

Time to talk: Getting it right at the end of life



*The Annual Report of the Director of Public Health for Staffordshire 2017
Executive Summary*

“ You don’t have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver’s chance of benefit. They are spent in institutions - nursing homes and intensive care units - where regimented, anonymous routines cut us off from all the things that matter to us in life. Our reluctance to honestly examine the experience of ageing and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by imperatives of medicine, technology, and strangers.”

“I wrote this book in the hope of understanding what has happened. Mortality can be a treacherous subject. Some will be alarmed by the prospect of a doctor’s writing about the inevitability of decline and death. For many, such talk, however carefully framed, raises the spectre of a society readying itself to sacrifice its sick and aged. But what if the sick and aged are already being sacrificed - victims of our refusal to accept the inexorability of our life cycle? And what if there are better approaches, right in front of our eyes, waiting to be recognized?”

Source: Atul Gawande - *The Brief*, Brief Books, 2016, digital downloads

Introduction

My annual report this year focuses on our experience at the end of life. It includes a number of recommendations that aim to improve people's quality of life and quality of care in our final years.

Life expectancy has increased substantially over the last 150 years but people now spend more time in chronic ill health before they die. Most people now die from cancer, cardiovascular, respiratory or age-related illnesses, such as dementia, often after a prolonged period of being admitted to hospital regularly during their last year. Staffordshire has a growing older population so planning for the end of life will be increasingly important for individuals, their families, carers and the health and care services that support them.

The report highlights the current and all too frequent consequences of an unplanned end of life, where people's wishes have not been stated or shared with care services. This results in multiple admissions to hospital, medical over intervention to prolong life temporarily, unnecessary suffering, and people dying in circumstances they would not have chosen.

Instead, the report recommends an approach based on anticipating and planning for the end of life, ideally before the early onset of serious illness. This enables people to make choices in advance about practical and spiritual matters as well as the care they want to receive at the end of their lives.

Discussing and planning for death

Most people don't like talking about death and this makes it hard to plan the end of life that we really want. Many people are not aware of the rights and choices they have or the tools available to help them – for example Power of Attorney and stating preferences for future medical treatment via an advance decision. Three-quarters of the public agree that if people felt more comfortable discussing the end of life it would be easier to have our wishes met.

We need to talk with our families, as well as with health and care professionals, about our preferences at the end of life, and then set out how we want to spend our final years. Communities can help by offering an environment where people feel comfortable talking about death, dying and bereavement, and able to offer support to the dying and bereaved, in the context of their cultural and religious beliefs. We are all individuals and have different wishes: if we take control of our end of life we are much more likely to get the experience we want.

The report aims to provide a prompt and an evidence base for an "honest conversation" with the public about end of life, led by Staffordshire County Council's Health and Wellbeing Board.

Changing the practice of health and care professionals

Health and care professionals find conversations about death, dying and bereavement just as difficult as the general public. This inhibits them from helping people plan for their end of life. They are also not very good at recognising when people are reaching the end of life, and tend to practice to a medical model, which prioritises extending duration of life over quality of life.

As well as a conversation with the public, the report promotes the need for a debate with professionals about the limitations of medical science and what people really want at the end of life, in order to avoid inappropriate treatments in their final years.

Care at the end of life

The Government's end of life commitments aim to enable:

- Honest discussions between care professionals and dying people
- Dying people to make informed choices about their care
- Personalised care plans for all
- The discussion of personalised care plans with care professionals
- The involvement of family and carers in dying people's care
- A key contact so dying people and their carers know who to contact at any time of day

Meeting this will require health and care organisations across Staffordshire to make end of life care a genuine priority and to develop a model of proactive and co-ordinated care in line with people’s choices. This will require training for health and care professionals to help people plan for the end of life, availability of services in the community to respond in a timely way as people approach their final days, sharing of records, and development of service algorithms that ensure that people’s wishes are followed.

The report references the quality frameworks available to inform good end of life care, as well as the funding that could be released to support it. Health and care are facing huge challenges at the moment and better end of life care is a real opportunity to improve people’s lives as well as ensure the sustainability of services.

Recommendations

1. Health and care organisations in Staffordshire should have an open and honest conversation with the public about planning for the end of life.
2. Health and care organisations should ensure that people have access to information that supports choice at the end of life.
3. Health and care organisations should encourage communities to play a role in helping people to deal with death as a normal part of life. Compassionate communities can respond sensitively to the needs of the dying person and their family and relatives.
4. Health and care organisations should ensure that people and families are aware and actively encourage advance care planning, so that it becomes the norm for everyone as they approach the end of life. This includes use of advance statements and decisions made by the dying person (some of which have a legal determination of care), as well the Advance Care Plans (ACPs) agreed with medical practitioners or care givers and Do Not Attempt Resuscitation Orders (DNARs) and how they can be used.
5. Health and care organisations should encourage and support professionals to recognise when people are nearing the end of their lives and to develop the confidence and skills to have difficult conversations with people who are dying, and their families.
6. Health and care organisations should ensure a local response to the review of choice in end of life care and subsequent government recommendations. This should identify how the Government’s six public commitments for end of life care will be fulfilled, locally. As part of this they need to ensure that services are appropriate and accessible to the needs of diverse communities.
7. Health and care organisations need to consider key improvements that could reduce hospital admissions and in-hospital deaths. This should include the review of service algorithms that can result in unnecessary admissions (e.g. relating to ambulance services), better access to primary care and increased use of community-based palliative care teams and hospices. This will allow us to refocus our resources on prevention and more appropriate end of life care.



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