1. The beginning of the "End"
   The end of the "End"
2. A continuum of conversations
3. A continuum of appropriate care

Sharing a different perspective

- Quality healthcare and patient relations
- Personal experience and reflection

Diagnosing the End

The beginning of the "End"

晚期、末期

Case…

the gold standards framework
4th Edition
October 2011

The GSF Prognostic Indicator Guidance

The National GSF Centre's guidance for clinicians to support earlier recognition of patients nearing the end of life

RCGP Royal College of General Practitioners

Why is it important to identify people nearing the 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-co-ordinated, high quality care.

This updated fourth edition of the GSF Prognostic Indicator Guidance, supported by the RCGP, aims to help GPs, clinicians and other professionals in earlier identification of those adult patients nearing the end of their life who may need additional support. Once identified, they can be placed on a register such as the GP's QOF / GSF palliative care, hospital flagging system or locality register. This in turn can trigger specific support, such clarifying their particular needs, offering advance care planning

2. Predicting needs rather than exact **prognostication**

Definition of End of Life Care
General Medical Council, UK 2010

1. Likely to die within the next 12 months

are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life-threatening acute conditions caused by sudden catastrophic events.

3 Triggers

Three triggers that suggest that patients are nearing the end of life are:

1. **The Surprise Question: 'Would you be surprised if this patient were to die in the next few months, weeks, days'?**
2. **General indicators of decline - deterioration, increasing need or choice for no further active care.**
3. **Specific clinical indicators related to certain conditions.**

ANALYSIS

Embracing inherent uncertainty in advanced illness

B Kimbell and colleagues argue that we should be helping people plan for possible future needs rather than trying to provide certainty

B Kimbell researcher, S A Murr… group representative, K Boyd c…

Primary Palliative Care Research Group, Usher… MAD, UK

Everyone dies, but uncertainty about how… happen is inevitable.[1] Uncertainty can be … to be constrained by medical science. We… that try to provide a reliable prognosis for … health conditions as far as six or 12 months … that meaningful choices require robust evi… However, such tools are not reliable when applied to individuals.[2] Uncertainty also drives fears about future debility, loss of control, and either inadequate or excessive healthcare.

We question the perception that uncertainty is a barrier to appropriate person centred care towards the end of life. Uncertainty may in fact be more friend than foe. An unpredictable but evident risk of deteriorating and dying should be a trigger for planning care with all people who have an advanced illness and in all care settings. It offers a prime opportunity to accept and manage the inherent uncertainties of living and dying well with progressive, advanced conditions.

Challenge for people with advanced conditions

Most people have a poor understanding of the underlying causes, severity, and future course of many long term conditions. Many struggle to make sense of events and experiences or to predict likely outcomes. They have difficulty finding the resources they need to cope with them. This in turn reduces their capacity for self management and puts patients and carers at risk of anxiety, depression, and poor outcomes. Professionals need to manage uncertainty, coordinate care, and help people to sustain their identity.[3]

When we consider the experiences of people with different advanced conditions, contrasting illness narratives and perceptions of uncertainty emerge among patients, carers, and professionals (table 1).[4–11] The diversity and variability of people's experiences of deteriorating health and dying belie attempts to specify what constitutes a "good" death. We can clarify some core principles but need to be ready to adapt our treatment and care plans in line with people's changing circumstances and evolving priorities.

Challenge for professionals and policy makers

For professionals, uncertainty has long been cited as a major barrier to identifying when treatment goals should be reviewed and the focus of care shifted towards prioritising quality of life and a comfortable death.[12–14] Treatment advances, public expectations, fear of litigation, and a plethora of evidence based guidelines combine with established beliefs about professional roles, responsibilities, and values to make "changing gear" and accepting the reality of death and dying challenging for professionals.[15] Primary care teams also face uncertainty because of perceived limitations in disease specific expertise, difficulties with judging prognosis if people do not have cancer, a lack of clarity about role boundaries across care settings, and conflicting information about the benefits of further treatments.[16–18]

Prognostic paralysis

A widely adopted strategy for addressing prognostic uncertainty in advancing illness involves making predictions about when a person is likely to die so that end-of-life care can be started. However, clinicians' estimates of prognosis are notoriously unreliable.[19] Despite this, more recent iterations of the well known "surprise question" (Would you be surprised if this patient died within the next year?) instruct clinicians to identify people who might die instead of using it, as originally intended, to support broader judgments about a risk of deteriorating and dying.[20] Strenuous efforts to develop more robust mortality risk scores and tools have not helped very much either.[1] Predicting how long an individual will live remains an inexact science in

Key messages

- Uncertainty characterises most advanced illnesses and is a challenge for patients, families, professionals, and health services
- Current focus is on determining when to trigger end-of-life care
- Instead we should plan for the future with people at risk of deteriorating health
- Acknowledging uncertainty is the basis of effective shared decision making about treatment and care options as a person's health declines

Diagnosing the End

The end of the "End"

臨终

Case…

BMA calls for proportionate treatment at end of life

Doctors should not pursue aggressive but non-beneficial attempts to prolong life, says a report from the BMA on end of life care and physician assisted dying.

symptoms simply because they seem to be approaching the end of life or have a terminal condition. It recommended individual assessments so that, while a

EDITOR'S CHOICE

Too much chemotherapy

Fiona Godlee *editor in chief*

第三代標靶藥 約一年或失效？

肺癌再變種打長期戰

When to let go,
to allow a serene 安祥的 passing away?

A challenge, a dilemma for healthcare professionals
(to do our best & more)

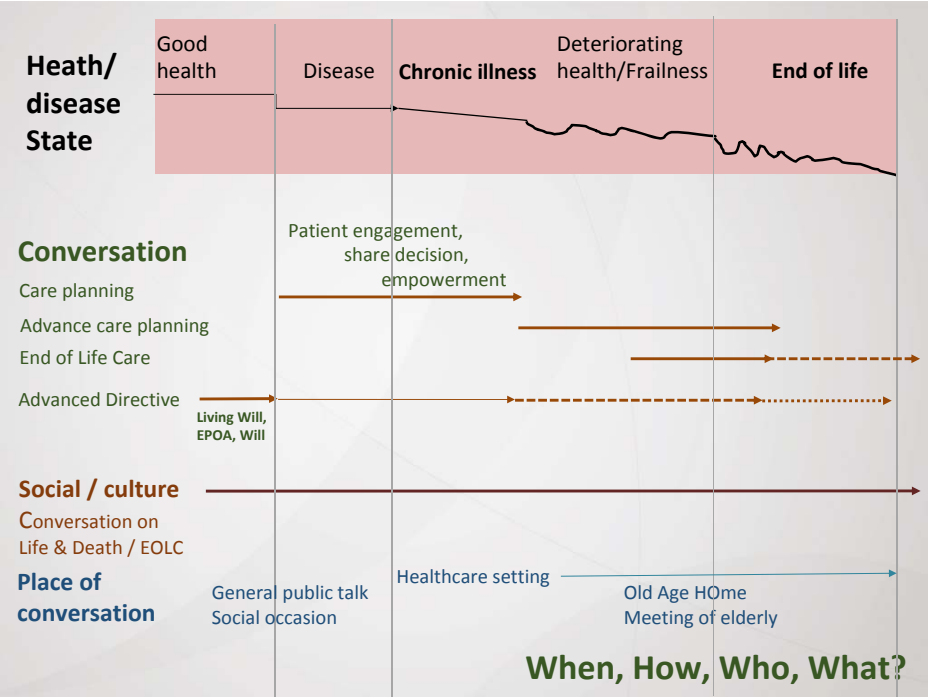
The beginning and the end
of THE END
is a <u>continuum</u> of conditions,
conversation & care.

End of Life Conversation

A difficult and challenging conversation for Healthcare professionals and patients and family.

盡在不言中

Not to talk about the issues is not a good way



5 End of life conversations

1. **Among healthcare team (doctor / nurse)**
2. **Inter-professional (HCP / Social)**
3. **HCP with patient/family**
4. **Among family members**
5. **Society (culture)**

End of life conversation (1) amongst healthcare team

Reaching a consensus amongst the healthcare team (doctors) at different stage of EOL care for the patient

We are good "Doctor" healing life.

We also need to be a good "Doctor" managing EOL.

我們是好的"醫生"的醫生

亦要做好的"醫死(亡)" 的醫生

Adopted from 死在香港-陳曉蕾著

End of life conversation (2)
Inter-professional

With other professionals / people:
social workers, religious people

Team work
Non-medical issues and support

End of life conversation (3)
HCP with patient / family

- **Lack of time!?**
  Lack of experience, uncomfortable
- **Must have trust of the patient / family**
  Should know patient well
- **Patient-centred approach**
  What matters to the patient?
- **To agree on management plan with patient / family: ACP, DNACPR, (AD)**

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J Gen Intern Med. 2000 Mar; 15(3): 195–200.
doi: 10.1046/j.1525-1497.2000.07228.x
PMCID: PMC1495357

A Physician's Guide to Talking About End-of-Life Care

Richard B Balaban, MD[1]

A large majority of patients and close family members are interested in discussing end-of-life issues with their physician. **Most expect their physician to initiate such dialogue.** EOLC discussion must go beyond the narrow focus of resuscitation.

Address the broad array of concerns shared by most dying patients and families: fears about dying, understanding prognosis, achieving important end-of-life goals, and attending to physical needs.

J Gen Intern Med. 2000 Mar; 15(3): 195–200.
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1495357/

A Physician's Guide to Talking About End-of-Life Care

Step 1. Initiating discussion
• Establish a supportive relationship with patient and family.
• Appoint a surrogate decision maker.
• Elicit general thoughts about end-of-life preferences. Go beyond stock phrases with probing questions.
Step 2. Clarifying prognosis
• Be direct, yet caring.
• Be truthful, but sustain spirit.
• Use simple everyday language.
Step 3. Identifying end-of-life goals
• Facilitate open discussion about desired medical care and remaining life goals.
• Recognize that as death nears, most patients share similar goals; maximizing time with family and friends, avoiding hospitalization and unnecessary procedures, maintaining functionality, and minimizing pain.
Step 4. Developing a treatment plan
• Provide guidance in understanding medical options.
• Make recommendations regarding appropriate treatment.
• Clarify resuscitation orders.
• Initiate timely palliative care, when appropriate.

Hong Kong Chinese version of Serious Illness Conversation Guide

Harvard Medical School Centre for Palliative Care
Ariadnelabs, Brigham and Women's Hospital, Harvard TH Chan School of Public Health
Dana-Farber Cancer Institute

現在希望和你談一談病情及未來進展，可以嗎？

1. 請問你此刻了解你病情狀況有幾多呢？
2. 關於你將來病情，你希望我告訴你幾多呢？
3. 病情: "我擔心時日無多" " 有幾多得幾多？"
4. 若你健康轉差，那幾項人生目標對你是最重要？
5. 關於你將來健康，你最担心及恐懼的是甚麼？
6. 當你考慮到將來的病況，有甚麼最能給到你力量？
7. 有那方面的能力你覺得是最重要，如果沒有了你不可以想像繼續活下去？
8. 若你病得更重，你願意接受幾多來換取更長壽命？
9. 你家人知道你所着重的及所願望的有幾多？
10. 似乎這_____ 對你來說十分重要？
11. 顧及到你的目標及首要考慮，及了解到你此刻的病況，我**建議** _____
12. 我們會一齊去面對.

Source: Dr. Raymond Lo

Talking Map: "REMAP"

- **Reframe** why status quo isn't working
- **Expert emotion**, respond with empathy
- **Map** out what's important
- **Align** with patient's values
- **Plan** to match values


Addressing Goals of Care: "REMAP"

Source: **VITAL**talk

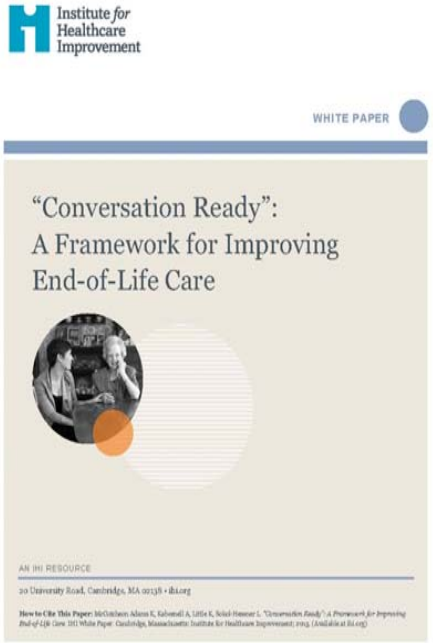
5 Questions to ask at Life's End Atul Gawande's

1. **What is your understanding of where you are and of your illness?**
2. **Your fears or worries for the future**
3. **Your goals and priorities**
4. **What outcomes are unacceptable to you? What are you willing to sacrifice and not?**
5. **What would a good day look like?**

End of life conversation (4) Amongst family members

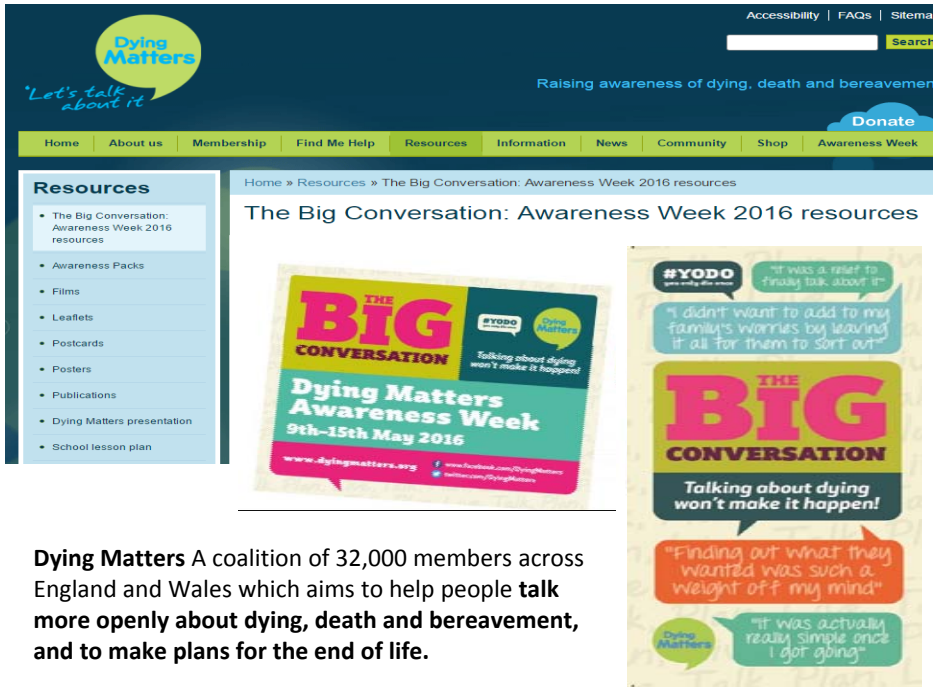
A "common" EOL conversation
Individual with his/her family

If the conversation is already started among the family, will help HCP to seek an understand with you on EOL Care.



A public campaign to encourage people to "**have the conversation**" about their wishes for end-of-life care with loved ones, with the aim that everyone's wishes are expressed and respected.

We believe that the place for this to begin is at the kitchen table—not in the intensive care unit, with the people we love, before it's too late.



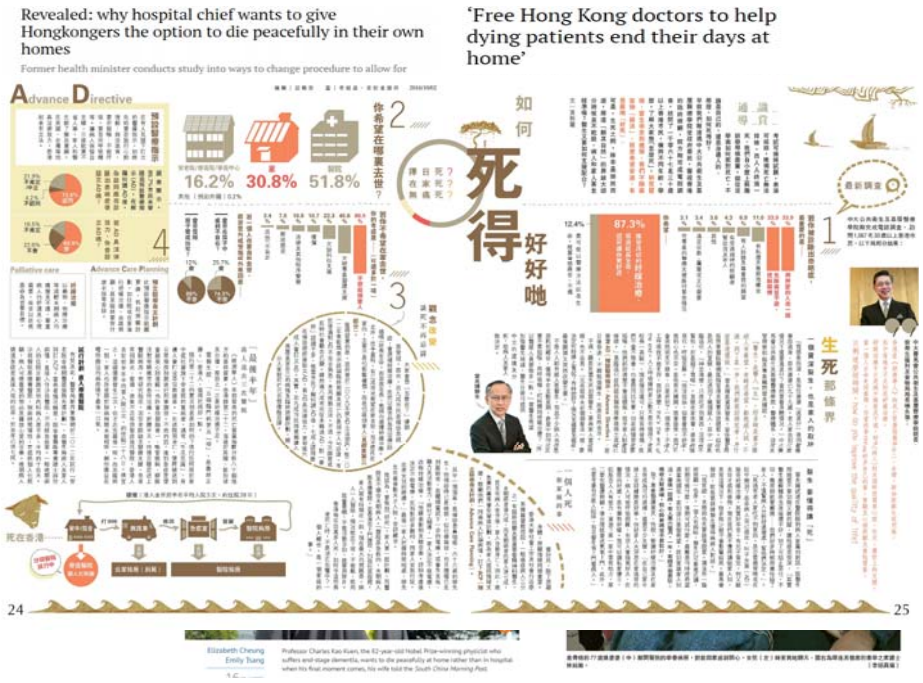
Dying Matters A coalition of 32,000 members across England and Wales which aims to help people **talk more openly about dying, death and bereavement, and to make plans for the end of life.**

End of life conversation (5)
Society / Culture

- **Social and cultural (readiness)**
- **Engage / educate the public**
- **"Death" should not be a taboo**
- **Explore interpretation "孝" for EOL**

End of Life Management

- There is a time towards the later phase of our care for a patient, to reassess his/her situation for a different mode of care (end of life/palliative care).
- There are many barriers and difficulties (perceived and real) to "end of life" care and conversation: what, when, who, how.
- The "Science" and "Art" of End of life care, touching on ethical and humane issues.



人生最後的路程 - 死亡
是合時的、不早不遲的、
是安祥的、是五福「善終」。

The final journey of life - DEATH,
is timely, not early, nor too late,
is serene, is a 5th blessing.
A good life to the very end.

A Reflection…
Lui Siu Fai 18.5.2016