

## **End of Life Care**

### **Adults' Health, Adults Care and Housing**

#### **Overview & Scrutiny Committee**

**Date: 27 September 2017**

#### **Introduction**

We all die. This means that care as we approach the end of our life and during those last few days and hours has to matter to everyone- in health and social care and the wider community.

End of Life Care can be difficult to define. The General Medical Council Guidance on End of Life Care defines patients who 'are approaching the end of life' as those who are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they 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

It is recognised that predicting if someone will die within 12 months is not always easy or even possible. To aid this, health care staff, nurses and doctors use the guidance as set out in the Gold Standards Framework Prognostic Indicator. This guidance states that it is more important to predict needs rather than provide an exact predication of how long someone may have left to live.

*"It is more about meeting needs than giving defined timescales. The focus is on anticipating patients' likely needs so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences".*

Ultimately we need to ensure that the care for those with advanced incurable illness means that they and their families live as well as possible until they die. The term Palliative Care is often used and is defined by the World Health Organisation (2002) as "an approach that improves the quality of life of patients and their families facing the problems 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 "

"You matter to the last moment of your life and we will do all that we can, not only to help you die peacefully, but to live until you die "Dame Cicely Saunders)

## Policy Context

As people live longer, we know more people will have long-term, advanced conditions requiring more complex support towards the final stages of life. There has been good progress for many cancer patients, however the majority of people who die have non-cancer conditions such as heart failure, chronic obstructive pulmonary disease (COPD), dementia, frailty and multiple co-morbidities. Many patients are still not receiving the best level of support and care as they near the end of life. This is in part because it is harder to identify them early enough, their course of decline is erratic, unpredictable or protracted, and they may require complex health and social care provision in a number of settings, crossing the boundaries of care.

Strategic reports by the Department of Health, End of Life Care Strategy (2008) and NHS England, Actions for End of Life Care, (2014-2016) set out how to improve access to services, particularly community based palliative care services, by introducing the 'End of Life House of Care Framework' and achieve one of the main outcomes enabling people to die in the place of their choosing.

Ambitions for Palliative and End of Life Care: A national Framework for Local Action 2015-2020 was published by the National Palliative and End of Life Care Partnership in September 2015. This is not a new strategy, but it has been developed to build on the 2008 Strategy for End of life Care in the context of the current NHS. The framework sets out a range of actions for service development and planning.

The Department of Health launched the national Strategy for End of Life Care in 2008, following extensive consultation with families, NHS teams, social care, hospices, voluntary groups and other stakeholders. This generated momentum and energy, which led to significant improvements in end of life care.

As a result of the national strategy the first ever national snapshot of end of life care in primary care was undertaken in 2009. In the national snapshot, practices 'predicted' or expected 27% of all deaths and these people were included on the palliative care register. A further 15% were thought by practices to have been predictable but were not put on the register. However, the National Audit Office found that only about 8% of all deaths are completely sudden. Therefore, out of the 92% of deaths that were predictable, 65% were absent from the register and 50% were not even thought of by practices to be predictable (Figure 1).

### *Figure 1. Patient Deaths*

It was also found that there continues to be inequity in the provision of end of life care for people with non-malignant diagnoses. Among participating practices, 71% of people on the register had cancer yet just 28% of people dying had a primary diagnosis of cancer.

The Leadership Alliance for the care of the dying patient published "One Chance to Get it Right". Improving peoples experience of care in the last few days and hours of life", in June 2014. It sets out the approach for the care of dying people that health

and care organisations and staff caring for dying people in England should adopt in the future. It should apply irrespective of the place in which someone is dying e.g. hospital hospice own or other home and during transfers between different settings.

The Neuberger report (2013) has been a major influence on end of life strategies. The report highlights many deficiencies in end of life care on reviewing the Liverpool Care Pathway. It advocates a national conversation about dying, as it describes alarming stories of poor care that ignored patient and family concerns. The findings of the report highlighted poor levels of care and communication and recommended areas that need to change.

Research into the cost of end of life care by the Nuffield Trust (2010), Blaney et al (2011), Seow et al (2014), Royal College of Physicians (2013), Marie Curie (2014) and Bristol University (2014) all provide compelling evidence that improved access to community based palliative care support can provide better value for money. In particular, the evidence demonstrates how supporting people with the care they need in their preferred location can reduce avoidable emergency hospital admissions during the last year of life. Other publications from the National Institute for Health and Care Excellence, Quality Standards for End of Life Care (2011 and 2015) and the Leadership Alliance for the Care of Dying People, One Chance to Get it Right (2014) focus on raising standards for end of life care.

During the transition of reviewing the national strategy NHS England have published a report *Actions for End of Life Care: 2014-2016* which sets out NHS England's commitments and intentions for improving end of life care for children and adults.

The report has been informed by comments and feedback from people who have experience of end of life care, as individual patients, carers, families and staff. In principle, it marks a shift in focus from 'place of death' to the broader 'experience' of end of life care. Wherever people are, the aim is to enable them to live and die well.

The report also referenced the focus on end of life care by the Care Quality Commission and recommended that they monitor both acute and community health care providers move to the new approach in their inspection and as part of their thematic review. A review of this is due this autumn.

We know end of life care accounts for a high proportion of NHS spending. It is estimated to be at least a fifth of NHS costs, and a total of £20 billion. Over the longer term, investment will need to shift away from the acute sector to the community, in order to reduce the number of people dying in hospital and to increase the number of people dying in their preferred place.

As we face the long-term challenge of an ageing population at a time of shrinking financial resources, it is vital that we get end of life care right. Failure to do so will result in spiralling costs for the public sector, and more importantly, a human cost for all of us who want to reach the end of our lives with dignity and control.

## **Patient Choice: Preferred Place of Care**

The national bereavement survey (2012), undertaken by VOICES, showed that of those who expressed a preference, the majority preferred to die at home (81%), but only half of these actually died at home (49%). The most common reported place of death was a hospital (52%). In order to achieve such a shift, the workforce looking after people in the setting of people's homes need to be accessible, capable, competent *and* supported to meet the care needs and preferences of people in a planned way.

In the 2012 British Social Attitudes survey, 60% of those who stated that they would prefer to die at home would change their mind if sufficient support from family, friends or social and medical professionals were not available. The need to be pain free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care.

Issues surrounding choice of place of death:

- Between 50-90% of patients with cancer wish to die at home but only 22% achieve this.
- Approximately a quarter of people express a preference to die in a hospice, but only 17% of those with cancer and 4% overall die there.
- Dying at home is associated with low functional status, an expressed preference (and carer agreement); home care and its intensity, living with relatives and dependable extended family support

Although individuals may have different ideas about what would, for them, constitute a 'good death', for many this would involve:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings; and
- Being in the company of close family and/or friends

Some people die as they would have wished, but many others do not. Some people experience excellent care in hospitals, hospices, and care homes and in their own homes but the reality is that many do not. Many people experience unnecessary pain and other symptoms, as well as unnecessary hospital attendances and investigations. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to.

In the past, end of life care within the NHS and social care has had a high profile with a negative response. Reflecting this, the quality of care has been very variable. The ambition of Swindon CCG is to commission a high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic deprivation.