Staffordshire
County Council

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

The Annual Report of the Director of Public Health for Staffordshire 2017

"   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

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Foreword

We will all die. We may not know when or where, but to secure the best experience possible we need to plan for the end of our life in the same way we plan for other life events. We need to consider our finances and wills and our plans for final care. For families and care professionals to give us the support we need, society needs to have the wider conversation about the issues and expectations surrounding end of life.

For most of history death was common at all ages and a normal topic for conversation. Nationally life expectancy doubled between 1841 and 2011. This increase was due to improvements in public health such as sanitation and immunisations. Advances in medical practice have also helped us to live longer lives. So we now have comparatively little experience of people dying. With that has come a change in our attitude towards death. As a society we find it difficult to accept death as a biological inevitability, and instead regard it as something that can and should be prevented by modern medicine.

Increased life expectancy is a good thing. But it has its limits. Death can be unexpected but there comes a point in many people's lives when death is inevitable and imminent. The conditions that are common causes of death: dementia, cancer, heart disease and respiratory disease, often cause people to suffer terribly in the final stages of their lives. There is a real debate to be had about whether as a society and individuals we want to prolong our lives at the expense of quality of life.

The current generation has not had to acquire the level of emotional and practical skills for supporting the dying and bereaved, which previous generations would have taken for granted. This means that we miss an opportunity to think about and set out our wishes for what we want at the end of life. In the absence of clear direction, many people end up in a spiral of repeated invasive medical treatment that they may not have wished for, had they had an earlier chance to reflect. Poor experiences at the end of life impact greatly on families and loved ones, worsening the grieving process and overshadowing their memories.

So we need to get back to thinking and planning for end of life and consider:

- How can I stay healthy and independent for longer?
- What is a good death?
- What do I need to do for myself to make this happen?
- What are the views of my family?
- What support will I need?
- How long do I want to prolong life at the expense of my quality of life?

This report considers the roles of the individual, family and relatives, professionals and the wider community in assuring a better end of life experience. The aim is to encourage and help Staffordshire residents and organisations to debate these issues and to improve the quality of death.

Dr Richard Harling
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Introduction

"End of life" usually refers to the final year of a person's life. The ambition is to help people to die with dignity, through good planning and good care.

End of life care should be an inclusive approach and be tailored to individual needs and wishes; it should encompass support to manage spiritual and family matters as well as finances and legal matters.

During the twentieth century, medicine became more focused on cure, and care of the dying was not seen as a priority. Medicine progressively lengthened life and doctors became less able to deal with frailty and death.[1] It is only more recently that we have come to recognise the need to refocus on the end of life from the perspective of both individuals and carers.

A range of research has highlighted the struggles which people, as well as health and care professionals, face when having conversations about the end of life:

- A recent survey in Scotland indicates that nearly three-quarters of people surveyed (74%) had not discussed what their wishes would be if they did not have long to live.[2] For 61% of these people, this was because they either felt "too young" to discuss death, or because death "felt a long way off". 79% of people also didn't have any written plans for their end of life care, financial wishes or funeral plans.

- The National Survey of Bereaved People identified that just one third of people (34%) had told their loved ones where they wanted to die.[3]

- A poll of GPs by the King's Fund found that family doctors were often reluctant to consider their own end-of-life needs and recognised that such reluctance could affect how they related to people, and how they dealt with death, dying and end-of-life care.[4] Some clinicians refrain from initiating the conversation with people because they are "difficult conversations to have".

- A Nursing Times survey in 2010 revealed that nearly a third of nurses who had treated people using the end of life care pathway did not feel competent to discuss end of life issues with people. Nearly half of nurses surveyed (48%) said their organisation was unable to provide relatives with sufficient support and explanation when someone entered the final stage of their life.[5]

Without these difficult conversations the things that are important to people as they enter the final stage of life can easily be forgotten:

- **Choice** – people want the choice to live the way they want to live

- **Autonomy** - people cherish their independence, but loved ones often prioritise safety over independence. Often the children's answer to parent frailty is to put them where they are safest, even if they are not happy

- **Risk** – people want to decide how much risk they accept into their lives

- **The present** – people want to be able to enjoy the moment including spending time with family and friends

- **Comfort and companionship** – people want to be with others and not be a burden

- **Help** - people want help to avoid suffering and pain and receive good quality support and care

# 1   Life and death in Staffordshire

Key points:
• Life expectancy in England and wales has doubled over the last 150 years; however the number of years we spend in ill-health has increased. The focus should be adding life to years not just years to life.
• Staffordshire's population is getting older so end of life issues will become even more important in the coming years.
• Dementia is now a leading cause of death in Staffordshire.

1.1   Our population

Staffordshire has a population of 862,600 with a high concentration of people in older age groups. Around 21% of our residents are aged 65 and over (compared to the England average of 18%) with 62,700 more people aged 65 and over in Staffordshire than 20 years ago. This trend is predicted to continue with Staffordshire seeing its older population grow faster than average (Figure 1), which means that end of life will become an increasingly important issue.

Staffordshire is a relatively affluent area but has pockets of high deprivation especially in some urban areas, with 9% of its population living in the most deprived (i.e. the bottom fifth) areas nationally. However, some of the remote rural areas in Staffordshire also have issues with hidden deprivation, particularly in relation to access to services.

Figure 1: Population projections, 2015-2025
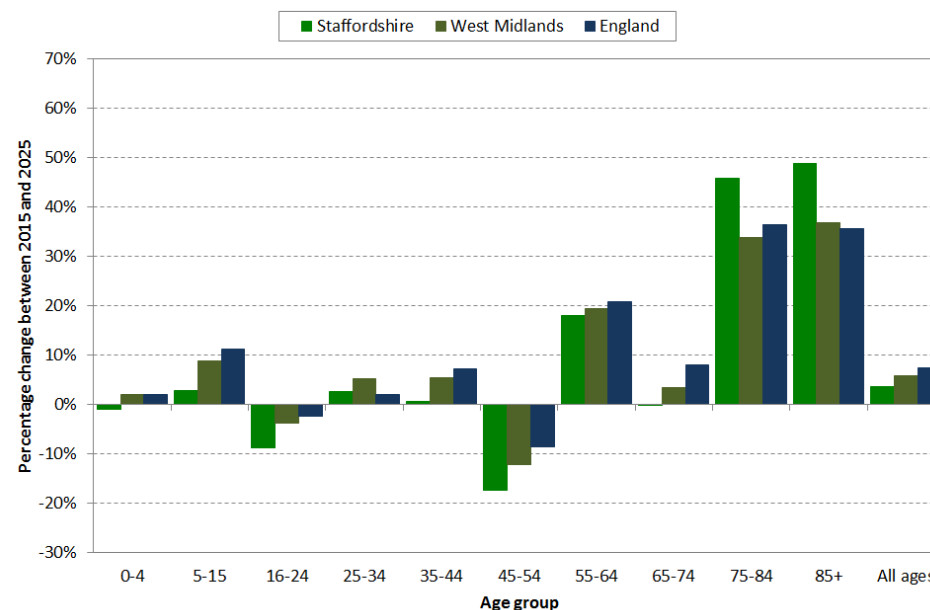
Source: 2014-based population projections, Office for National Statistics, Crown copyright

1.2   Life expectancy

Improvements in our living standards, public health measures (such as improved sanitation and immunisations), and better access to healthcare mean we are living longer than ever before. Nationally life expectancy has doubled from around 41 years for men and 43 years for women in 1841 to around 79 years for men and 83 years for women in 2015 (Figure 2). There have also been significant improvements in life expectancy in older age groups (Table 1). These national trends are mirrored in Staffordshire.

In recent times, the "quality of life years" (i.e. the number of years spent free from illness or disability) has not kept up with increases in life expectancy, particularly for older people, so the number of years we spend in poor health in older age has increased. Healthy life expectancy (HLE) in Staffordshire is 64 years for both men and women, with men spending an additional 15 years of life in poor health, while women spend an additional 19 years in poor health (Figure 3). Inequalities in health also exist, for example men and women living in the most deprived areas of Staffordshire have a HLE which is 12 years shorter than those living in the most affluent areas of Staffordshire.

People in Staffordshire are therefore being encouraged to take personal responsibility for their health and wellbeing, as not only will this extend life, it will also reduce the number of years spent living with ill health or disability. Lifestyle changes such as stopping smoking, losing weight and keeping active all have a positive health impact, even in later life.

Table 1: Life expectancy at different ages in England and Wales

|	Males			Females		
	1981	2015	Annual growth	1981	2015	Annual growth
At birth	71.1	79.2	0.3%	77.1	82.7	0.2%
65 and over	13.1	18.7	1.2%	17.1	20.9	0.6%
75 and over	7.7	11.4	1.4%	10.2	13.0	0.8%
85 and over	4.4	6.1	1.1%	5.4	6.7	0.7%

Source: Office for National Statistics

Figure 2: Trends in life expectancy at birth in England and Wales
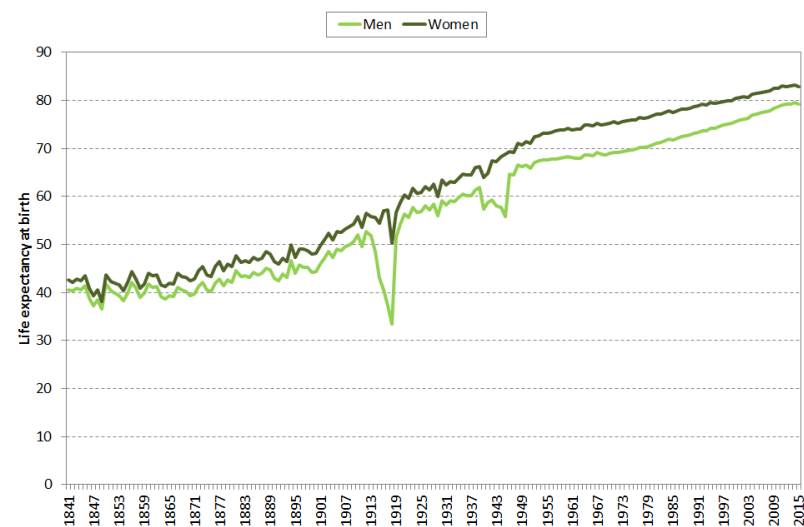
Source: Office for National Statistics

Figure 3: Healthy life expectancy at birth, 2013-2015
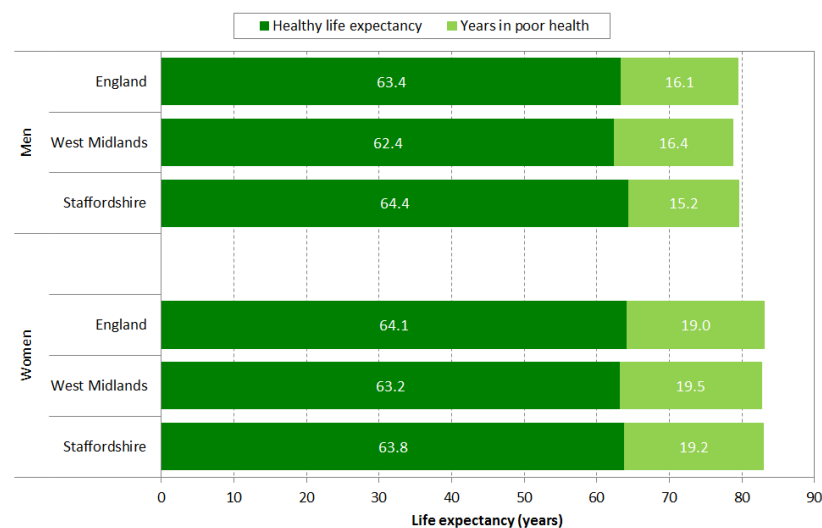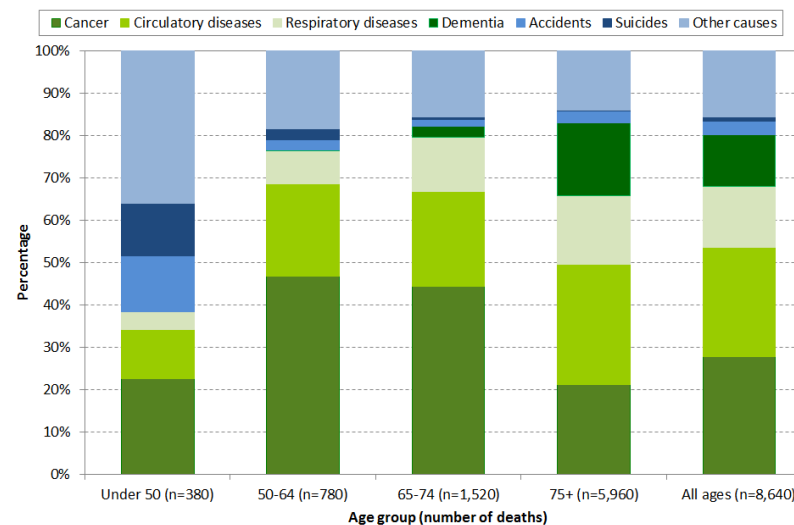

Source: Office for National Statistics

1.3 Deaths and causes of death

Around 8,600 people died in Staffordshire during 2015, with almost seven in every ten deaths occurring in those aged 75 and over and four in ten aged 85 and over. The number of deaths is set to increase more rapidly in Staffordshire than the England average. With an ageing population, the number of people dying will increase in Staffordshire by 20% (compared to England average of 11%) leading to 10,400 people dying by 2035.

Similar to the national picture the common broad causes of deaths in Staffordshire during 2015 were cancer, cardiovascular disease and respiratory disease. Dementia deaths are also particularly high in people aged 75 and over (Figure 4) Again, similar to national trends there has been a rise in the number of dementia deaths in recent years and it is now a leading cause of death in Staffordshire making up around 12% of all deaths (Figure 5).
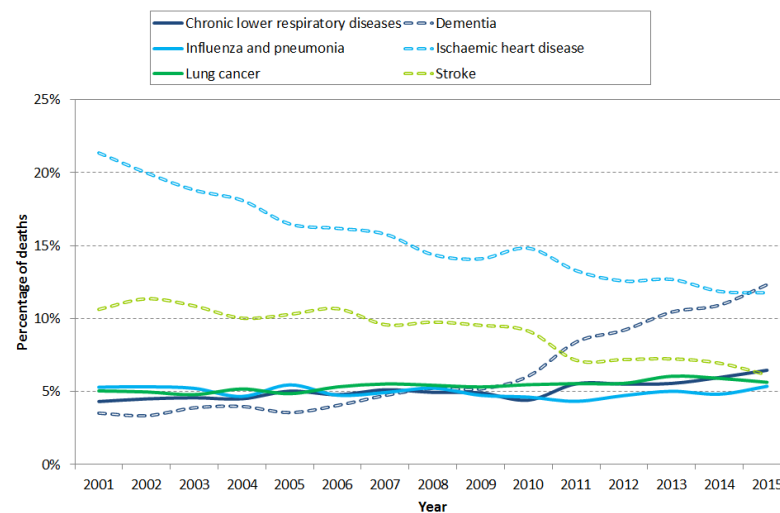
This is due to people living longer, improved detection and diagnosis of dementia and accompanied reductions in other causes such as heart disease and stroke.

Figure 4: Deaths by disease group and age group in Staffordshire, 2015

Source: Primary Care Mortality Database, Office for National Statistics

Figure 5: Trends in leading causes of death in Staffordshire

Source: Primary Care Mortality Database, Office for National Statistics

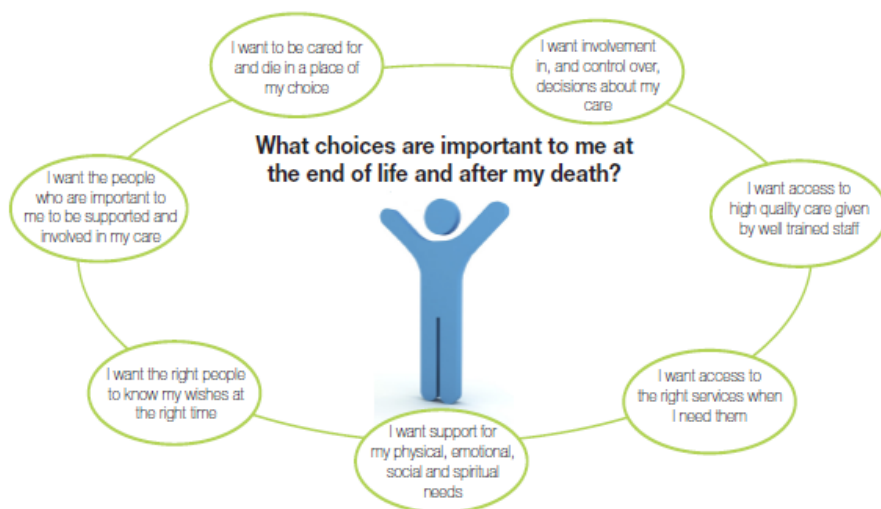## 2   What is a good end of life experience?

Key points:
Key components to a good end of life experience: • **Individuals, their carers, families and clinicians openly discussing and planning for death.** • **Individuals and their families understanding their choices and being empowered to take control of their care.** • **Communities that can support individuals and families.** • **Professionals who feel confident and able to discuss end of life care, can identify when people are beginning to die and know when to stop active intervention.** • **Clearly defining and applying good quality end of life care.**

2.1   What do we mean by a good quality end of life experience?

Research into the experience and needs of people (Figure 6) has resulted in recent proposals which define people's aspirations at the end of life.

Figure 6: Wishes identified by people and carers

Source: *What's important to me? A Review of Choice in End of Life Care, the Choice in End of Life Care Programme Board, February 2015*

A good end of life experience (generally recognised as being the last year of a person's life) should be available regardless of an individual's condition, setting or circumstances. It should take into account the person's wishes, and not be hindered by organisational or geographical boundaries. People's preferred experiences will be different, based upon the nature of their illness, their own cultural background and religious beliefs.

Meeting these aspirations is not always straightforward. It requires change across society, not only in terms of individual attitudes and behaviours, but also in terms of health and care processes and systems. All of the best practice guidance describes a changing role for individuals, families, communities, professionals, and health and care services.

| Dying matters |
|---|
| The 2008 end of life strategy, the National Council for Palliative Care (NCPC) set up the national coalition "Dying Matters" to promote public awareness of dying, death and bereavement: http://www.dyingmatters.org/ |

2.2 Supporting individuals and families: discussing and planning for death

Our ability to have open and honest discussions about death, dying and planning for the end of life is crucial. We know that discussing death is not always easy. It can be uncomfortable and emotive for many people. However, it is something that will happen to us all and planning for the future can help us to achieve a positive experience. Open and transparent communication, particularly with those closest to the dying person, is the best way to ensure person-centred and co-ordinated care.

The statements in Figure 7 are derived from the 2014 VOICES survey of bereaved relatives, and articulate what person-centred care means from their perspective.

Figure 7: "Every Moment Counts" - narrative of what "person-centred coordinated care" means in the context of end of life care
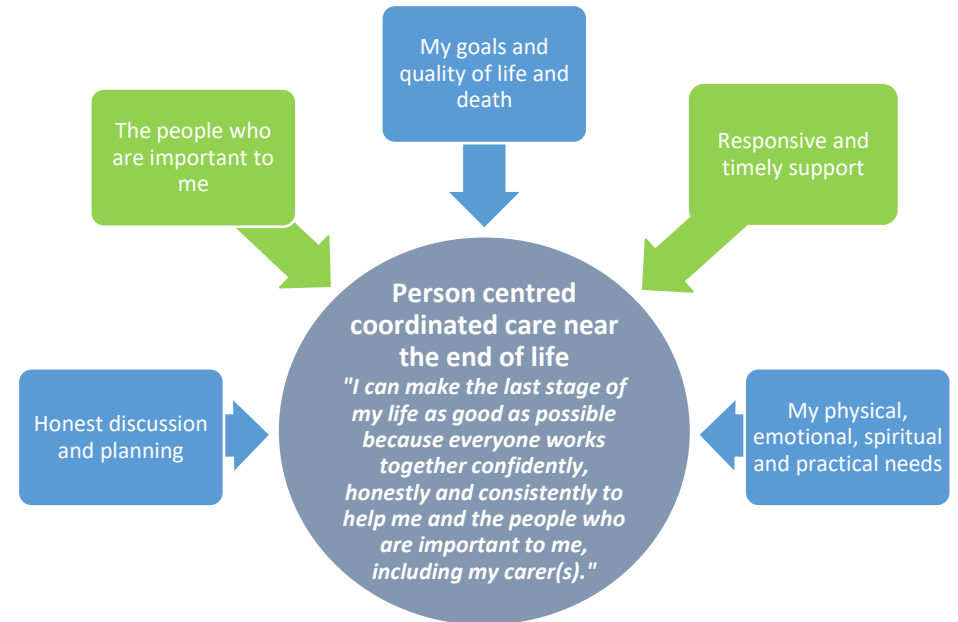
Source: NHS England, Actions for End of Life Care: 2014-2016, November 2014

Planning for care in advance can help to ensure a positive experience for the person and the family, and it can be more beneficial for certain health conditions. This provides a plan for dealing with practical issues and the often unpredictable nature of the disease process, especially for chronic diseases (such as dementia or heart failure). This includes what to do in the latter stages of life, particularly when it is recognised that the person is beginning to die.

Ensuring that individual **Advance Care Plans (ACP)** are in place and that legal matters such as **Power of Attorney** are considered in anticipation of future care, is particularly important. For example, for a person living with a diagnosis of dementia, an ACP is both for future care and end of life arrangements. Ideally an **Advance Decision** can also be made before or during the onset of an illness that will affect the persons' capacity to decide on appropriate medical treatment at the end of life. People with dementia often live for many years after their diagnosis and the likelihood of their symptoms worsening means there may be a time when they are no longer able to give consent.

National research indicates that people in hospices who had an Advance Care Plan (ACP, spent significantly less time in hospital. The average time spent in hospital in the last year of life was 18.1 days for people with ACP, compared to 26.5 days for those without.[6]

Anticipating difficult choices is a key aspect of planning future care. Here, tools such as **Do Not Attempt Resuscitation Orders** are important. Cardiopulmonary resuscitation (CPR) for people on end of life pathways can be a traumatic experience for them, their family and health professionals administering it. For the majority of people at end of life who undergo it, CPR results in a *"distressing and undignified death"*.[7] For the small proportion of people at the end of life who survive CPR, many will not regain consciousness, and those who do will be at increased pain from the impact of the procedure on their body.

What is an Advance Care Plan?

A person's Advance Care Plan (ACP) includes all the details of their wishes for the future, discussions with professionals and contacts with any health care providers. It will also include names of important people as well as any emergency contacts. It is important that the document is updated on a continual basis in line with the person's health needs, taking into account any changes in carer support.

What is Power of Attorney?

Power of Attorney gives a relative the power to make decisions about the person on their behalf, and means that any health or legal matters are anticipated, taken care of and controlled by those closest to the individual.

Advance Statement

This is any personal statement of the person's wishes and preferences for future care and may include medical or non-medical matters and explain reasons for care preferences (e.g. religious, cultural). It is a guide to treatment but not legally binding.

Advance Decision ("Living Will")

This is a particular type of Advance Statement which relates to refusal of specific medical treatment and is legally binding. It can specify circumstances for that refusal. It will come into effect when the individual has lost capacity to give or refuse consent to treatment. Careful assessment of the validity and applicability of an Advance Decision is essential before it is used in clinical practice.

What is a Do Not Attempt Resuscitation Order (DNAR)?

This is a document issued and signed by a doctor, which tells the medical team not to attempt cardiopulmonary resuscitation (CPR). The form is designed to be easily recognised and verifiable, allowing healthcare professionals to make decisions quickly about how to treat someone. It is not a legally binding document. Instead, it acts as a tool to communicate to the healthcare professionals involved that CPR should not be attempted. The reason that a DNAR form exists is because without one the healthcare team will always attempt CPR. DNAR orders can help to avoid unnecessary suffering, although they may pose ethical and legal dilemmas for medical staff, individuals and families.

"….there is disparity between the public and professional perception of the outcome of cardiopulmonary resuscitation (CPR). Television melodrama and the lay press convey a much more optimistic view of the whole process than professionals believe to be realistic. The public believe that people have a 50:50 chance of surviving, where the professionals accept that survival to discharge is less than 15%. Nor does public appreciation factor in the chance that survival will often involve disability."

Source: Time to Intervene? A review of patients who underwent cardiopulmonary resuscitation as a result of an in-hospital cardiorespiratory arrest. A report by the National Confidential Enquiry into Patient Outcome and Death 2012;
http://www.ncepod.org.uk/2012report1/downloads/CAP_fullreport.pdf

More controversially some people may consider **assisted dying or euthanasia**. This is particularly so when a person is going to die and may be suffering greatly, but this is not currently a legal option in England.

What is assisted dying or euthanasia?

Public opinion - The idea that doctors should be allowed to prescribe lethal medication for people who are close to death or suffering greatly is gathering some support across the West. In June 2015 a national survey polled attitudes towards doctor assisted dying in 15 countries, including Britain.[8] The majority of people polled in all but two of the countries (Poland and Russia), thought the practice should be legalised for terminally ill adults and Britain ranked eighth in terms of overall support for assisted dying. More recently, some countries including Belgium and also the Californian Medical Association in Sacramento have neutralised their stance on assisted dying.

Professional opinion - This is also divided with the British Medical Association, opposing all forms of assisted dying whilst the Royal College of Nursing is taking a neutral stance.[9]

Political opinion - MPs for England and Wales have recently rejected the plans for a right to die (September 2015). It was MPs first vote on the issue in almost 20 years and during this time, opinion has not shifted - 74% of MPs voted against this bill in 2015 compared to 72% back in 1997. The emphatic nature of these results would suggest politicians in England and Wales are unlikely to discuss the issue again soon.

Whilst public opinion for the right to assisted dying is gathering momentum, critics have argued that some people have been helped to die who should have been helped to live. However, the call for change may intensify with increased public support for assisted dying and an ageing population.

2.3   Supportive communities

"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of crisis and loss. People are ready, willing and confident to have conversations about living and dying well and to support each other in emotional and practical ways."

Source: Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020

In the **Compassionate Cities** vision, Professor Allan Kellehear argues that public health should embrace end of life care, and death and dying should be seen not just as a medical, but a social issue.[10] In fact, end of life care should be everyone's business. This approach suggests that care for those dying or experiencing loss should involve the whole community and is not confined to hospice and palliative care services or care of the elderly or bereaved. It allows for a wider health promoting and community development approach involving whole communities.

However, the approach recognises that "community" may mean different things to different people, dependent upon where they live, people they know, as well as their own cultural or religious background. A complex combination of factors determines the extent to which people may be willing to engage with, and participate in, community initiatives relating to end of life care.

Thus, *"Compassionate Communities"* aims to create supportive environments to accommodate death, dying, loss and care. It encourages educational institutions, workplaces, faith organisations, trade unions and those in other social organisations and settings to reflect upon their own end of life care experiences, in order to develop their own supportive local policies and responses to those experiences.[11]

Through the Compassionate Cities (Communities) approach:

- Death, dying and bereavement would cease to be taboo subjects and would become more normalised within society
- People's expectations of death and dying would change, as would how death is managed
- Palliative care would support health and social care staff to work with the community in providing care to those at the end of life, and their loved ones

A national summary of Compassionate Communities activities includes locally the Diocese of Lichfield (which serves about two million people including and extending beyond Staffordshire), in integrating compassionate community principles in to the work of the church in local parishes, and with local partners (including the St Giles hospice).[12] More recently Compton Hospice has introduced a Compassionate Communities programme for its local catchment area which includes South Staffordshire.[13]

Good Life, Good Death, Good Grief and Dying Matters

UK initiatives to provide people with the facts, skills, strategies, information and opportunities they need to deal with (and to help others deal with) death, dying and bereavement. Each year in May, they hold an awareness week providing individuals and organisations with an opportunity to promote a society where people can be open about death and bereavement. http://www.dyingmatters.org/

The hospice movement

Hospices were formed in response to the poor care for people terminally ill with cancer in the early 1980s and have evolved to support people with other serious illnesses. Hospices offer a wide range of services to individuals and their loved ones, our communities and healthcare partners. Hospices support people to live well with serious illnesses through the management of symptoms such as pain, fatigue and breathlessness, both in the community or through staying in one of the hospices. They also help people and their loved ones to talk about and plan for their end of life. Support for carers and people who are bereaved are an intrinsic part of good end of life care and a key part of what hospices offer.

Hospices are predominately funded by their local communities and recognise the growing need for increased end of life care support. They are often involved in various ways in supporting the development of resilient, "Compassionate Communities", where people are able to care for each other - either informally by speaking with people who are dying or who are grieving, or more formally by volunteering to support services.

In its 50th year, the founder of the modern hospice movement, Dame Cicely Saunders' words are as relevant today in the aspirations for both palliative and end of life care:

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Staffordshire's hospices

Staffordshire has six charitable hospices: two providing services for children (Donna Louise and Acorns) and four for adults: Compton, Douglas Macmillan, Katharine House and St Giles. Combined, the hospices support approximately 12,000 people every year (based on 2015/16 data), employ 1,215 staff and have 4,000 volunteers dedicated to providing high quality care.

There are many examples of how Staffordshire hospices and communities are demonstrating they are prepared to help. This includes supporting future generations through the St Giles Hospice school bereavement project (which aims to provide young people with peer mentor support at school) and supporting the next generation of healthcare employees through hospice work experience, curriculum enrichment days and summer schools. Both of these aim to raise the profile of end of life care and encourage young people to get involved as volunteers, or ideally, as a career option.

2.4 Supporting change for health and care professionals

Health and social care professionals need to feel confident and equipped to discuss death and dying with a wide range of people, encouraging people to talk about what their wishes might be and how advance care planning can enable them to address those wishes.[14] Individuals and families should be involved in important decision making when it comes to advance care planning.

In 2016, the Government set out a comprehensive response to the needs identified by the Review of Choice in end of life care[15]. It described an enabling framework of action and six commitments to the public, which closely align to the ambitions for palliative care and aim to end variation in end of life care by 2020. The 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

Palliative care
This generally refers to the active holistic care of the terminally ill – people with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support for the person, their family and carers is paramount for effective care. The goal of palliative care is to achieve the best quality of life for people and their families. In terms of setting, palliative care is often associated with care in hospices, but of course many aspects of palliative care can occur at home and where applicable, earlier in the course of a disease. For example, palliative care may take place in hospital alongside other treatments which aim to prolong life.

Having the right conversations, at the right times and places enables:

- People to be seen as an individuals
- People to explore their preferences around place of care
- People to discuss what matters most e.g. often individuals are worried about their loved ones, their financial situation or how they can retain control of key decisions
- The reduction of crisis calls (e.g. for urgent pain relief or for carer support at homes)
- The reduction of avoidable admissions to hospital (e.g., through Hospice Care Home Support programmes, which aim to improve end of life care conversations and planning)

This process also has a wider goal of helping people to take control of their care (and related non-medical, practical and spiritual matters) at the end of their life. It closely aligns with the wider policy frameworks described below:

- **Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020** - this sets out the ways in which people can expect to receive a positive end of life experience challenging us to achieve the six ambitions illustrated in Figure 8.[14]

- **Gold Standards Framework** - this aims to increase levels of confidence and competence across health and care staff; encourages care co-ordination across organisations and strong team working.

- **NICE Quality Standard for End of Life Care for Adults** –this highlights the improvements required in health care services. These include ensuring that end of life care is aligned to individual needs and preferences; increasing the length of time spent in the preferred place of care in the last year of life; reducing hospital admissions and subsequent deaths in hospital (against individual wishes) and deaths in inappropriate places such as on a hospital trolley.

Figure 8: Six ambitions for Palliative and End of Life Care

Source: http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf

However, there is also a growing body of evidence which (by exploring the views of health and care professionals and auditing of care) highlights the challenges we need to overcome to improve care at the end of life:

- Difficulty in timely identification of when people are dying - across both primary and secondary care.[16,17,18]
- Doctors are over-optimistic in their prognoses for people who are terminally ill.[19]
- Difficulty (in non-palliative care sectors) in defining a "working practice" definition for palliative care.[17]
- An over medicalisation of care, stemming from traditional models which focus on prolonging life, and requiring a culture shift in professional attitudes and understanding.[20]
- Subsequent risk of too much medical treatment in the latter stages of life when palliative care would be more appropriate.[21]
- Organisational and clinical pressures and uncertainties (e.g. staff shortages) which make it difficult to introduce and apply new standards or changes in practice (alongside sometimes ineffective staff training packages).[22,23,24,25]
- Difficulty dealing confidently and appropriately with people and their carers, particularly as an individual's wishes may change towards the end of life.
- Poor communication across services resulting in fragmented, reactive care, and care outcomes which do not address the person's wishes.[26]
- Where carers refuse to acknowledge dying this can act as a barrier to open, transparent communication with the dying person and appropriate care.[27]

More recently public and professional engagement undertaken by Healthwatch in the West Midlands has fully supported these findings.[28] In particular the report notes the lack of joined up systems, including supporting information technology (IT) and appropriate documenting of people's care preferences. There appears to a fear of talking about death, a lack of public awareness of advance care planning, and a lack of staff time, confidence and experience in dealing with end of life issues.

The changing role of hospices - support for health and care professionals

Better end of life planning requires the development of confidence and skills in dealing with very sensitive conversations and situations. Training provided by hospices in Staffordshire may relate to technical clinical practice of professional colleagues or development of confidence to discuss issues relating to dying with a person and their loved ones.

Staffordshire hospices run a range of training and support programmes for external healthcare and social care staff. These staff are typically specialists (e.g. working within palliative care or the hospice team), may frequently deal with end of life as part of their role (e.g. secondary care staff: Accident and emergency , oncology and care of the elderly), or work as specialists or generalists within other services supporting end of life care, (Including care home and social care staff).

Staffordshire hospices also support care homes through training programmes with direct input from experienced palliative care nurses. Improving education and coordination across the health and care workforce can result in earlier referral and better support for symptom control, quality of life and end of life care.

3   The role of health and care services at the end of life

"Our commitment is that every person nearing the end of their life should receive attentive, high quality, compassionate care, so that their pain is eased, their spirits lifted and their wishes for their closing weeks, days and hours are respected. We shall ensure that all the needs of the dying person – spiritual, physical and familial – are provided for in a way that is as that person and those closest to them wish them to be"

Source: *https://www.gov.uk/government/publications/choice-in-end-of-life-care-government-response*

3.1   The national commitment to improving end of life care

The Government's national commitment to end of life care focuses on offering choice-led, person-centred care across all care settings at the end of life. It identifies key themes for improving care, including systems to ensure that personal needs are identified, recorded and can be shared across staff and care organisations.

The response envisions a system wide commitment to improving end of life care, with local leadership (through Clinical Commissioning Groups and Health and Wellbeing Boards) to develop local programmes which support the Ambitions for Palliative and End of Life Care Framework. Local detailed background information and an end of life commissioning toolkit have already been produced to support this process. The toolkit can be found at: https://www.england.nhs.uk/wp-content/uploads/2016/04/nhsiq-comms-eolc-tlkit-.pdf).

The intention is to monitor the quality using a range of measures that are currently being developed. To date monitoring of end of life care outcomes of services has been through the National Bereavement Survey (VOICES). National findings from the latest 2015 Survey are:[29]

- Over three-quarters of respondents viewed the overall quality of care across all services in the last three months of life as outstanding, excellent or good. However one in ten said it was poor which means that some people and their families feel they are not getting high quality care at the end of their life.
- The quality of care was rated significantly lower for people who died in a hospital, compared to people dying at home, in a hospice or care home.
- Hospice staff received the highest proportion of respondents who believed they were "*always showing dignity and respect*" in the last three months of life (87% for hospice doctors and 86% for hospice nurses) whilst hospital staff received the lowest (60% for hospital doctors and 54% for hospital nurses).
- Pain was most effectively relieved in the hospice setting (64%) and least effectively at home (19%).
- Around a third of respondents reported that the hospital services did not work well together with GP and other services outside the hospital.
- Around three-quarters of bereaved relatives agreed that the person's nutritional needs were met in the last two days of life and 78% agreed that the person had support to drink or receive fluid in the last two days of life.
- There are inequalities in end of life care with differences in people's reported experience of quality of care by gender, deprivation and condition, for example perceptions of quality of care by people living in the more affluent areas are better than those of people living in deprived areas.

3.2   Quality of services

Those responsible for commissioning and providing end of life care should aim to ensure that care is high quality and co-ordinated across organisational boundaries. There are however challenges to this due to the pressures on health and care services and the way in which they are organised. The organisational structures, funding models, commissioning processes and historical relationships do not lend themselves to a co-ordinated approach to planning, providing and assuring quality in end of life care.

In addition, health and care services are under pressure. The combination of a growing and ageing population, more people with long-term conditions and a challenging economic climate, is producing a greater demand on services and more problems for people in accessing care.[30] The recent CQC report on health and care notes "the fragility of the adult social care market and the pressure on primary care services are now beginning to affect the people who rely on these services and the performance of secondary care".

In the West Midlands Healthwatch have recently identified the need for workforce development to support the quality of end of life care, particularly challenges around staff workload, recruitment and retention, and appropriate training.[31]

However, providing a seamless service which ensures consistent delivery not only across settings, but also across different user groups is vital at the end of life. We know, for example that pain is not as well managed and expert palliative care advice not as accessible at home, compared to in hospital.

We also know that certain groups, including people from minority ethnic groups, people living in deprived areas, homeless people and people in secure and detained settings report poorer end of life care experiences. People with learning disabilities, dementia, or living in isolated or rural areas may have problems accessing the care they need.

The national commitment to end of life care recognises these challenges and proposes a raft of measures which aim to build high quality personalised end of life care in to wider policy and strategy and spread innovation and good practice. This includes:

- The rolling out of shared digital palliative and end of life personal care records to all areas by 2020 (By NHS England).
- A new right in the NHS Constitution, by 2020, for everyone to be offered choice in end of life care and have their preferences recorded.
- The implementation of the NHS England "Transforming End of Life Care in Hospitals" programme (including priorities around urgent care and dementia).
- The integration of End of Life care in to the inspection regimes of the Care Quality Commission (CQC) across all care settings.
- Piloting new models of care such as the use of "serious illness conversations" (which aim to link long term disease management with end of life care) and the use of care coordinators to enable individual choice and navigation of complex care systems.
- Access to round the clock expert palliative care advice within the national development plans for urgent care advisory hubs.

The intention is that this will be delivered through effective implementation of the NHS five year forward view and local Sustainability and Transformation Plans (STP). These set out a system wide approach to transforming health and care services and ensuring that they remain affordable. The Staffordshire and Stoke-on-Trent STP includes five work streams: Prevention, Enhanced Primary and Community Care, Urgent Care, Planned Care and Cost Reduction.

Tackling unacceptable variation in care is a priority and this includes the importance of working with faith groups and production of specific resources for commissioners and providers of end of life care, to support holistic cross faith approaches. The importance of health and care commissioners including end of life care within local needs assessments, and community capacity building, is also emphasised.

NHS Five Year Forward View (2014)

Sets out a shared view on how health and care services need to change and considers what models of care will be required in the future. It proposes a focus on prevention and public health with people having more control of their own care and asks local systems to account for how they will manage implementation of personal choice, particularly at the end of life.

3.3   Workforce development

''Within NHS and social care, there is approximately 2.5 million staff. Of these only 5,500 staff work in palliative care services…these staff have the required expert knowledge and skills and will be essential in supporting the development of the wider workforce"

Source: End of Life Strategy, Department of Health 2008

The Government commitment to deliver high quality personalised end of life care aims to ensure that we have the **right people with the right knowledge and skills** for all involved in end of life care. This is supported by mandates for comprehensive workforce development led by Health Education England (HEE), and for the Chief Social Worker for Adults to develop clearer roles and capabilities for social workers in end of life and palliative care.[15] It will also require end of life care in to be included in the wider workforce planning to deliver the NHS Five Year Forward View.

The recommendations can be found in Annex A (pages 39 to 57) in the Government's *Response to the Review of Choice in End of Life Care* which can be found at: http://endoflifecampaign.org/wp-content/uploads/2017/02/choice-response.pdf.

3.4   Focusing on end of life care in Staffordshire

Locally the Staffordshire Health and Wellbeing Board, through the Joint Health and Wellbeing Strategy for Staffordshire, "Living Well in Staffordshire", have identified End of Life as a key priority. Historically a range of organisations have been responsible for providing different elements of end of life care in the county, which means that care is disjointed. Staffordshire and Stoke-on-Trent STP's Enhanced Primary and Community Care work stream includes an ambition to improve end of life care. The intention is to develop a seamless end of life care pathway. However, the local system wide approach for coordination and integration of care, as people move between organisations, will need to be reviewed in the context of planning an effective local response to the recommendations made in the governments' national commitment to end of life care.

4 What is our end of life experience like now?

Key points:
• **People could prepare much better for the end of life**
• **Professionals could be much better at identifying people who are likely to die so that they can plan appropriate care**
• **Most people would like to die at home**
• **Too many people are admitted to hospital during the last year of life**
• **Many more people die in hospital than would choose to**

4.1 Discussing and planning for death

Our reluctance to talk about death, dying and bereavement affects the way we experience death. Key findings from the 2016 Dying Matters survey found:[32]

- 73% believed that our culture in Britain meant that we are uncomfortable discussing dying and death, but 78% thought that if we were more comfortable it would be easier to have our end of life wishes met.
- 64% said they actually did feel comfortable talking about dying with their friends and family.
- 35% had written a will and 33% had registered to become an organ donor or have a donor card.
- 30% had let someone know about their funeral wishes; 25% had talked to somebody about their own end of life wishes; 25% had asked a family member about their end of life wishes; and only 7% had written down their wishes or preferences about their future care, should they be unable to make decisions for themselves.
- Only 19% of respondents were aware of the type of care and support their partner would want at the end of life.
- The 2015 survey also found that 79% felt that quality of life was more important than how long they lived.[33]

4.2 Identifying people at end of life

Identification of individuals who are in the last year of life has many advantages: individuals, their family and carers have time to plan; they can be offered advance care planning and are less likely to receive treatments of limited clinical value.

There are generally thought to be four trajectories of decline at the end of life which, as shown in Figure 9, are very different. Recognising these can help both individuals and professionals plan end of life care needs.
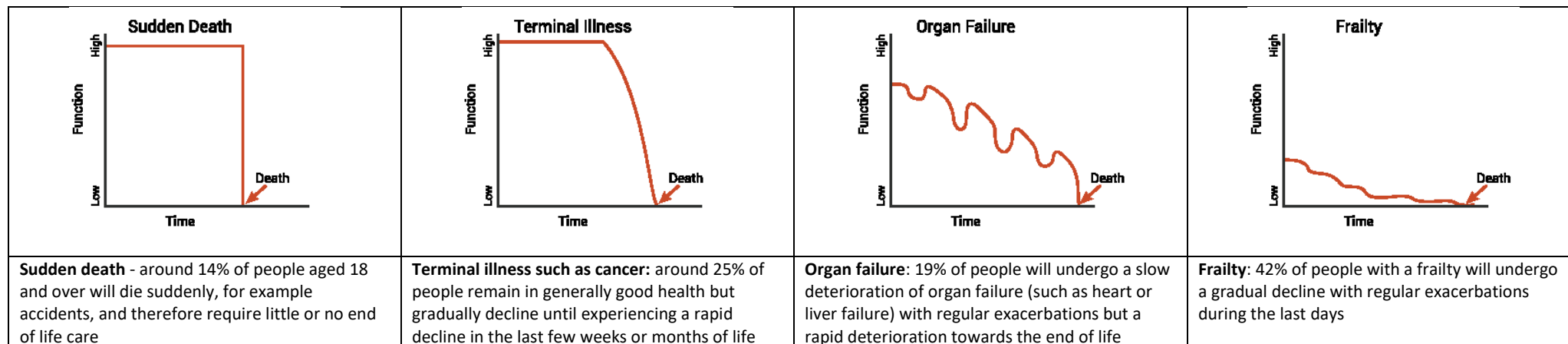
GP practices maintain palliative care registers which record the number of people who are likely to die within the next 6 to 12 months. The prevalence of selected long-term conditions from GP disease registers that may require end of life care planning is shown in Table 2.

Table 2: Summary of selected GP disease registers, 2015/16

	Staffordshire	West Midlands	England
Cancer	2.9%	2.4%	2.4%
Chronic kidney disease (18+)	4.1%	4.6%	4.1%
Chronic obstructive pulmonary disease	1.9%	1.8%	1.9%
Coronary heart disease	3.7%	3.3%	3.2%
Heart failure	0.8%	0.8%	0.8%

Source: Quality and Outcomes Framework (QOF) 2015/16, Copyright 2016, Health and Social Care Information Centre. All rights reserved

Figure 9: Trajectories of dying

Sudden death - around 14% of people aged 18 and over will die suddenly, for example accidents, and therefore require little or no end of life care	Terminal illness such as cancer: around 25% of people remain in generally good health but gradually decline until experiencing a rapid decline in the last few weeks or months of life	Organ failure: 19% of people will undergo a slow deterioration of organ failure (such as heart or liver failure) with regular exacerbations but a rapid deterioration towards the end of life	Frailty: 42% of people with a frailty will undergo a gradual decline with regular exacerbations during the last days

Source: https://www.researchgate.net/figure/5415365_fig2_Figure-2-Theoretical-Trajectories-of-Dying

Research by the End of Life Care Intelligence Network (now Public Health England) suggests that on average around 25% of deaths are unexpected.[34] This means that around 75% of people who have died should be on palliative care GP registers. This equates to around 6,500 deaths in Staffordshire. However during 2015/16 only around 2,500 Staffordshire residents were on such registers.

4.3   Choice of place of death and actual place of death

A good end of life experience includes people dying where they choose. Most people would prefer to die at home, but this view may change if people become concerned that appropriate support such as pain relief is not available.

A quality marker for end of life care is that individuals should be able to die in their place of choice. The 2015 National Bereavement Survey found that of those who expressed a preference; 81% said they would like to die at home (compared to the 42% who did die at home); 8% said they would like to die in a hospice, 7% in care home and 3% in hospital (compared to 50% who actually died in hospital). The survey also found that only 53% of people died in their preferred place of choice.

The survey also asked if the deceased had died in the right place - around eight in 10 respondents felt this to be the case (Figure 10). Around nine in 10 people who died in hospices or at home were believed to have died in the right place for them. However, whilst around three-quarters of respondents felt hospital was the right place for the person to die, this may conflict with the dying person's wishes, for example, only 3% of respondents stated their relative wanted to die in hospital and we know that 50% of people actually die in hospital.

More could be done to help relatives discuss and understand the wishes of their relatives and the likely impacts of these when end of life becomes imminent, to help them react appropriately: for example considering alternatives to calling 999 in the event of a crisis.

Encouraging families to have "transparent and honest conversations", with a shared understanding of a dying person's wishes, and the choices available, is vitally important. Particularly in anticipating critical choices (e.g. at the point of emergency hospital admission), which can have a lasting impact on the care path taken in the final year of life.

4.4 Use of health and care services towards the end of life

People's use of health and care services increases as they get older. Increasingly, research suggests that the main factor driving this is people's proximity to death rather than their age itself (Figure 11). The hospital setting therefore also provides us with an opportunity to identify those who may be approaching death.
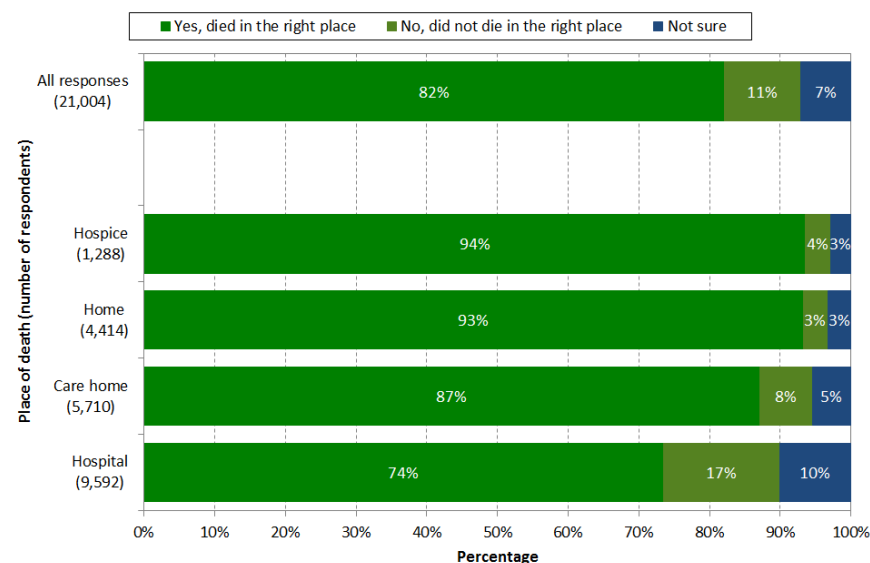
4.5 Hospital admissions at the end of life

The most obvious manifestation of increasing use of health and care services towards the end of life is hospital admissions. Many people are admitted to hospital as an emergency during the last year of life, including right at the end as they die. Research suggests that on any given day a third of people in hospital are in their last year of life and one in ten will die before they leave.[35]

The last hospital admission before death may have been preventable for many people.[36] This may be due to a lack of forward planning, because professionals fail to recognise that people are dying and continue active intervention, and/or due to a lack of appropriate care available in the community. Inadequate support in the community and fear of poor pain management means that many people agree to go to hospital at the last minute in an unplanned way, when there are limited clinical benefits to them being there.[37]

Research by the local Commissioning Support Unit (CSU) found that across the West Midlands:[38]

- The number of emergency admissions and accident and emergency (A&E) attendances rise as the person approaches end of life, peaking at one month prior to death (Figure 12)
- Elective (planned admissions) and people's attendances as an outpatient also both peak towards the last two months prior to death but then fall away sharply.

Figure 10: Did the person die in the right place, by place of death, England, 2015

Source: National Survey of Bereaved People (VOICES): England, 2015, Office for National Statistics, https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015

Figure 11: Relationship between age, proximity to death and use of health and care service
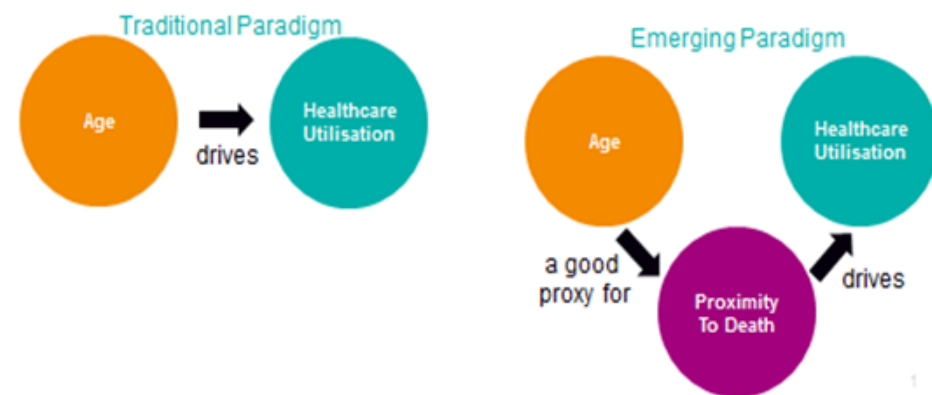
Source: Proximity to death, Midlands and Lancashire Commissioning Support Unit, 2016

In Staffordshire during 2015/16 there were 88,000 emergency hospital admissions of which 4,350 people (3.8%) died in hospital. 17% (580 people) of those who die in hospital were admitted from a care home.

Emergency admissions rise more steeply as patients approach end of life. They peak one month prior to death and then level off. Average costs for emergency admissions show a gentle upward slope until one month before death when they reduce slightly. The result for total costs is a curve that is similar to that for activity.

A local audit of deaths in hospital showed that very few people had been admitted with evidence of advance care planning.

Figure 12: Emergency admissions prior to death in West Midlands, 2012/13

Emergency admissions – average costs

Emergency admissions – activity

Emergency admissions – total costs
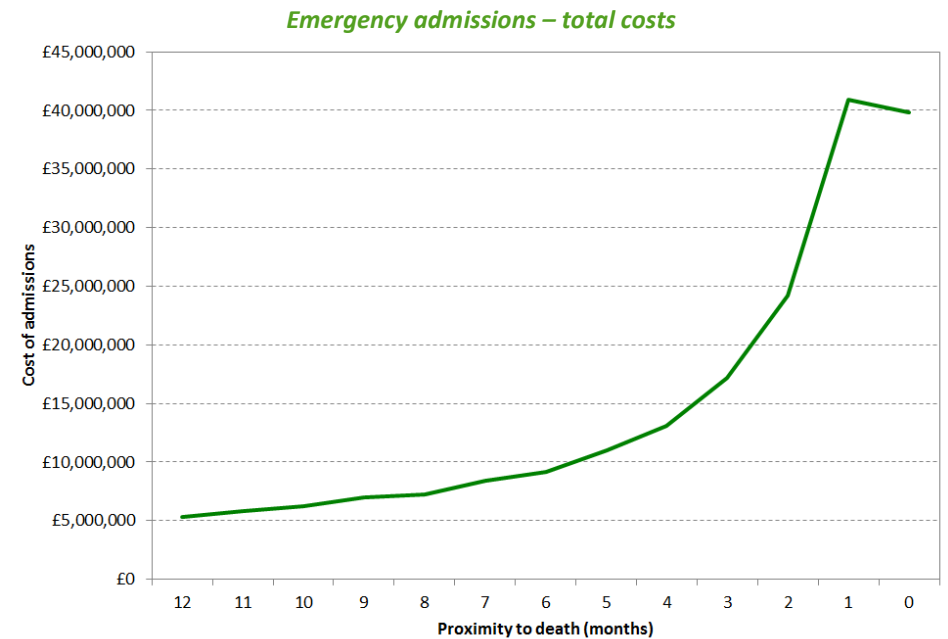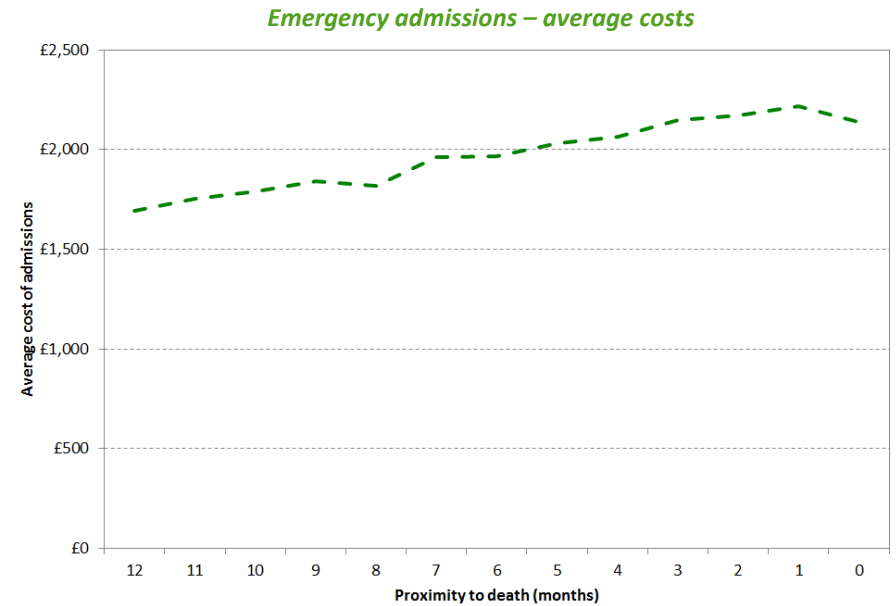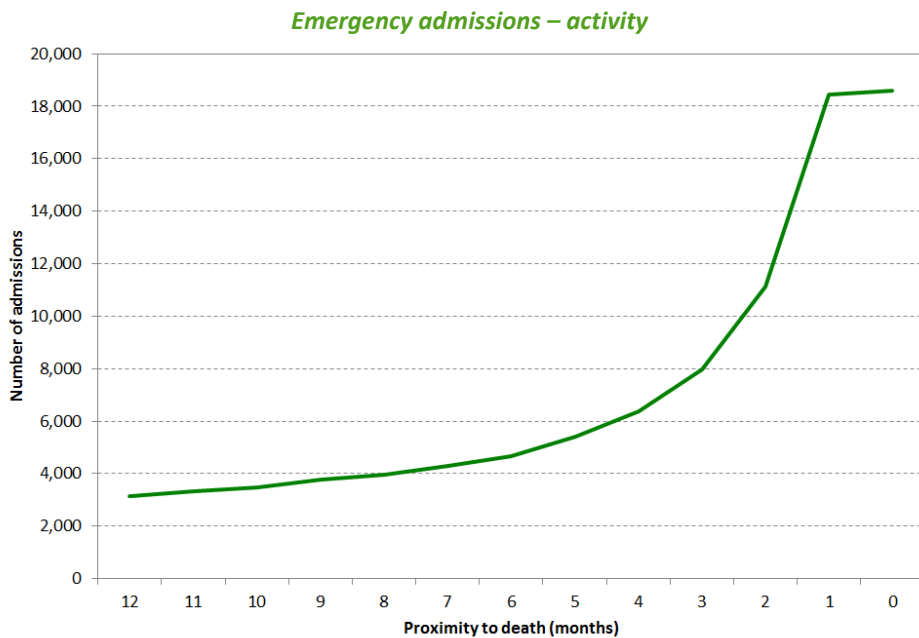
Source: Understanding the Variation in Patterns of Acute Healthcare Utilisation Prior to Death, the Strategic Unit, Midlands and Lancashire Commissioning Support Unit, March 2015

4.6   Deaths in hospital

Hospital is the least likely place that people choose to die compared with home, hospices and care homes. Nationally only 3% of people choose to die in hospital but 50% of people actually die in hospital and nearly 30% of all hospital beds are occupied by someone in their last year of life.[39]

Hospitals are rated by bereaved relatives as providing poorer care and lower levels of dignity and respect for people at the end of life compared to other providers.[40] Admitting people to hospital to die is inappropriate when this is not their choice: it is not in the interest of the individual, it is costly, and it stops the bed from being used by others.

In Staffordshire, the proportion of people dying at home or their usual place of residence is 42%, lower than the England average of 46%. Trends over the last five years show very little change (Figure 13).

Figure 13: Trends in proportion of Staffordshire residents dying by location
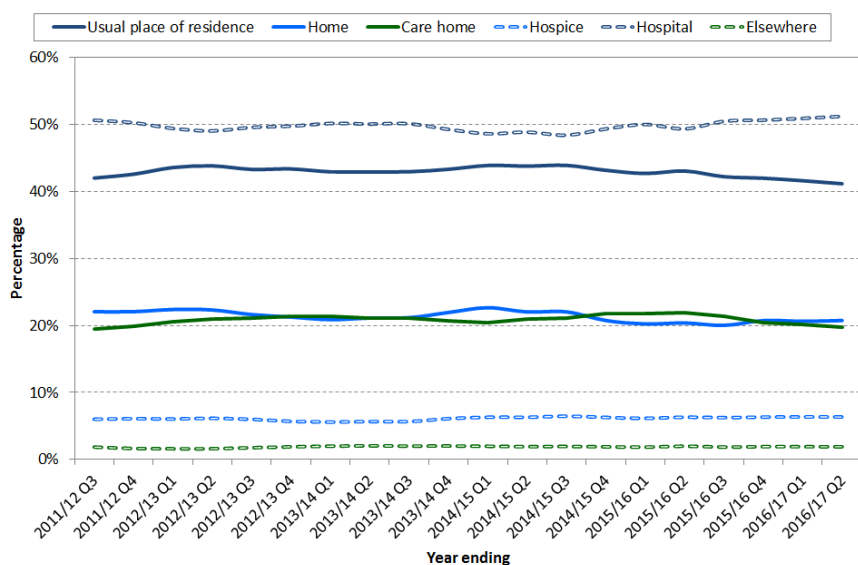
Source: http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death

The proportion of people dying at home or their usual place of residence varies considerably across the county from 38% in Newcastle-under-Lyme to 47% in Lichfield. People in deprived areas are more likely to die in hospital.[1] There may also be other influences on place of death such as variations in the quality of general practice, availability of NHS community care and people's proximity to a hospital.

In Staffordshire we also admit more people to hospital to die than the England average. People also tend to have a longer stay in hospital prior to death; the average length of stay for Staffordshire residents who died in hospital was 12 days compared to people who don't die whose average length of stay is five days.

Around 17% of people who died in hospital died within one day, around a third dying within the first three days whilst over half were in hospital for more than eight days before their death (Figure 14). Older people, especially those aged 85 or over, have particularly long spells in hospitals prior to dying compared to younger age groups (for example, of people who died in hospital, 49% were aged 85 or above, compared with 34% of people aged under 45).

This is probably because we are less effective at preventing hospital admission at end of life or moving people out of hospital to a more appropriate setting.[41]

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[1] *There are some caveats with using the ONS place of death category, for example some hospitals will have palliative care beds. In additional community hospital beds will also be included in the hospital total.*

Figure 14: Length of stay in hospital before death, 2015/16
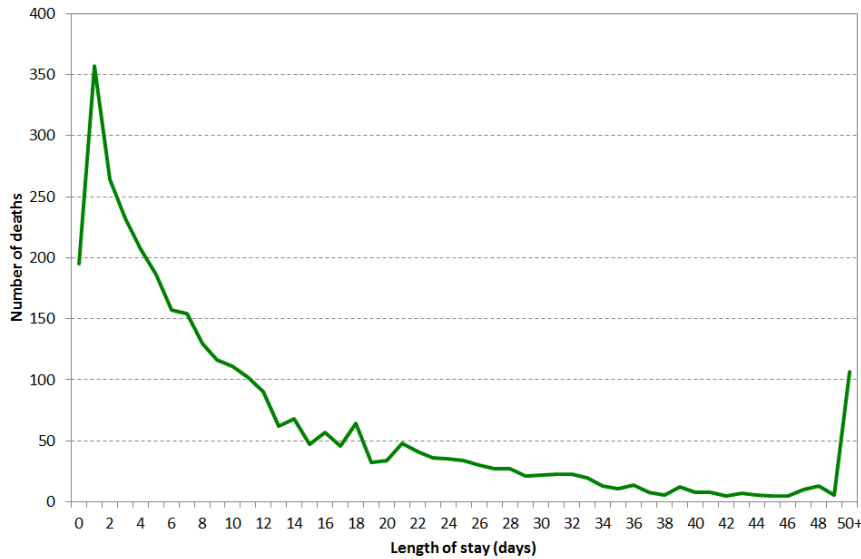
Source: Hospital In-patient Data Extract, Midlands and Lancashire Commissioning Support Unit

4.7 Costs of care at the end of life

The costs of care at the end of life are high. National research conducted by the Nuffield Trust in 2014 shows that hospital costs are by far the largest cost element.[42] Care in the final three months of life averaged over £4,500 per person who died, largely due to emergency hospital admissions. Hospital costs increase rapidly in the last few weeks of life. Around a quarter of people who died also used local authority-funded social care in their final year of life.

Based on this national study the estimated costs for hospital and social care **in the last three months** of dying for Staffordshire residents are thought to be in the region of £46.4 million (£37.7m for hospital activity and £8.7m for local authority funded social care).

In addition a local study based on matching deaths to hospital activity by the local Commissioning Support Unit also estimated end of life costs to acute care **in the last 12 months** for Staffordshire totalled £48.2 million:[43]

- £2,200 per person for emergency admissions equating to £31.5 million
- £670 per person for elective admissions equating to £9.3 million
- £120 per person for A&E attendances equating to £1.8 million
- £90 for people attending as out-patients equating to £5.6 million

This puts the **total end of life costs for acute care in last 12 months at around £48.2 million**.[2] These costs make a clear case for preventing inappropriate admission to emergency care and focusing valuable resources instead on prevention and improving the quality of people's lives.

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[2] At three months hospital costs from this study are estimated to be considerably less at around £25.9 million which is lower than those estimated from the Nuffield Study. The differences between the two studies are largely due the differences in the cost of an emergency admission (£3,465 in the Nuffield study compared to £2,200 in the CSU study).

5   Conclusion and recommendations

"The taboo about discussing death and dying means that too many people can reach this critical point of their life unprepared, without having thought about how or where they would like to be cared for"

Source: Healthy People, Health Lives: Our strategy for public health in England, 2010

This report shows how over the last century the age, cause, and place of death have changed significantly. In the early 1900s, most people died at home, often from acute infections, and many more deaths occurred during childhood and early adulthood. Most people now die in older age from cancer, cardiovascular, respiratory or age-related illnesses, such as dementia, after a prolonged period of being admitted to hospital regularly during their last year.

5.1   The need for a debate

We don't like talking about death and dying and this makes it hard to plan the end of life that people really want. Three-quarters of the public agree that if people in Britain felt more comfortable discussing death and bereavement it would be easier to have our end of life wishes met. We need people to be talking with their families as well as health and care professionals about their choices at the end of life and for discussing death to become the cultural norm. The more mindful we are of our death, the less fear and anxiety it will give us. The Governments national commitment to end of life calls for a widening of public understanding to support informed choice at the end of life.

Recommendation 1: Health and care organisations in Staffordshire should have an open and honest conversation with the public about planning for the end of life.

Recommendation 2: Health and care organisations should ensure that people have access to information that supports choice at the end of life.

5.2   Dying, death and bereavement is everybody's business

Death and bereavement are not primarily health and social care events; they affect every aspect of people's lives and experience. Dying is a social issue and "Compassionate Communities" can create a wider acceptance and a supportive environment for individuals and their families.

Cultural influences can significantly impact the person's reaction to the dying process and the decisions the person and family make. Health care professionals may sometimes assume that people from certain minority ethnic groups take care of their family members at home, which can lead to a lack of referrals to services, and often poor outcomes for the person and family. Compassionate communities need to be inclusive and take into account cultural and religious beliefs.

Religious traditions and family roles might also be seen as incompatible with palliative or hospice care, for example, feeling able to accept a terminal prognosis if this implies a lack of faith. For many ethnically diverse cultures, the approach to health and illness is through the interconnection of mind, body and spirit with nature or the environment. Faith and spirituality can play a significant role in the perception and response to the dying process.[44]

Recommendation 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.

5.3   Preventing unnecessary medical intervention

There are some measures available that can be used to prevent medical intervention when a person has no longer wishes to be treated. In order to achieve the goal of personal control it is vital that people's wishes are clearly documented and uptake monitored if inappropriate treatment is to be avoided.

> **Recommendation 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.**

5.4   The health and care workforce need to be better able to support end of life and not consider death as a failure of treatment

There is a clear need for planning for dying and death as soon as it is appropriate. In line with the Government commitment to having the "*right people with the right knowledge and skills*" in place to achieve this, professionals will need to be confident that individuals are on an end of life course and what stage they are at. Communities, families and professionals need to work together to raise the issue of dying and support people develop their plans. As well as personal plans, professionals need to agree with people and families the degree of medical intervention they would expect at end of life. Many people die in hospital and experience traumatic unsuccessful interventions which would not have been their choice.

> **Recommendation 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.**

5.5   Recognition of end of life care needs and improving services outside hospital could improve care and reduce hospital costs

The costs of hospitalisation in the last three months of life are high. This money could be much better spent outside hospital funding high quality care that allows people to die in a way of their own choosing.

Quality care at the end of life is achieved when strong networks exist between specialist palliative care providers, primary and secondary care, community based providers, other stakeholder organisations and local communities – all working together to meet the needs of local people.

> **Recommendation 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.**

> **Recommendation 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.**

Special thanks

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