Managing difficult conversations

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Aims

- Definition of palliative care, end of life care and dying
- How to break the barrier when people are resistant to having conversations around palliative care
- National framework for supporting the dying patient and how to have these conversations
- Key hints and tips.

Trigger Warning

Palliative

A person is considered palliative if they have a **diagnosis of a life limiting illness**

A life limiting illness is an illness that **cannot be cured**. Examples include metastatic cancer, motor neurone disease and dementia.

Palliative dose not refer to a time scale. Some people receive palliative care for many years, others just a few short weeks.

People can receive palliative care **at any stage** in their illness and **receiving palliative care does not necessarily mean they are likely to die soon.**

Palliative

Palliative care can be given alongside treatments, therapies and medicines aimed at controlling the illness and reversing particular conditions.

The aim of palliative care is to help people to have a good quality of life.

End of life

End of life is an **important** part of palliative care

It refers to patients who are thought to be in the last year of life and includes patients whose death is imminent.
Time frame can be **difficult to predict**.
Some patients may only receive end of life care in their last weeks or days

End of life care involves **taking to patients and those who are important to them.**

Dying

When a person is judged to be **within a few hours or days of death**

It is important to note there is **no time scale** for dying

People can be dying for more than 2-3 days. It **varies from person to person** due to factors such as age and existing comorbidities

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Pancreatic Cancer Statistics

1 in 5 people with pancreatic cancer are diagnosed at stage one and stage two.

80% (4 in 5) are diagnosed at stage three and stage four.

7 in 10 people with pancreatic cancer do not receive any active treatment.

1 in 10 people with pancreatic cancer will receive potentially curative surgery.

2 in 10 people will receive chemotherapy.

Pancreatic cancer statistics - Pancreatic Cancer UK

Scenario

Ann, 53-year-old lady with a diagnosis of locally advanced pancreatic cancer
No distant metastatic disease
Completed 3 cycles of FOLFIRINOX

Recent CT scan reveals liver metastasis despite treatment

Attended oncology clinic last week for results.

Referred to ESC clinic for symptom management of RUQ pain

What do we do?….

Poll
Symptom management review only
Symptom management review & acknowledge disease progression
Symptom management review, acknowledge disease progression & approach ACP

SPIKES

Setting the scene

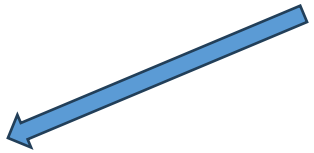
Prior knowledge

Invitation to proceed

Knowledge delivery

Empathy

Summary



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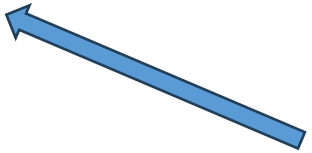

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Baile WF, Buckman R et al. (2000)

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Difficult questions

Clarify the question
"What do you mean by 'how long'?"

Acknowledge
"That must be a very difficult question for you to ask"

Why are they asking?
"Can I ask what's made you ask me that now?"

Do they have any expectations?
"Do you have any thoughts about that already?"

Do they really want to know?
"Is this the kind of information that you would really want to know?"

How long have I got?

Will I have pain?

Am I dying?

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Advance Care Planning (ACP)

What is advance care planning?

Advance care planning (ACP) offers people the opportunity to plan their future care and support, including medical treatment, while they have the capacity to do so.

It involves planning and discussion about future care between the person making the advance care plan, their family and their healthcare professionals.

We would love everyone to have a plan but it is a voluntary process

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What are the barriers preventing conversations?

Healthcare professionals find these conversations difficult as they do not know when the best time is to initiate the conversation. They fear that honesty about prognosis may cause patients distress or destroy hope or a patient may complain.

People are often waiting until healthcare professionals initiate discussions about advance care planning.

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What are the barriers preventing conversations?

Some people do not want to engage in discussions about their future care as this involves thinking about the future and possible deterioration in their condition.

Having a conversation about the future does not hasten death and is not bad luck.

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What questions do I use?

“How have you been doing recently, and has anything changed?”

“How can we best care for you if you became unwell?”

“What do we need to plan for? Who needs to know?”

“Is there anything you do not want to happen or wish to avoid”

“Are you a person who thinks about the future or takes things day by day?”

Recording Conversations

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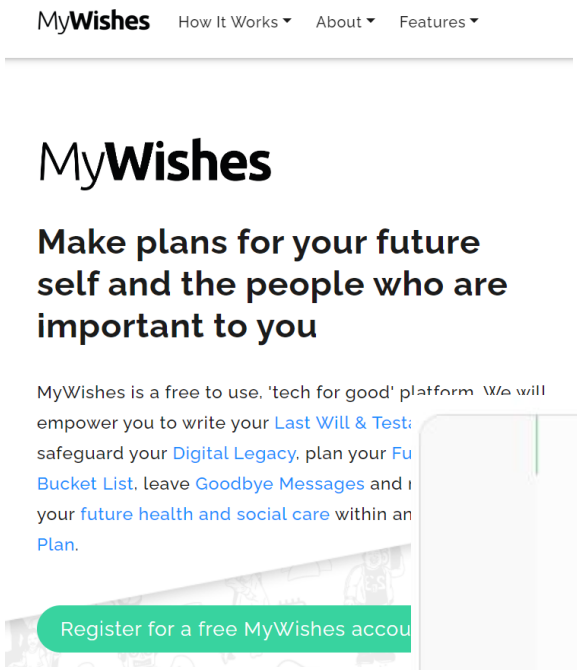

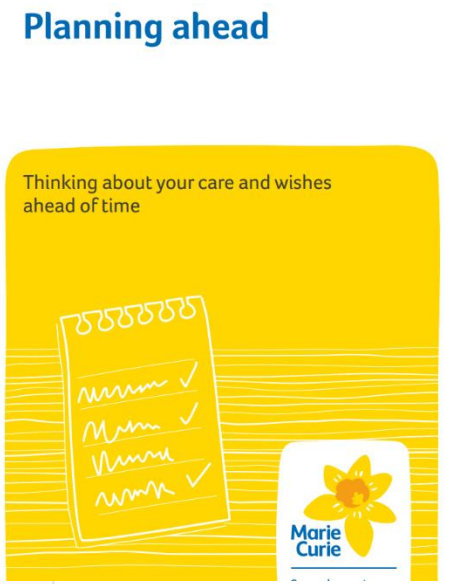

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Gold Standards Framework (GSF)

Gold Standards Framework (GSF) is a model that enables good practice to all people in the last 12 months of life. It is a way of ensuring levels of care are raised and promotes better coordination of care.

If we recognise that a person is in the last 12 months of life or has progressive disease, they are appropriate to be supported by a GP's Gold Standards Framework (GSF) Register or End of Life Care Register to optimise their ongoing care.

If we do not communicate this then GP's don't know.

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How to initiate this conversation…

“I would like to inform your GP regarding your advanced disease and that you are aware or decided not to know your prognosis”

“Provide coordinated and joined up care. You will be treated with dignity and respect, as an individual person, and your views and preferences sought and acted upon where possible”

“Do I have your consent?”

Scenario

Ann arrives in clinic in a wheelchair, poor appetite, cachexic, tired & fatigued. Distended abdomen. Felt unwell since last week

Treatment has been deferred for 2 weeks

Bloods show deterioration in liver function (Bilirubin 125) and renal function (AKI 2). She has a fever 38 degrees Celsius

Admitted to cancer centre for IV antibiotics, IV fluids, referred to UGI team

CT scan has shown disease progression

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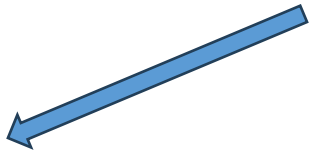
What do we do now?

SPIKES

Setting the scene

Prior knowledge

Invitation to proceed



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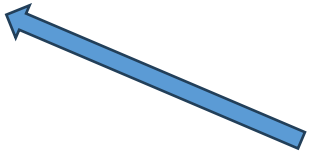
Knowledge delivery



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Empathy

Summary

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What we can do…

What we can’t do…

What we will do next

The AMBER Care Bundle

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Patients whose recovery is uncertain

The **AMBER** care bundle aims to improve the quality of care for inpatients whose potential for recovery is uncertain.
It supports the recognition of patients who are at risk of dying during ***this*** episode of care despite treatment.
It identifies patients that are for active treatment, but who have

- Uncertain recovery
- Limited reversibility
- That may be approaching the end of their lives

the AMBER care bundle

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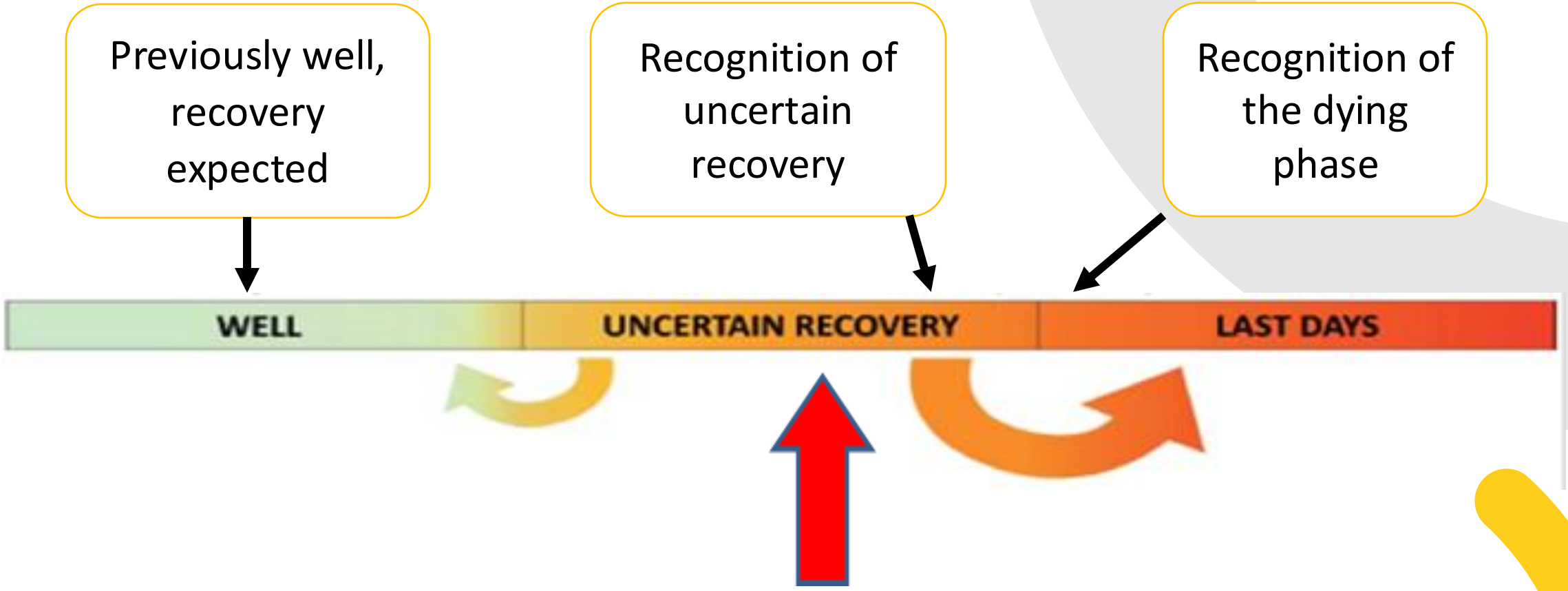

The AMBER Care bundle is the step in the middle

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Dying

Unfortunately, despite treatment, Ann's condition continues to deteriorate

Unable to get out of bed because of fatigue

Sleeping for long periods at a time

Unable to swallow medication including anti-emetics and opioids

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One Chance to Get it Right

One Chance to Get it Right- 5 Key Priorities

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Priorities for Care of the Dying Person

Duties and Responsibilities of Health and Care Staff

Published June 2014 by the
Leadership Alliance for the Care of Dying People

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

Local palliative care contact:

If unsure, or the dying person or those important to them raise concerns, a senior clinician must review the person and the goals and plan of care. The titles above are intended as memory prompts and attention should be paid to the whole description for each section. Expanded explanations are included overleaf.

Last Hours of Life

Ann dies peacefully with her family around her.

References

Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. Oncologist. 2000;5(4):302-11. doi: 10.1634/theoncologist.5-4-302. PMID: 10964998.

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https://www.pancreaticcancer.org.uk/what-we-do/media-centre/pancreatic-cancer-statistics/