Enhancing the Palliative and End of Life Care Experience

‘One chance to get it right’
The Palliative and End of Life Care Experience

- Why are we getting it wrong?
- Why is it important we get it right?
- What can I do to enhance the patient’s / family experience?
- What strategies help?
- What resources are out there?
Finding your 1%

Identifying end of life patients

Essential tools to help GPs and other end of life care health professionals identify patients in the last 6-12 months of life.
End of Life Care

- People are ‘approaching the end of life’ when they are *likely to die within the next 12 months*. *(GMC 2010)*

- 1% of the population die each year
Average GP’s workload – average 20 deaths/GP/year approx. proportions

- Frailty / Co-morbidity / Dementia: 8
- Organ Failure: 5-6
- Cancer: 5
- Sudden Unexpected Death: 1-2

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Rapid “Cancer” Trajectory, Diagnosis to Death
- Time: Often a few years, but decline usually seems ≤2 months

Organ System Failure Trajectory
- Begin to use hospital often, self-care becomes difficult
- Time: 2-5 years, but death usually seems “sudden”

Onset could be deficits in ADL, speech, ambulation
- Time: quite variable - up to 6-8 years

Death
Ask the Surprise Question
Would you be surprised if the patient were to die in next months, weeks or days?

Step 1

NO

Don’t Know

YES

Reassess regularly

Step 2

Do they have General Indicators of Decline?

YES

Reassess regularly

NO

Don’t Know

Step 3

Do they have Specific Clinical Indicators?

YES

Begin GSF Process

Identify Include the patient on the GP’s GSF/QOF palliative care register or locality register if agreed. Discuss at team meeting.

Assess Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.

Plan Plan and provide proactive care to improve coordination and communication.

NO

Reassess regularly
• *Surprise* Question

—*Would you be *surprised* if the patient were to die in the next 6 - 12 months?*
General Indicators of Decline

- Look for $\geq 2$ of the following;
  - Poor performance status (needs help with personal care, in bed $>50\%$ or more of the day)
  - $\geq 2$ unplanned admissions
  - Weight loss 5-10$\%$ or BMI $<20$
  - Persistent troublesome symptoms
  - New event or diagnosis
  - Nursing care resident or needs care at home
# Specific Indicators of Decline

<table>
<thead>
<tr>
<th>Advanced heart/vascular disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>NYHA Class III/IV heart failure, or extensive coronary artery disease:</td>
</tr>
<tr>
<td>- breathless or chest pain at rest or on minimal exertion.</td>
</tr>
<tr>
<td>Severe, inoperable peripheral vascular disease.</td>
</tr>
<tr>
<td>Advanced respiratory disease</td>
</tr>
<tr>
<td>Severe chronic obstructive pulmonary disease (FEV1 &lt; 30%) or severe pulmonary fibrosis</td>
</tr>
<tr>
<td>- breathless at rest or on minimal exertion between exacerbations.</td>
</tr>
<tr>
<td>Meets criteria for long term oxygen therapy (PaO2 &lt; 7.3 kPa).</td>
</tr>
<tr>
<td>Has needed ventilation for respiratory failure.</td>
</tr>
<tr>
<td>Advanced kidney disease</td>
</tr>
<tr>
<td>Stage 4 or 5 chronic kidney disease (eGFR &lt; 30 ml/min).</td>
</tr>
<tr>
<td>Kidney failure as a recent complication of another condition or treatment.</td>
</tr>
<tr>
<td>Stopping dialysis.</td>
</tr>
<tr>
<td>Advanced liver disease</td>
</tr>
<tr>
<td>Advanced cirrhosis with one or more complications in past year:</td>
</tr>
<tr>
<td>- diuretic resistant ascites</td>
</tr>
<tr>
<td>- hepatic encephalopathy</td>
</tr>
<tr>
<td>- hepatorenal syndrome</td>
</tr>
<tr>
<td>- bacterial peritonitis</td>
</tr>
<tr>
<td>- recurrent variceal bleeds</td>
</tr>
<tr>
<td>Serum albumin &lt; 25 g/l, INR prolonged (INR &gt; 2).</td>
</tr>
<tr>
<td>Liver transplant is contraindicated.</td>
</tr>
<tr>
<td>Advanced cancer</td>
</tr>
<tr>
<td>Functional ability deteriorating due to progressive metastatic cancer.</td>
</tr>
<tr>
<td>Too frail for oncology treatment due to advanced multimorbidity or advanced cancer.</td>
</tr>
<tr>
<td>Advanced neurological disease</td>
</tr>
<tr>
<td>Progressive deterioration in physical and/or cognitive function despite optimal therapy.</td>
</tr>
<tr>
<td>Speech problems with increasing difficulty communicating and/or progressive dysphagia.</td>
</tr>
<tr>
<td>Recurrent aspiration pneumonia; breathless or respiratory failure.</td>
</tr>
<tr>
<td>Advanced dementia/frailty</td>
</tr>
<tr>
<td>Unable to dress, walk or eat without help.</td>
</tr>
<tr>
<td>Eating less; difficulty maintaining nutrition.</td>
</tr>
<tr>
<td>Urinary and faecal incontinence.</td>
</tr>
<tr>
<td>Progressive weakness, fatigue, inactivity.</td>
</tr>
<tr>
<td>Unable to communicate meaningfully; little social interaction.</td>
</tr>
<tr>
<td>Fractured femur; falls.</td>
</tr>
<tr>
<td>Recurrent febrile episodes or infections; aspiration pneumonia.</td>
</tr>
</tbody>
</table>
Cancer

• Single most important factor is functional ability
• >50% of time in lying down = approx 3 months or less
Benefits to Prediction

- Patient
- Patient’s support
- Practice
- Secondary care
- CCGs
GSF Register

- Electronic Palliative Care Co-ordination System (EPaCCS)
- Optimal care
- Initiates ACP discussions
- Autonomy
- Increase QoL
Audit in Practice

• What % of dying patients are on your register?
• What % are non-cancer patients?
• What % die at home?
“Let’s Start the Conversation”
EoLC Conversations - Why initiate?

- Ensures the patient feels heard and understood
- Achieves an understanding of the patient’s concerns and needs
- Enables a trusting relationship
- Reduces uncertainty
- Prevents unrealistic expectations
- Maintains ‘realistic’ hope
- Provides ‘appropriate’ information and ‘choices’
Effective EoLC Conversations

- Helps plan for the future
- Improves compliance
- Clarifies priorities
- Resolves ethical dilemmas
- Achieves informed consent
- Promotes effective MDT working

Maguire 2008
Failure to start the conversation and find patient or family’s perspective can lead to .................

• Failure to assess people’s concerns
• Failure to identify and treat psychological morbidity
• Failure to tailor information and help psychological adjustment
• Lack of participation in decision-making
• Unnecessary distress and poor end of life care particularly over the last few days of life
• Increased risk of complaints and litigation
Why identify concerns?

- > 50% of cancer patients develop an affective disorder requiring intervention
  
  Burgess et al 2005, BMJ

- Patients were more involved when concerns taken seriously and acted upon
  
  de Silva D (2013)
Why Tailor information?

- Participants value the ability of an oncologist to recognize the gravity of the news of cancer recurrence for an individual patient and make a connection at the “human-to-human” level
  
  Back, A L (2011)

- Patients who feel they are given inadequate information (too little or too much) at time of diagnosis are at greater risk of affective disorders (anxiety, depression)

  Fallowfield et al 1990, BMJ

- Patients who had all their questions answered reported cancer had less impact on their lives

  Schofield et al 2003, Annals of Oncology
Hence government recommend ........

All health & social care professionals should demonstrate effective information giving, compassionate communication & general psychological support skills

NICE (2004)

Emphasis on early recognition/prognosis, advance care planning, holistic assessment and person centred decision making all of which requires sensitive, open and honest communication

End of Life Strategy (2008)
• Despite the high number of people with cancer who are distressed, many go undetected and untreated by clinicians, Butow, P. et al. 2007

• Up to 60% of concerns remain undisclosed in hospice setting

  Heaven & Maguire 1996, Psychology Oncology Abstract

• 80% concerns remain undisclosed in in-patient hospital setting

  Farrell et al. 2005, Pt Education and Counselling

• 24% cancer patients stated they need more support from their GPs, including information on who to contact with their concerns

  Royal College of Physicians (2012)
Psychological morbidity

70% of significant distress undetected by doctors in cancer centres

Fallowfield et al 2001, British Journal of Cancer

Psychological Distress

Distress is often underdiagnosed during cancer care

Despite the frequency, relevance to the provision of holistic treatment, morbidity, and amenability to management

Ziegler L et al (2011)
Some good news though .......

Cancer Patient Experience Survey 2011/12

(where 71,793 patients completed a survey with an overall national response rate of 68%)

the most significant increases in positive scores are on information and communication issues.

On the other hand ...
Key complaints

- 47% of patients do not feel fully involved with their discharge planning from hospital.

- 39% reported that they were “completely” told about medication side effects to watch out for when they went home.

- 43% were “completely” told about any danger signals they should watch out for at home.
A survey of prognosis discussions held by healthcare providers who request palliative care consultation found:

- Most HCPs interviewed stated they did not include psycho social issues

- 21% patients reported lack of information regarding prognosis
Priorities for Care of the Dying Person

**Recognise**
The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.

**Plan & Do**
An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

**Support**
The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

**Communicate**
Sensitive communication takes place between staff and the dying person, and those identified as important to them.

**Involve**
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.

For further guidance www.nhsiq.nhs.uk/endolifecare
Let’s Hear it from the patient ......

http://www.youtube.com/watch?feature=player_detailpage&v=d3FAZbyCLZQ
Why is it so difficult sometimes?
Why can we struggle to talk about dying?

What prevents people from sharing worries and needs?

Why can we struggle to talk about dying?
Difficult because ...................... concerns about impact on patient

- Uncontrollably upset
- Angry and shout
- Go silent
- Start asking difficult questions
- That we may make things worse
Concerns for ourselves

- Taking up too much time
- Coping with our own emotions
- I won’t know what to do about the problems raised
- I may not be able to manage the emotions /problems expressed
- Wanting to avoid problems that I can’t change & focus on those I can help with
- I have no support for myself
- I have no-one to refer on to
But how can we be more effective?
Six attributes of an effective EoLC conversation:

- Playing it straight
- Staying the course
- Giving time
- Showing you care
- Making it clear
- Pacing information

Key behaviours to help patients to talk

Non-verbal:
– Being attentive
– Eye contact
– Nodding
– Appearing interested / concerned
– Leaving space for patient to talk
– Mirroring
– **Responding to cues**

Verbal:
– Open questions (open directive)
– Questions about feelings / naming feelings
– Clarifying
– Summarising and reflecting back
– Use of silence
– Empathy
– Educated guesses
– Avoiding jargon
– **Responding to cues**
Recognise behaviours that block patients talking

- Leading questions
- Closed questions
- Multiple questions
- Focusing only on the physical
- Giving advice prematurely
- Offering premature or false reassurance
- Normalizing
- Using jargon
- Jollying along
- Changing the topic
- Blaming
- Being defensive
A Concern

• Concerns, contrary to cues, help the health provider to recognize emotional distress in patients.
• Concerns suggest greater accessibility of patients to their emotions

Zimmermann, C (2011)

A Cue ........... something that a patient says or does that is a hint that there is something more to be explored
Importance of cues

- Facilitative questions linked to cues increase the probability of further cues and are key to a patient-centred consultation

- Open questions linked to a cue are 4.5 times more likely to lead to further significant disclosure than unlinked open questions

- Facilitating the first patient cue appears to be important (20% drop in cues during consultation if first cue is not facilitated)

Zimmerman et al 2003, Epidemiology & Social Psychiatry
Fletcher PhD thesis 2006
Cues

**Verbal**
- Verbal hints to hidden concerns
- Words/phrases suggesting vague or undefined emotions
- Psychological symptoms
- Words / phrases describing physiological correlates of unpleasant emotional states
- Repeated or emphasised mention of an event or issue

**Non-verbal**
- Clear expression of a negative or unpleasant emotion (e.g. crying, pacing room)
- Hints to hidden emotions (sighing, silence, frowning, negative body posture)
Apply our strategies for effective consultations:

- The Calgary-Cambridge model
- I.C.E
- SPIKES
SPIKES protocol for breaking bad news

- S- Setting
- P- Perception of condition/seriousness
- I- Invitation from the patient to give information
- K- Knowledge: giving (medical) facts
- E- Explore emotions and empathize
- S- Strategy and summary

Utilise the available Tools

- Advance Care Plan Documentation
- Preferred Priorities of Care
- Treatment Escalation Plans – DNaCPR, ADRT
- Best Interest Decision Making
- EPCCS – electronic register
What do we mean by Advance Care Planning?

“All people approaching the end of life need to have their needs assessed, their wishes and preferences discussed and an agreed set of actions reflecting the choices they make about their care recorded in a care plan”

The NHS End of Life Care Strategy (2010)
Preferred Priorities of Care

- Around 70% patients express a wish to die at home
- However about 50% die in hospital
- How can we in primary care help our patients to achieve their wishes?
A typical case

- Mrs Smith has been discharged from the acute hospital to a care home
- She is no longer able to cope at home
- She has multiple co-morbidities including COPD, heart failure and CKD
- She tells you she does not want to go back to hospital in any circumstances
- How can we ensure she gets her wishes?
Planning for Your Future Care

Advance Care Planning

Preparing for the future
Assisting with practical arrangements
Enabling the right care to be given at the right time

Adapted from the Weston Hospicecare Advance Care Plan and National Preferred Priorities for Care Guidelines
Advance Care Planning

What I *do* want

- Statement of wishes and care preferences
- Includes preferred place of care and next of kin details
- Not legally binding

What I *don’t* want

- Advance decision to refuse treatment (in specific circumstances)
- Related to capacity
- Is legally binding (if valid)
Statement of my wishes and care preferences

My preferred priorities for care

My priorities, special requests or preferences regarding my future care (including details regarding my wishes, feelings, faith, beliefs and values)

If my condition deteriorates wherever possible, the place I would most like to be cared for is..

Things I would ideally prefer not to happen to me..

My other comments or wishes I would like to share with others are..
**Advance Decision to Refuse Treatment Document (part 4 of 5)**

I declare that if I become unable to participate effectively in decisions about my medical care, then and in those circumstances, my directions are as follows (only sign the sections you feel are applicable).

This advance decision applies to the specific treatments stated below, even if my life is at risk.

Signature

(Continue in box below/on a separate sheet if necessary)

<table>
<thead>
<tr>
<th>Treatment to be refused (e.g. resuscitation, stoma formation, surgery)</th>
<th>Details of situations you have anticipated in which the refusal would be valid (see examples below)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

**Examples**
- If your heart and lungs stopped functioning that you do not wish for them to be restarted (Cardiopulmonary Resuscitation).
- I do not wish to be artificially fed or hydrated.
- I do not wish to receive antibiotics for a particular infection (please state).
- I do not want to receive Electro Convulsive Therapy (ECT) in the event of being depressed.
Additional features of booklet

• Putting your affairs in order
• Appointing someone to make decisions for you (lasting power of attorney)
• Making a Will
• Funeral Planning
Back to Mrs Smith

- Mrs Smith has now had an opportunity to discuss and document her wishes
- Now comes the difficult bit – *resuscitation*
- How do you approach this?
- Do you ask “would you like to be resuscitated”?
- Is it her choice?
Treatment Escalation Plan and Resuscitation Decision Record

• Devon-wide form for use across all health care sectors, and into the home
• Enables continuity of decisions from secondary to primary care
• Avoids repeated resus discussion
• Original form travels with the patient
Treatment Escalation Plan (TEP) and Resuscitation Decision Record

This form is for clinical guidance and it does not replace clinical judgement.

Mental Capacity
Do you have reason to doubt the capacity of the individual to be involved in making these decisions? Circle: Yes/No

If yes you must complete the 2 stage Mental Capacity Assessment overleaf. Mental Capacity Act (2005)

If the patient is currently very unwell or in the event their condition deteriorates

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is admission to an acute hospital appropriate?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Are IV fluids appropriate?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Are antibiotics appropriate?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Is artificial feeding appropriate?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Is deactivation of implantable Cardioverter Defibrillator (ICD) appropriate?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

If a referral to critical care appropriate? Yes/No

If a referral for dialysis appropriate? Yes/No

In the event of a cardiorespiratory arrest this patient is:

FOR RESUSCITATION

DO NOT ATTEMPT RESUSCITATION (DNACPR)

Sign: ____________________________
Date: ____________________________
Time: ____________________________

Name: ____________________________
Role: ____________________________
GMC No: ____________________________

Document rationale/Best interest for treatment decisions and resuscitation status (be as specific as possible):

Has the Treatment Escalation Plan and resuscitation decision been discussed with the patient? Circle: Yes/No
If no, document reason:

Have the treatment decisions been discussed with the patient’s relatives / NOK / carers? Circle: Yes/No
If no, document reason:

Provide a brief summary of what was discussed and with whom:

Date: ____________________________
Time: ____________________________

All treatment decisions above should be reviewed as the patient’s clinical condition changes.

Documentation that TEP form has been completed in medical notes. Circle: Yes/No

If appropriate, has the Electronic Palliative Care Coordination System (EPaCCS) register been updated? Circle: Yes/No

Date this document was discontinued: ____________________________
Signed: ____________________________
Role: ____________________________
GMC No: ____________________________

On discharge, if appropriate and the patient and or family have been informed of the decisions, then the original form should accompany the patient and a photocopy should remain in the patient’s medical notes.

NHS

TEP and Resuscitation Decision Record/Version 10. Review 07/16
Mental Capacity Assessment

The Mental Capacity Act (2005) requires you to assume that individuals have capacity, unless you suspect the person has an impairment or disturbance of the mind or brain. It also requires any assessment to be decision specific. If you suspect someone lacks capacity you are required to complete the 2 stage Mental Capacity Assessment.

Stage 1:
Document the reason you believe the individual has an impairment or disturbance of the functioning of the mind or brain.
Reason: ____________________________________________________________

Stage 2: Can the individual:
<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Understand information about the decision to be made?</td>
<td></td>
</tr>
<tr>
<td>2. Retain that information in their mind?</td>
<td></td>
</tr>
<tr>
<td>3. Use or weigh that information as part of the decision making process?</td>
<td></td>
</tr>
<tr>
<td>4. Communicate their decision (by talking, using sign language or any other means)?</td>
<td></td>
</tr>
</tbody>
</table>

Is the response yes to all four Stage 2 questions?

- If Yes: Complete TEP form as part of discussion with patient.
- If No: Set decision review date: ___________________________

This form should be completed legibly in black ball point ink.
- Complete patient details or affix the patient's identification label to the top right hand corner
- The date and time of writing the form should be entered
- This form will be regarded as 'INDEFINITE' unless it is clearly cancelled
- The form should be reviewed whenever clinically appropriate or whenever the patient is transferred from one healthcare setting to another, and admitted from home or discharged home
- The TEP V10 Guidance can be found on the Devon TEP website (www.devontep.co.uk)

If following clinical review, treatment decisions are changed:
- Clearly score through this form, then sign and date the discontinuation box overleaf
- File at the back of the patient's medical notes
- Document the change of decision in the patient's medical notes
- Complete a new form and insert in the patient's medical notes

"On discharge, if appropriate and the patient and or family have been informed of the decisions, then the original form should accompany the patient and a photocopy should remain in the patient's medical notes"
TEP form Key Messages

• Not legally binding – common sense and professional judgment should be applied to who should have one and how it is used

• Wherever possible, discuss with patient and relative, and document this discussion

• It is only effective if everyone knows it exists – update EPaCCS

• www.devontep.co.uk
How do we make sure everyone knows what Mrs Smith wants?

• Having had the conversation and completed the documents, it is now important to share this information with our colleagues.

• How do we achieve this?
Electronic Palliative Care Co-ordination System (EPaCCS)

- Held on Adastra system (with SPM)
- Accessible to SWAST, acute trusts, hospices, community nurses, as well as Devon Doctors
- Allows presence of TEP form, ACP document, anticipatory drugs to be flagged up
- Able to share other useful information about our patients with OOH clinicians
### Note Questions

**Template**: Devon\EQLOR

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has patient given consent for information sharing?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency consent?</td>
<td>Yes</td>
<td>No</td>
</tr>
</tbody>
</table>

*Please select YES to this question if the patient cannot give consent themselves but you feel, as a clinician, it is in the interest of the patient or the family have requested emergency consent or you have answered YES to the previous question.*

[Return to top of Note Questions](#)
<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td>Other ethnic groups</td>
</tr>
<tr>
<td>Main diagnosis</td>
<td>Chronic lung disease</td>
</tr>
<tr>
<td>Co-existing disease, complications or details</td>
<td>Dementia, Depression, Heart failure</td>
</tr>
<tr>
<td>Fire / Amber / Green Status</td>
<td>Amber</td>
</tr>
<tr>
<td>Amber Status Explanation</td>
<td>Patient lives alone</td>
</tr>
<tr>
<td>Is the patient aware of the diagnosis?</td>
<td>Yes</td>
</tr>
<tr>
<td>Is the family aware of the diagnosis?</td>
<td>Yes</td>
</tr>
<tr>
<td>Patient lives alone?</td>
<td>Yes</td>
</tr>
<tr>
<td>Resuscitation Status</td>
<td>DNAR (allow a natural death)</td>
</tr>
<tr>
<td>Is there a TEP / DNAR form with the patient?</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Notes:**
- **TEP** = Treatment Escalation Plan
- **DNAR** = Do Not Attempt Resuscitation
Is there a TEP / DNAR form with the patient?

TEP = Treatment Escalation Plan
DNAR = Do Not Attempt Resuscitation

Has resuscitation been discussed with the family?

Doctors are not obliged to offer treatments such as resuscitation to their patients, where it is thought that this will be futile. However, GMC guidance suggests that it is good practice to discuss the issue of resuscitation where possible, as long as such a discussion is appropriate and not overly burdensome for the patient.

Does the patient have ACP documentation in place?

ACP = Advance Care Planning

Various Advance Care Planning documents are available in Devon, including the booklet for patients called "Planning For Your Future Care", which incorporates information about Advance Decisions to Refuse Treatments (ADRT), Lasting Powers of Attorney (LPA) and Preferred Priorities for care (PCC) documents.

Anticipatory prescribing medication with patient?

Is the patient on an End of Life Care Pathway? (eg. LCP)

Syringe driver available with patient?

Allergies/Adverse drug reactions

NSAID

Do any Cultural, Religious or Spiritual aspects need to be considered?

Preferred place of death

Additional information regarding location
Preferred place of death: Home
Additional information regarding location: Home is first choice but appreciates this may not be possible alone

Is there a Lasting Power of Attorney for Welfare? No

Contact name:
Contact number(s):

Any disability for clinician to be aware of? Yes

Hospital: Demilled
Unit/Department:

Has organ donation been discussed and agreed? Yes

Known to hospice? No
Hospice details:

Notes:
This is the most important part as essential info can be communicated e.g. Does not have a POA but there are family divisions. If discussions are to be had regarding best interests please contact Jane Bloggs on 01234 567897 as she feels she will best represent his interests. Please see PPC document for further information regarding wishes.
The Outcome

- Mrs Smith declines gradually and dies in her preferred place of care in the nursing home.
- Her family are grateful that she achieved her wishes.
Please select YES to this question if the patient cannot give consent themselves but you feel, as a clinician, it is in the interest of the patient or the family have requested emergency consent or you have answered YES to the previous question.

- [ ] Current Information
- [ ] Contacts
- [ ] After Death

**Reason for patient leaving Register**

**Date of discharge/death**

**Actual place of death**

**Please state**

**Variance between preferred and actual place of death**

- [ ] No
- [ ] Yes

**Has the family been offered bereavement services?**

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**Notes**

This is the most important part as essential info can be communicated
e.g. Does not have a POA but there are family/kinship. If discussions are to be had regarding best interests please contact Jane Blogg on 01752 123457 as he feels she will best represent his interests. Please see PI document for further information regarding wishes.
Mental Capacity at End of Life

• But what if Mrs Smith had dementia?
• How would you assess her capacity to be involved in the decision making?
• How would you document this?
• Who else might you need to involve?
The Mental Capacity Act 2005

- Always start by assuming the patient has capacity
- You are required to maximise the person’s capacity
- All practicable steps must be taken to facilitate communication
- An eccentric or unwise decision does not imply lack of capacity
Assessing Capacity

1. Can they understand the information?
2. Can they retain the information?
3. Can they use or weigh up the information?
4. Can they communicate their decision?

This can be recorded on a FACE document
Making a best interests decision

• Is there a valid ADRT and/or a Personal Welfare Power of Attorney?
• Is there anyone that could be consulted about the patient’s best interests?
• If no to above:
  ➢ in an emergency act in the patient’s best interests
  ➢ Otherwise involve an Independent Mental Capacity Advocate (IMCA)
Scenarios

- Jack
- Margaret
- Alfred
- Jim
- Bill
- Phyllis

End of Life Care Conversations
References


References

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