled, state valid reasons here. Document full explanation in the clinical record.

Date, names and roles of those involved in discussion, and where records of discussions can be found:

7. Clinicians' signatures

Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC Number	Signature	Date & time
Senior responsible clinician				

8. Emergency contacts

Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend			
GP			
Lead Consultant			
Other			

9. Confirmation of validity (e.g. for change of condition)

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC number	Signature

Summary

- It is hard, but important
- Good evidence it is helpful

- Think about these discussions at every opportunity – your patient probably is!

- NHS website - https://www.nhs.uk/conditions/end-of-life-care/

Thank you

- Any Questions?

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