Showing the “Early palliative care” video to a group of health professionals

This short video aims to help health professionals identify people who are living with progressive illnesses better, to assess their needs in a timely manner, and to start discussing and planning future care with them.

The video talks about how people’s health changes as they get older, frailer or ill. The information is based on detailed research with patients, families, doctors, nurses and other health and care professionals about people’s experiences of living with declining health and dying. It is produced by a team of health professionals who care for people with many different life-limiting illnesses.

Possible questions to discuss in groups

You can discuss these questions in a small group (such as a primary care team, or a hospital team). In larger groups such as teaching medical students, nurses and/ or postgraduate teaching, the audience may be divided into smaller groups.

Activity	Group interaction
Welcome	Introduction by the facilitator
Full-length screening of the video	
Introducing group activities	Now we have an opportunity to consider these trajectories, and how this understanding can help us identify when palliative care might begin, to assess different dimensions of need, and how and when to plan. Feel free to ask questions and to share your experience Suggested questions: *(these may be altered according to the setting and purpose of showing the video)*
Question 1	How can we improve the ways we identify, assess, and plan for people on the rapid trajectory (typically **cancer**)?
Question 2	How might we do the same (identification, assessment, planning) for people on the intermittent trajectory (typically **organ failure**)?
Question 3	How might we do the same (identification, assessment, planning) for people on the gradually declining trajectory (typically **physical frailty** and **dementia**)?
Question 4	What may hinder or facilitate the introduction of anticipatory care planning or early palliative care with individual patients and their carers?
Question 5	How can we help our patients to access palliative care when they associate it with dying imminently, usually from cancer?
Closing the session	Thanks Take-home messages (x3)

PS: whatever time is available, from 10 to 60 minutes, these may be useful learning activities (just focus on the questions most relevant to your learning objectives)

Text of the voiceover

This short video explains the rationale, the reason for early palliative care. It describes the three different typical patterns or trajectories of physical decline that most people have at the end of life, each with other typical dimensions of need.

Palliative care improves life's quality and in some cases may even prolong life. It offers an alternative to treatments of low benefit and promotes "realistic medicine". Patients, families and clinicians can all benefit from considering early palliative care fully integrated with ongoing care to meet the likely needs of people with advanced illnesses.

So what does early palliative care look like for people with different conditions?
There are three main patterns of physical decline as people's health deteriorates in the last phase of life

- a relatively rapid decline, typically of progressive cancer
- an intermittent decline, typically organ failure and multi-morbidity
- a gradual decline, typically of frailty or dementia

But research studies have confirmed that dying like living is a 4-dimensional experience: physical; psychological; social and spiritual. So let's consider these 4 dimensions for people with each of these three patterns of physical decline.

Let's consider the **rapid trajectory** first. Physical decline may occur quite quickly after a relatively stable period. The social dimension tends track the person's physical decline However psychological distress and anxiety tend to be worse at four times in the cancer journey - around diagnosis, after treatment ends, at recurrence and around death, similar times to when existential issues may be expected.
So people on this trajectory can benefit from aspects of early palliative care even when they may still be physically well; other dimensions such as anxiety can cause major distress early on– so addressing anxiety and other symptoms and family stress from first presentation is really helpful.

So in the **intermittent trajectory** of organ failure and multi-morbidity – what's happening here? Well the physical trajectory has these episodic dips, usually followed by partial recovery- but death can occur during one of these episodes of deterioration or in between them. Social contacts reduce and psychological distress often occurs at these same points. Spiritual problems are harder to predict, - these may be moderated by good relationships and support.

So for people with progressive heart, lung, liver or kidney failure – early interventions that address and reduce psychological or family problems may be more effective than just focussing on the physical health and treatment plan. And similarly, when managing the acute episodes, we should consider all the dimensions of need.

The **gradually declining health trajectory**, let's look at that one now, typically found in people with frailty. A gradual decline in physical health may happen over many months or years. For people with dementia this is accompanied by increasingly impaired cognitive function. Looking at the social dimension and the psychological decline and even existential distress, these often dip considerably before the end of life: depression or family or social isolation or loss of meaning may predate a final physical illness.

The message here is to support people in these other dimensions, not just the physical one and promote resilience by enabling people to do as much as they can, by discussing and addressing common anxieties and fears such as loss of independence, dementia or being a burden which are more distressing than dying.

So the **plan to help everyone** live as well as possible until the end of life by offering early palliative care is

- **identify people early** (if appropriate from diagnosis) and introduce early, integrated palliative care
- consider people's **different dimensions of need** at present, and discuss what matters most to them
- **discuss** what often happens in the different illness journeys with patients and their carers so they know when they might need more help and help them cope in their own ways
- While acknowledging the uncertainty, make an individual anticipatory care plan with patients and families, and document and communicate and review this regularity with everyone who needs to know.

Identify early, assess all dimensions, and plan for all predictable eventualities.

☞ Remember: identify, assess, talk and plan, and communicate with all involved.

For further resources see below (or alter these to your local environment)

Scottish National Anticipatory Care Planning Programme (*Health Improvement Scotland*)

Anticipatory Care Planning is **about helping individuals think ahead and understand their health**.

Using the Supportive and Palliative Care Indicators Tool (SPICT)
http://www.spict.org.uk/using-spict/

Effective Communication for Healthcare resources: Talking about deteriorating health and anticipatory care planning

Early Palliative Care – BMJ Analysis by Murray & Boyd (2017) discussing the benefits of early identification, holistic assessment and anticipatory care planning for people living and dying with different conditions and illness trajectories. Power point slides may be freely downloaded

Realistic Medicine in Scotland – Realistic Medicine 2015; Realising Realistic Medicine 2016

Patient information – leaflets and online resources: Patient.co.uk and NHS Inform

Let's talk about illness, death and dying (Age UK)
Think ahead – Planning for death and dying (The Irish Hospice Foundation)

Videos for patients, families, and public awareness projects.

Talking about death and dementia – *Alzheimer Scotland resources and video collection*

Primary Palliative Care Research Group, Usher Institute of Population Health Sciences and Informatics (University of Edinburgh)

EAPC Primary Care Reference Group (European Association for Palliative Care)

THE UNIVERSITY of EDINBURGH

EAPC ONLUS Primary Care Reference Group