End of Life Care
K&M Care Home
30th Sep 20

Kent and Medway NHS
NHS and Social Care Partnership Trust

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Overview

Why you?

What Really Matters?

How To Recognise Anyone Coming to EOL?

How Can You Best Support and Talk?

What Resources and Support is Available
Care Homes Teams!

Thank You
Inspirational Opportunity and Privilege
The Immediate Pandemic Challenges…
How many?...C:615 R:12000 and S:30000

June 19 - Dec 20

- 93475
- 16305 (84.1%)
- 3089 (15.9%)
- 19394 (100%)
Some of our aims…and CQC Questions!

- access to care is fair, personalised and coordinated
- trained staff have enabled the person to express their preferences
- a person stays for as long as possible where they want to stay
- emergency admissions to hospital are avoided
- quality of life is maximised, and pain and other distressing symptoms controlled
- carers are informed and supported
- requirements relating to their religion or ethnicity are fully respected.

You are simply THE BEST and we NEED your help!
What does a good death mean?
At least...?

01 Being treated as an individual, with dignity and respect
02 Being without pain and other symptoms
03 Being in familiar surroundings
04 Being in the company of close family and/or friends
Humanity or EoLC?
Every Moment Counts

A narrative for person-centred coordinated care for people near the end of life
What Matters Daily For Care Homes?
“How people die remains in the memory of those who live on.”
Six ambitions to bring that vision about

01 Each person is seen as an individual
02 Each person gets fair access to care
03 Maximising comfort and wellbeing
04 Care is coordinated
05 All staff are prepared to care
06 Each community is prepared to help

“I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s).”
Think what if...Just In Case?

Rainy day thinking.

“Hope for the best but prepare for the worst.”
Identification...what can help us?
BETTY 90 YEARS OLD: 1989 v/s 2020

- Retired midwife, lives alone
- Funny turn…? AF and TIA
- DMT2, COPD, BP, Osteoporosis, IHD,
- Mild memory impairment
- Early Breast Ca diagnosis recently
- Multiple medications

- What really matters to her…?
Why is it important to identify the people nearing End Of Life?

• ‘Earlier identification of people nearing the end of their life and inclusion on the register leads to earlier planning and better co-ordinated care’ (GSF National Primary Care Snapshot Audit 2010)

• About 1% of the population die each year. Although some deaths are unexpected, many more in fact can be predicted. This is inherently difficult, but if we were better able to predict people in the final year of life, whatever their diagnosis, and include them on a register, there is good evidence that they are more likely to receive well-coordinated, high quality care.
What Difference Does it Make?

• **Care Homes**: better coordinated holistic care and reduces hospital deaths

• **Acute hospital teams**: About 25% of all hospital beds are occupied by someone who is dying. The National Audit Office estimates that at least 40% of those people have no medical need to be there

• **Specialist teams**: Specialist palliative care teams play a vital role especially with cancer patients, but there is a need for collaboration with other specialist teams for non-cancer patients to provide optimal care.
The Surprise Question

• “Would I be surprised if this person were to die in the next 12 months?”

• This simple question is accurate seven out of ten times.
GSF Prognostic Indicators
General Indicators

- Decrease activity
- Co-morbidity
- General physical decline
- Advanced disease
- Poor response to treatments
- Choice of no further treatment
- Progressive weight loss
- Repeated crisis admissions

- Sentinel event eg, fall,
- Considered eligible for DS1500
Supportive and Palliative Care Indicators Tool (SPICT™)

The SPICT™ is used to help identify people whose health is deteriorating. Assess them for unmet supportive and palliative care needs. Plan care.

Look for any general indicators of poor or deteriorating health:
- Unplanned hospital admission(s).
- Performance status is poor or deteriorating, with limited reversibility. (e.g., the person stays in bed or in a chair for more than half the day).
- Depends on others for care due to increasing physical and/or mental health problems.
- The person’s care needs more help and support.
- The person has had significant weight loss over the last few months, or remains underweight.
- Persistent symptoms despite optimal treatment of underlying conditions.
- The person (or family) asks for palliative care: chooses to reduce, stop or not have treatment; or wishes to focus on quality of life.

Look for clinical indicators of one or multiple life-limiting conditions:

**Cancer**
- Functional ability deteriorating due to progressive cancer.
- Too frail for cancer treatment or treatment for symptom control.

**Dementia/Alzheimer**
- Unable to dress, walk or eat without help.
- Eating and drinking: loss of appetite, difficulty with swallowing.
- Urinary and fecal incontinence.
- Not able to communicate by speaking, writing, social interaction.
- Frequent falls, fractured bone.
- Recurrent febrile episodes or infections: aspiration pneumonia.

**Neurological**
- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive difficulty with swallowing.
- Recurrent aspiration pneumonia, breathless or respiratory failure.
- Persistent pain after stroke with significant loss of function and ongoing disability.

**Heart/Vascular**
- Heart failure or other severe, unstable coronary artery disease; with breathlessness or chest pain at rest or on minimal effort.
- Severe, incapacitating peripheral vascular disease.

**Respiratory**
- Severe, chronic lung disease: with breathlessness at rest or on minimal effort between exacerbations.
- Has needed ventilation for respiratory failure or ventilation is contraindicated.

**Kidney**
- Stage 4 or 5 chronic kidney disease (GFR < 15 ml/min) with deteriorating health.
- Kidney failure complicating other life-limiting conditions or treatments.
- Severe malnutrition.
- Dependent on dialysis.
- Liver disease
- Cirrhosis with one or more complications in the past year:
  - diuretic resistant ascites
  - hepatic encephalopathy
  - hepatic encephalopathy
  - Hypersplenism
  - Bacterial peritonitis
  - recurrent variceal bleed
  - Liver transplant is not possible.

**Other conditions**
- Deteriorating and at risk of dying with other conditions or complications that are not reversible; any treatment available will have a poor outcome.

Review current care and care planning:
- Review current treatment and medication to ensure the person receives optimal care: minimize polypharmacy.
- Consider referral for specialist assessment if symptoms or problems are complex and difficult to manage.
- Agree a current and future care plan with the person and their family. Support family carers.
- Plan ahead early if loss of decision-making capacity is likely.
- Record, communicate and coordinate the care plan.
Cancer trajectory

Short period of evident decline

- Onset of incurable cancer
- Mostly cancer
- Specialist palliative care input available
- Often a few years, but decline usually over a few months
- Death

Time →
Organ System Failure Trajectory

- Long term limitations with intermittent serious episodes
  - Mostly heart and lung failure
  - Sometimes emergency hospital admissions
  - 2-5 years, but death usually seems "sudden"

Time
Frailty

Prolonged dwindling

Function
High

Mostly frailty and dementia

Low
Onset could be deficits in functional capacity, speech, cognition

Death
Quite variable – up to 6-8 years

Time →
Deterioration: Unexpected or Expected?
Life savers...obviously!
ART FHVS or Similar… Key in K&M!
Advance Care Planning

- The patient’s wishes
- The feelings, beliefs or values
- The family members ?LPA
- Interventions such as CPR
- Preferred place of care and death
- Any religious, spiritual or other personal support
ACP…

- Voluntary
- Patient-centred over a period of time
- Documented
- Regularly reviewed
The “D” Word...
The thought of starting such a conversation may fill you with dismay. This is human.

participants used words such as "trepidation, dread, sadness, helplessness", and 60% of the GPs involved rated themselves as 'not confident' or 'not very confident' in initiating conversations about end of life, although many were experienced in end of life care.

that nine out of ten patients continued a conversation about end of life care if the GP started it. Other research has shown that the majority of people believe that their doctor will tell them if they are dying, and expect the doctor to start the conversation.
Starting The Conversation!

- Conversation Triggers
- Preparation is Key
- Practice builds confidence and competence
- After the conversation
- Support and development for having the conversation

www.dyingmatters.org
So What Can Managers and Team Leaders Do?

- The GSF Prognostic Indicator could be used as part of an end of life care strategic plan, with improved provision of services for all patients nearing the end of life and introduction of a locality register.
Needs Based Coding and Needs Support Matrices (GSF)

- □ A – All – stable from diagnosis years
- □ B – Unstable, advanced disease months
- □ C – Deteriorating, exacerbations weeks
- □ D – Last days of life pathway days
What Can Help Us Plan?
TEP and JiC...
Ensuring a Good Death for People with Dementia
Dementia: Alzheimer’s Society

• Progressive condition currently no cure
• May die from it or complicate the care of other condition
• Diminishing Capacity means important to plan for EoLC early
• Communication difficulties leading to undignified care
• Under-treatment of symptoms in particular pain
Advance Planning for EoLC

• Involve people in decision making early wherever possible
• Diminishing and eventual loss of capacity means decision made on behalf of sufferers
• Taboos about death and dying discussions, as well as poor understanding of dementia
• Support to use their right as to who should make decisions on their behalf and any treatment they would not want via the MCA
Improved Training for HCP

• Declining ability to communicate characterises the later stages of dementia

• HCP need training to provide high quality person centred care to improve dignity and QoL

• HCP also need communicate sensitively themselves to the person with dementia and their families, best practice set out by SCIE: (www.scie.org.uk)
Focus...NOT Length

- Withdrawing or withholding treatment is ethically complex and emotionally challenging, more so if ACP not in place
- Honest open discussions with MDT, family and friends
- Artificial feeding and hydration should not commence if condition is not reversible given background deterioration (NICE-SCIE Guidelines)
- Specialist Palliative and Supportive Care at all times
- Emotional support for the families and friends
Would you recognise when a person with a learning disability is at the *end of their life*?

A study shows that all groups with definite or possible learning disabilities died younger than people without. *(IHAL 2010)*

So when do you consider the 3 triggers for Palliative Care? *(Prognostic Indicator Guidance, GSF)*
The Disability Distress Assessment Tool

*Distress may be hidden, but it is never silent!*

**Background**

In the late 1990’s a combined learning disability and palliative care team at Northgate Hospital in Northumberland, UK, began to explore the issue of identifying distress in people with severe communication difficulties. They made three observations:

- Lay and professional carers were skilful at identifying distress, but had little confidence in that skill.
- This lack of certainty in what carers were observing made it difficult for them to advocate for the person with the communication difficulty when faced with a challenge to their observation.
- A number of pain score tools existed for people with cognitive impairment despite the absence of any evidence in the literature that pain produced any specific signs or behaviours.
Assisted Suicide

NOT SAFE
Improved Emotional and Spiritual Support

- Emotional and Spiritual needs disproportionately neglected (Sampson et al 2006)
- Upset, distress and depression may coexist but hard to detect
- Holistic care that recognises and responds to individual wishes and needs
How aware are you?
Sleep...the elixir for health?
Resources …

• Kent and Medway Wide Hospices
• https://www.dyingmatters.org/
• https://www.hospiceuk.org/
• https://www.macmillan.org.uk/
• https://www.e-lfh.org.uk/

• Most importantly ALL the health care teams in your locality are happy to help…if all else fails
r.koria@nhs.net
MACMILLAN CANCER SUPPORT

We’re here to help you find your best way through and live life as fully as you can.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk
Thank You