

# End of life care planning- why it is everyone's concern.

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## What is end of life care planning?

There is little doubt that end of life care is important to everyone. People generally recognise that both they themselves, and those around them, may have specific fears, wishes, or requests when it comes to the end of life care. Starting any discussion surrounding end of life care can induce anxiety amongst health and social care professionals but also generate anxiety in those close to the person who is reaching the end of their life and to the individual facing that prognosis. Without those discussions however, there is a definite risk that the individuals wishes may not be determined or, worse still, professionals and loved ones run out of time before they can put plans into place.

Everyone has a right to the highest quality care no matter what diagnosis, geographical area, age, socioeconomic status and, in addition, marginalized groups should have equal access e.g. travelers, prison population (National Council for Palliative Care 2014). Having those key, important discussions in a timely manner is vital in being able to determine a persons wishes regarding the

end of life.

### **When to initiate end of life care planning**

A shared anxiety may be ensued concerning when to initiate palliative and end of life care. Tools have been initiated e.g. The Gold Standards Framework Prognostic Indicator Guidance (2006), in order to aid professionals with the difficult decision about when is the right time to discuss end of life planning? Thinking about the surprise question asked in this guidance can be helpful in informing that decision surrounding end of life planning discussions. The surprise question is:

- Would you be surprised if this person died within the next 6-12 months?

This should not be the only consideration, experience surrounding discreet and obvious deterioration can all help to identify when a person is nearing the end of life. Ascertaining that they are nearing the end of life can help to ensure they receive the support, care and interventions which may aid a 'good death' rather than patients experiencing urgent care that has not been anticipated and the patient has had very little time to think about what they would want or worse still no time to discuss their wishes.

## Communication and its importance in end of life care

The National Council for Palliative Care pledges to raise awareness surrounding death, dying and bereavement using, amongst numerous publications, the 'dying matters' website and have a dying matters awareness week. Their current work surrounds the question 'what can you do?' and its aim is to get more people active in planning for death and dying.

There are, however, numerous barriers to achieving high quality, end of life care in addition to lack of planning. These include lack of recognition that a person was approaching end of life, failure to communicate effectively to carers/family, people kept in hospital unnecessarily, lack of education and knowledge and lack of understanding surrounding commissioning resources for end of life care. This means that there are significant challenges in delivering end of life care in a proactive, effective manner, in a patient's place of choice.

Discussing end of life care requires constant reiteration; checking and information provision as people can change their mind particularly when they are faced with new fears, concerns and/or symptoms on a daily basis. To ensure that there is a mutual understanding and awareness regarding the current issues

in the patient's journey, the plan of care, and any new symptoms or concerns that may present, regular discussion utilising a holistic approach is vital in ensuring a responsive approach to their care needs. Communication in palliative care sets the tone for all the care which may be required because without effective communication, patients and relatives may be left feeling isolated, unaware of the current situation presented and begin to lack trust in those providing care.

### **And finally!**

Patients have the right to self-determination in other words, their autonomy should be maximised. When approaching the end of life, a patient's right to make decisions rather than decisions being made for them is even more crucial to facilitate a patient-centred experience. Care delivered which is in conflict with the patients' wishes falls far short of what they deserve therefore clear communication is paramount. A compassionate and non-judgmental approach is crucial in allowing the those who are nearing the end of their life, to be open and honest. A poor or less than adequate assessment and discussion may leave those being cared for feeling anxious, upset or frustrated, feeling, they are misunderstood or not listened to. Making every moment count with an individual at the end of life is crucial as this may be the last contact a health or social care professional has with the dying person making it the last thing that

anyone does for them. Ensuring care remains patient-centred and maximizing any opportunity to hear the patient's wishes and preferences is fundamental as a patient approaches the end of their life.