Recognising dying and predicting death
Kerry Macnish RN
“the possibility that a person may be dying should be communicated to dying people/their family and carers”
The NMC Code
Four Themes, One Code

- Prioritise People
- Practice Effectively
- Preserve Safety
- Promote Professionalism and Trust

Public Protection
Definitions of “death”

- Pushing up the daisies
- Kicked the bucket
- Expired
- Passed…./away
- Pegged it
- Taken to Jesus
- Deceased
- Brown bread
- Shuffled off this mortal coil
- Acutely unwell
- When someone has ceased to be

Medical: A poorly understood phenomenon characterized by a gradual systemic shutdown, followed by an absence of criteria that define life.
Definitions of “dying”

“Dying is not only a physical event- It is the conclusion of life defined in its nature, content and connections within a society and its cultures that are every bit as important as how dying happens.”
You cannot prevent the birds of sorrow from flying overhead; but you can prevent them from nesting in your hair.
Really Curious Individuals Support People who are Dying

Or…CRISP

Recognise
Communicate
Involve
Support
Plan & Do
## Priorities for Care of the Dying Person

### Duties and Responsibilities of Health and Care Staff

<table>
<thead>
<tr>
<th>RECOGNISE</th>
<th>COMMUNICATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td>Sensitive communication takes place between staff and the dying person, and those identified as important to them.</td>
</tr>
<tr>
<td>Always consider reversible causes, e.g. infection, dehydration, hypercalcaemia, etc.</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>INVOLVE</th>
<th>SUPPORT</th>
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<tbody>
<tr>
<td>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.</td>
<td>The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.</td>
</tr>
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<thead>
<tr>
<th>PLAN &amp; DO</th>
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<tbody>
<tr>
<td>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.</td>
<td></td>
</tr>
</tbody>
</table>

Published June 2014 by the Leadership Alliance for the Care of Dying People
Meet Percy and Polly Pecker
Group work
When is dying?

- From the moment we are born
- When one is past the prime of life
- Last 6 months
- Last 24-48 hours
- When Patient says
- When Doctor says
- When blood tests/scans indicate
- When performance status declines
- All or none of the above
### Integrated end of life care approaches

#### THE END OF LIFE

<table>
<thead>
<tr>
<th>DISEASE(S)</th>
<th>CHANGE UNDERWAY</th>
<th>RECOVERY LESS LIKELY</th>
<th>DYING BEGINS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relentless Progression is less reversible. Treatment benefits are waning</td>
<td>Benefit of treatment is less evident</td>
<td>The risk of death is rising</td>
<td>Deterioration is weekly/daily</td>
</tr>
</tbody>
</table>

#### THE DYING PHASE

<table>
<thead>
<tr>
<th>2-9 months</th>
<th>1-8 weeks</th>
<th>2-14 days</th>
<th>0-48 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Months</td>
<td>Short weeks</td>
<td>Last days</td>
<td>Last hours</td>
</tr>
</tbody>
</table>

- **At risk of dying in 6-12 months but may live for years**
- **Dying begins**
  - Deterioration is weekly/daily
  - The body is shutting down
  - The person is letting go

**More care, Less pathway A Review of LCP 2013**
Trajectories of Decline at End of Life

Is this helpful?

- Organ failure (n=6)
- Physical and cognitive frailty (n=7)
- Other (n=2)

* Adapted from: Murray SA, Sheikh A. BMJ 2008; 336: 958-959
People have more complex needs

The number of people in England with at least three long-term conditions is expected to have risen from 1.9 million in 2008 to 2.9 million in 2018.

44% of adults in the last year of life have multiple long-term conditions.

Source: Newman et al 2012 in Triggers for Palliative Care 2015 Marie Curie
Earlier recognition of decline leads to earlier anticipation of likely needs, better planning, fewer crisis hospital admissions and, more importantly, care tailored to peoples’ wishes.

(Gold Standards Framework Mar 2017)

http://www.goldstandardsframework.org.uk/
‘Palliative care’ makes you think that someone is going to die immediately, but if it was normal care for long term life-threatening conditions it would help so many people to be prepared. I know I certainly wasn't. (Caroline’s Story in Heart Failure and hospice care Hospice UK 2017)
If you need to make decisions about your healthcare, understanding your rights and planning in advance can give you peace of mind.

We are here to ensure your wishes will be respected.

What rights do I have to make decisions about my medical treatment and care?

LEARN MORE »

How are decisions about my care made if I am unable to communicate?

LEARN MORE »

Can I make decisions on the behalf of family and friends?

LEARN MORE »

How can I ensure my wishes about treatment and care are respected?

LEARN MORE »
What now?
Questions to ask after a terminal diagnosis

Click on the picture to visit web page to download a copy
“Can I predict the future?”

Is it possible to tell the difference between reversible illness and dying?

Does it matter?

http://journals.plos.org/plosone/article?id=10.1371%2Fjournal.pone.0161407#pone.0161407.ref067
A Systematic review of predications of survival in palliative care: How accurate are clinicians and who are the experts?

Click on the picture to visit Marie Curie's web page to download the study.
Table 1. Number and percentage of patients identified for palliative care and referred to specialist palliative care, and median time before death

<table>
<thead>
<tr>
<th></th>
<th>Cancer (n=200)</th>
<th>Organ failure (n=170)</th>
<th>Frailty and/or dementia (n=160)</th>
<th>All trajectories (n=530)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No. identified on the palliative care register (PCR)</td>
<td>149</td>
<td>32</td>
<td>32</td>
<td>213</td>
</tr>
<tr>
<td>% of all patients identified for palliative care</td>
<td>75%</td>
<td>19%</td>
<td>20%</td>
<td>40%</td>
</tr>
<tr>
<td>Median time identified on the PCR before death (weeks)</td>
<td>7.3</td>
<td>13.4</td>
<td>2.4</td>
<td>6.6</td>
</tr>
<tr>
<td>No. referred for specialist palliative care (SPC)</td>
<td>137</td>
<td>18</td>
<td>8</td>
<td>163</td>
</tr>
<tr>
<td>% of all patients referred for SPC</td>
<td>69%</td>
<td>11%</td>
<td>5%</td>
<td>31%</td>
</tr>
<tr>
<td>% of patients on the PCR referred for SPC</td>
<td>92%</td>
<td>5.6%</td>
<td>25%</td>
<td>77%</td>
</tr>
<tr>
<td>Median time referred for SPC prior to death (weeks)</td>
<td>5.3</td>
<td>5.2</td>
<td>2.0</td>
<td>4.9</td>
</tr>
</tbody>
</table>


Source: Triggers for palliative care Marie Curie 2015
Can tools help me predict?

- Performance status/score
- Lab tests
- Clinical indicators/local guidance
- GSF – Proactive Identification Guidance PIG tool
- The Surprise question
- Intuition/experience
The Australia-modified Karnofsky Performance Scale (AKPS)

<table>
<thead>
<tr>
<th>AKPS ASSESSMENT CRITERIA</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal; no complaints; no evidence of disease</td>
<td>100</td>
</tr>
<tr>
<td>Able to carry on normal activity; minor sign of symptoms of disease</td>
<td>90</td>
</tr>
<tr>
<td>Normal activity with effort; some signs or symptoms of disease</td>
<td>80</td>
</tr>
<tr>
<td>Cares for self; unable to carry on normal activity or to do active work</td>
<td>70</td>
</tr>
<tr>
<td>Able to care for most needs; but requires occasional assistance</td>
<td>60</td>
</tr>
<tr>
<td>Considerable assistance and frequent medical care required</td>
<td>50</td>
</tr>
<tr>
<td>In bed more than 50% of the time</td>
<td>40</td>
</tr>
<tr>
<td>Almost completely bedfast</td>
<td>30</td>
</tr>
<tr>
<td>Totally bedfast and requiring extensive nursing care by professionals and/or family</td>
<td>20</td>
</tr>
<tr>
<td>Comatose or barely rousable</td>
<td>10</td>
</tr>
<tr>
<td>Dead</td>
<td>0</td>
</tr>
</tbody>
</table>
### RAG tool/Stability Score

Patients in final 6 – 12 months of life (GSF)

1. **Surprise Question**

2. **Clinical Indicators.**

| Stable Green | The patient's needs are stable  
| | - The patient has no symptoms  
| | - Offer discussion for Advance Statements/decisions  
| | - Identify Keyworker  
| | - Consider current and future clinical and personal needs  
| | - Gold Standard framework/register  
| | - Support for families/Carers assessed  

| Stable/Unstable Condition likely to change Amber | Stable condition and symptoms managed at present with medications but there is potential for change, OR Patient's condition and/or symptoms unstable and may require Medical/Specialist review  
| | - Offer discussion for Advanced Statements/Decisions, DNAR Status, Preferred Place of Care, Treatment Escalation Plan  
| | - Current Clinical needs assessment tools for pain, depression etc  
| | - Yellow Folder, documentation that can be transferred with patient  
| | - Anticipating and planning for future possible clinical needs, GSF, Prognostic indicators, Communicating needs  
| | - Support for families/Carers assessed  

| Rapidly Changing Red | Patient distressed by fluctuating and severe symptoms  
| | - Death may be difficult or sudden  
| | - G.P, Specialist Palliative care review/advice, 5 Priorities for care, Anticipatory prescribing, Assessment tools, DNAR Status, Out of Hours / Special Messages  
| | - Advance statements and Decisions  
| | - Support for families/Carers assessed  

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[Rowcroft hospice education]
Clinical Frailty Scale*

1. Very Fit – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2. Well – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

3. Managing Well – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

4. Vulnerable – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being “slowed up”, and/or being tired during the day.

5. Mildly Frail – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6. Moderately Frail – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

7. Severely Frail – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8. Very Severely Frail – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. Terminally Ill - Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common symptoms in mild dementia include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In moderate dementia, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In severe dementia, they cannot do personal care without help.

‘As the LCP documentation acknowledges, diagnosing imminent death is a far more imprecise science than people realise. And accurate prediction in non-cancer patients is particularly difficult. There are no precise ways of telling accurately when a patient is in the last days of life’

‘the alliance has considered the various prognostic tools that may help clinicians assess whether someone is in the last few days and hours of life, but has concluded that at the moment, there is insufficient evidence base for any specific tool to be endorsed by the alliance’
4 observed end of life patterns in care homes?

- Anticipated dying - end stage cancer
- Unexpected dying - pneumonia
- Uncertain dying - frailty and old age
- Unpredicted - myocardial infarction

Living in uncertain times: Trajectories to death in residential care homes
Stephen Barclay, Katherine Froggatt, et al.
British Journal of General Practice, September 2014
Dying - a continuum

- It is not always possible or helpful to make a definitive diagnosis of dying
- Onus on clinicians is to identify patients in whom dying is a possibility and share uncertainties about this
- Care for people potentially in last days/hours of life should be a continuum
Doctors and nurses must acknowledge, accept and communicate uncertainty that exists about the prognosis.

Priorities for Care for the Dying Person: Duties and Responsibilities of Health and Care Staff LACDP June 2014
Communicating about dying
Group work - more about the Pecker family
The SAGE & THYME model

SETTING - Think first of the setting, create some privacy - sit down
ASK - “Can I ask what you are concerned about?”
GATHER - Gather all of the concerns - “Is there something else?”
EMPATHY - Respond sensitively - “You have a lot on your mind.”
TALK - “Who do you have to talk to or support you?”
HELP - “How do they help?”
YOU - “What do YOU think would help?”
ME - “Is there something you would like ME to do?”
END - Summarise and close - “Can we leave it there?”
SPIKES ‘plus’ model

**S**etting
- introductions

**P**erception
- elicit full perception & concerns
- obtain permission to give info
- give a warning shot & PAUSE
- confirm perception OR
- deliver new information - small chunks
- check understanding / impact

**I**nvitation
- acknowledge distress / check feelings
- identify new concerns and needs

**K**nowledge
- tailor information, negotiate a plan
- check for new concerns
- summarise, screen
- check how the patient is left feeling

© 2015 Maguire Communication Skills Unit™ The Christie NHS Trust

rowcroft hospice education
### BARLEY- “gather B4 you give”

<table>
<thead>
<tr>
<th>B</th>
<th>(Be aware of) <strong>body</strong> language</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Ask people about <strong>feelings</strong> and <strong>concerns</strong></td>
</tr>
<tr>
<td>R</td>
<td>Respond to <strong>cues</strong> about <strong>feelings</strong> and <strong>concerns</strong></td>
</tr>
<tr>
<td>L</td>
<td>Listen empathetically and show that you have heard</td>
</tr>
<tr>
<td>E</td>
<td>Explain what help is available</td>
</tr>
<tr>
<td>Y</td>
<td><strong>Your exit</strong> plan and summary</td>
</tr>
</tbody>
</table>

Model adapted from McGuire Communication skills training by Kerry Macnish Rowcroft Hospice
Having no solution is not the same as having no response.....

Leonard Lunn Chaplain
St Christopher's hospice 1990
Recognising Imminent Dying
The terminal phase

When is the terminal phase?

- ‘The period of inexorable and irreversible decline in functional status prior to death’.
  - Oxford textbook of Palliative Medicine 4\textsuperscript{th} ed. 2010

- Days or weeks
- Fluctuating or precipitous
- Following planned withdrawal of life-sustaining interventions
- An individualized process
Signs of Dying
Changes in breathing

• Cheyne-Stokes respiratory pattern:
  – Not exclusive to dying phase
• Shallow breathing
• Use of accessory muscles of respiration
• Respiratory secretions
• Tachypnoea (rapid respiration)
• Agonal Breathing
• Apnoeic spells (1->3 minutes)
Signs of dying
Changes in Cognition

- Decreased interaction
- Delirium: >80% in final days
- Decreasing levels of consciousness- leading to coma
- Agitation/restlessness
- Paranoia
- Combativeness
Signs of dying
Non specific

- Decreased/Absent oral intake
- Haemodynamic decline: Tachycardia, Weak pulse, Cool extremities, Mottling
- Decreased urine output
Identifying the actively dying patient

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>Profound progressive weakness</td>
</tr>
<tr>
<td>Bed-bound state</td>
</tr>
<tr>
<td>Sleeping much of the time</td>
</tr>
<tr>
<td>Indifference to food and fluids</td>
</tr>
<tr>
<td>Difficulty swallowing</td>
</tr>
<tr>
<td>Disorientation to time, with increasingly short attention span</td>
</tr>
<tr>
<td>Low or lower blood pressure not related to hypovolemia</td>
</tr>
<tr>
<td>Urinary incontinence or retention caused by weakness</td>
</tr>
<tr>
<td>Oliguria</td>
</tr>
<tr>
<td>Loss of ability to close eyes</td>
</tr>
<tr>
<td>Hallucinations involving previously deceased important individuals</td>
</tr>
<tr>
<td>References to going home or similar themes</td>
</tr>
<tr>
<td>Changes in respiratory rate and pattern (Cheyne-Stokes breathing, apneas)</td>
</tr>
<tr>
<td>Noisy breathing, pooling of airway secretions</td>
</tr>
<tr>
<td>Mottling and cooling of the skin due to vasomotor instability with venous pooling, particularly tibial</td>
</tr>
<tr>
<td>Dropping blood pressure with rising, weak pulse</td>
</tr>
<tr>
<td>Mental status changes (delirium, restlessness, agitation, coma)</td>
</tr>
</tbody>
</table>

Reproduced from: Bicanovsky L. Comfort Care: Symptom Control in the Dying. In: Palliative Medicine, Walsh D, Caraceni AT, Fainsinger R, et al (Eds), Saunders, Philadelphia 2009. Table used with the permission of Elsevier Inc. All rights reserved.
“Readiness to die” - 4 modes of dying

(Copp 1999: Facing Impending death)
Care of dying adults in the last days of life

Guidance

This guideline covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It aims to improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity. The guideline covers how to manage common symptoms without causing unacceptable side effects and maintain hydration in the last days of life.

Recommendations

This guideline includes recommendations on:

- recognising when people are entering the last few days of life
- communicating and shared decision-making
- clinically assisted hydration
- medicines for managing pain, breathlessness, nausea and vomiting, anxiety, delirium, agitation, and noisy respiratory secretions
- anticipatory prescribing
A useful Guide for carers

What to expect when someone important to you is dying

A guide for carers, families and friends of dying people

Summary...and some resources

• Identifying patients nearing the end of life is important.
• Exact prognostication is very difficult (we are not always good at it!)
• Anticipating and planning for needs is more important than getting the exact time right.
• Communicate well: Discussing uncertainty with compassion and empathy is at the heart of prognostication.
Free access to end of life e learning

http://www.e-lfh.org.uk/programmes/end-of-life-care/

Related to recognising dying workshop:

01_01 ACP and different illness trajectories
01_03 How to handle patients questions and concerns
02_14 Assessment of dying phase and after death care
04_05 Influence of transition points and crises on decision making and symptom management
06_06 End of Life Care in care homes and domiciliary care settings
More than half of us do not know the dying wishes of our nearest and dearest

Social workers reveal the extent of social care meltdown

Nearly 3 million over 65s struggling financially

Misleading missed delivery cards posted through letterboxes

Half of older patients’ families struggle to complain about poor care in hospital

8 in 10 unpaid carers have experienced loneliness

1.2 million older people are still chronically lonely – beyond the reach of friendship this summer

Baby boomers in poverty must be offered more support – Age UK response

Rise in State Pension Age has pushed women into poverty

Thousands more older people to get online thanks

Author: Age UK
Published on 21 September 2017 12:01 AM

Click on the picture to watch the 5 minute film made by Age UK about talking about dying
Another learning opportunity?.....

ONLINE COURSE

Palliative Care: Making it Work

Learn how palliative care is managed in Europe and find out about best practice in delivering integrated palliative care

A free 3 week (3 hours per week) open learning course.
https://www.futurelearn.com/courses/palliative