



Hoping for the best, planning for the worst

A talk by Annette Duck; Respiratory Specialist Nurse

In today's hectic, busy technological, materialistic age many people do not stop to think about life and the future.

They are 'on the go' all the time as they notch up experiences and try to enjoy everything that is available in life.

In fact we live life as if we will live forever. True?

If we are diagnosed with a serious illness, it throws us into confusion; we did not expect this. It is a shock and naturally many of us experience a high degree of stress. It makes us think about the present and how that has changed; we start to reflect on the past and how good things used to be. It makes us realise how we took so much for granted.

Sadly we will start thinking about the future which may be uncertain. We make comparisons of our 'old' self with the 'new' self and then start to wonder what the future will bring.

For most people an illness diagnosis will cause extreme emotional stress, but over time with the support of family, friends and colleagues, most people will adjust to illness and their changed health. For some people it may be the first time that they have faced the fact of their own mortality. This is something modern society is not used to doing.

Throughout history death has always been cloaked in spirituality, but in today's' secular society death is rarely talked about making it something morbid and scary. Death is not today seen as part of life, meaning that it is not something most of us feel comfortable talking about.

In 18th Century Victorian England, people died at home surrounded and cared for by their families and loved ones. Queen Victoria publically mourned the loss of her husband Albert for many years.

The Victorians celebrated death with the building of vast cemetery's' throughout the country. They raised huge and impressive statues of those they honoured and loved to immortalise them. People were 'open' and talked about death. Death was a part of life.

In the early 20th century the First World War witnessed the tragic unnecessary loss of millions of young men in the trenches.

This was closely followed by the Second World War, and the atrocities of the holocaust; all of which made death a sad and painful experience, as most people were affected in one way or another. Suddenly death was not a part of life; it became associated with emotional pain, sadness, loss and often despair.

With the development of the new NHS in post war Britain, free healthcare became available to all with the building of new hospitals and the development of new drugs, antibiotics and surgical techniques.

A new sense of optimism thrived throughout the 1950's and 60's as peace was maintained. With all these new developments, people started going into hospital, but they also started dying in hospital as sometimes treatment and surgery failed.

Suddenly death became viewed by the public and some healthcare practitioners not as a part of life, but as a failure; a failure of treatment; a failure to survive.

What do we know today?

Around 500,000 people die in England each year. This will rise to around 530,000 by 2030. We know that the hospice movement developed by Cecily Saunders have set a gold standard for care, but only deal with a minority of all patients at the end of their lives.

We know that there is a major mismatch between people's preferences for where they should die and their actual place of death. Most people when asked would probably like to die at home, but only around 18% do so with a further 17% in care homes. Acute hospital trusts account for 58% of all deaths in England with only 4% of deaths taking place in hospices.

What else do we know?

As a society we do not talk about death and dying - this contributes to its low profile in health and social care. Only around one third of the general public have discussed death and dying with anyone.

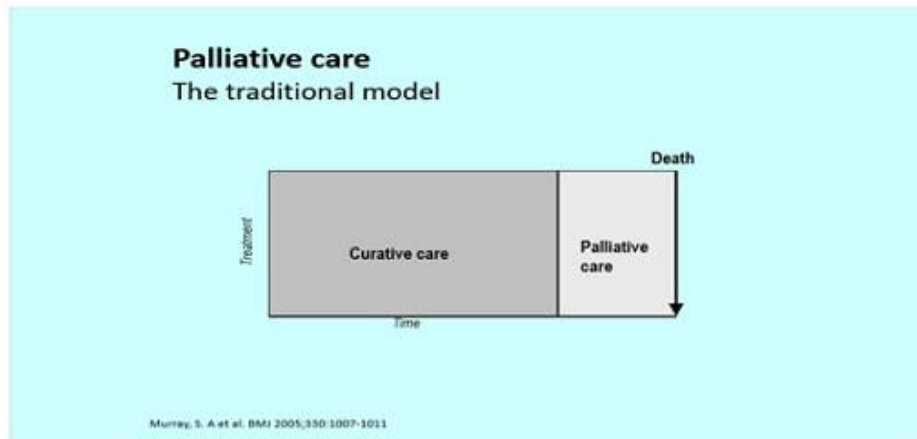
Most people do not discuss their own preferences for care with their partner or family, which hampers individual planning. We know that from their experience in cancer care that palliative care teams are best placed to lead on improving management of advancing disease.

We think therefore that clinical specialists, who are familiar with the clinical disease and palliative care teams working together will provide best care for patients with advancing disease.

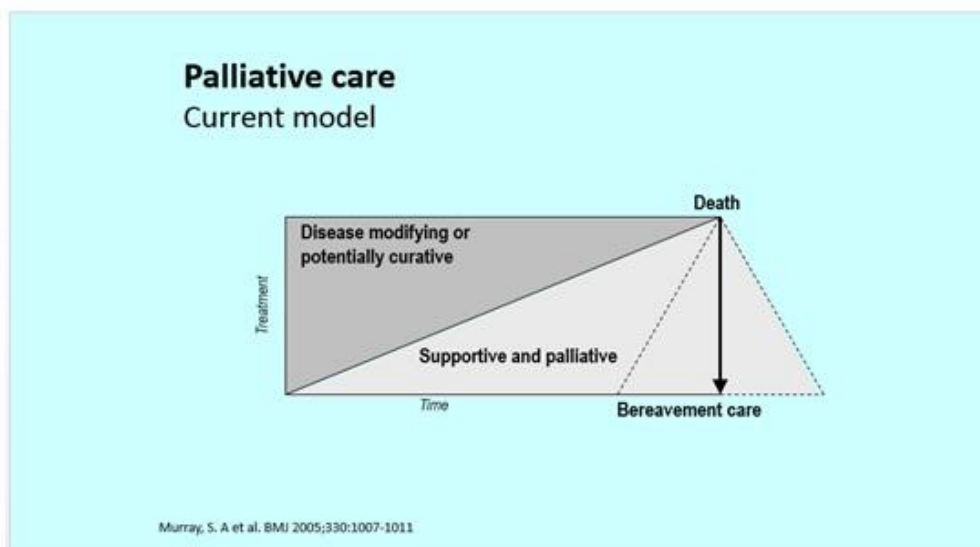
The WHO definition of Palliative Care (WHO 2013) says:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

Traditional model of palliative care



Current model of palliative care



Palliative care is being employed much earlier in the management of chronic disease, particularly for help in managing symptoms. Palliative care can also be used alongside disease modifying treatments. Palliative care does not mean 'end of life' care only.

Talking about an uncertain future can be difficult for both patient and healthcare professional. We know from the research evidence that patients expect healthcare practitioners to tell them what they think they should know.

We also know that healthcare practitioners are fearful of bringing up discussions about the future and dying for fear of upsetting their patients. We also know that patients who are fearful for the future can become anxious and depressed (Parker et al 2007).

Both healthcare practitioner and patient tend to focus on the physical things of illness and treatment and avoid discussions about the future and 'hope for the best'.

It is important for anyone with a serious, life-limiting illness to know that there is support and help available whatever happens. There is a framework of policies that have been developed by the department of health to support people as they approach the end of their lives.

Advance Care Planning

This is the process whereby a discussion takes place between an individual and their care provider about what they would want if they were to deteriorate. This discussion can include their family or a friend if they want it.

The discussion is recorded by writing it down; it should be reviewed regularly and communicated to all key care providers. It is not legally binding but may give the opportunity to discuss other legally binding issues such as advance decision to refuse treatment or power of attorney for financial and health and social care.

Preferred Priorities for Care

This is an opportunity for a person to write down and keep with them what they would like, in the event that their illness deteriorates, what they would like to happen to them. It is something they can keep, review and amend as necessary.

They can talk to their family and healthcare team about it and let people know that they have a Preferred Priorities of Care.

It is not legally binding, but will be taken into account when planning care and will aid both the healthcare team and family to make decisions about future care.

Gold Standards Framework

The Gold Standards Framework is also known as the GSF or palliative care register. This allows general practitioners to identify those patients who might need more care as they are approaching advancing illness.

Those patients once placed on this register will be nominated a key professional to coordinate all their health and social care.

It will mean that their needs will be regularly discussed by the GP practice in an attempt to maximise the community support available, to ensure that they receive best care.

The care may involve a nurse, an occupational therapist, a social worker, and the palliative care team.

Wills

Most people will have thought about making a will to ensure that their possessions and money are taken care of as they wish, once they die.

However, very few people will consider making an advance care plan to ensure how they are taken care of if their health deteriorates and they cannot make decisions for themselves.

These decisions inevitably become the responsibility of their family and those closest to them for those people to guess what they might have wanted should they be capable of making that decision for themselves.

Most people leave this important decision up to chance. Families and friends have to guess what to do, when they are emotionally upset and distraught themselves.

Talking about death and dying does not bring death any closer. Hoping for the best is fine, but planning for the worst, is something we should all consider.

It means those closest to us will not have to guess what we might want. Making an advance care plan, like a will, is something that is important to us all. Once done, it can be 'parked' and we can forget about it.

We can remain hopeful, but confident in the fact that we have set in place plans for the future whatever that might be.