



Suffolk Annual Public
Health Report 2018

.....

LASTING LEGACIES

.....

Conversations about end
of life in Suffolk

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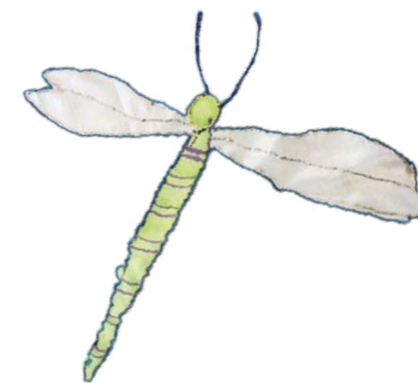
ACKNOWLEDGEMENTS

Thanks go to the many organisations and colleagues who contributed to this year's report. It would not have been possible without you.

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AUTHOR'S NOTE

This year, we really wanted to illustrate our report title - that everyone leaves a *lasting legacy*. The designers of this year's annual public health report have taken inspiration from artwork produced by individuals at St Nicholas Hospice Care during their Orchard Day Therapy sessions.

Activities facilitated by staff and volunteers give people the chance to express themselves in ways that they may otherwise not feel able to.

One individual was only able to paint in black because of the difficulties they had expressing their feelings and emotions when they first started taking part in creative sessions. However, they were able to move on to using colour.

Creative activities can generate opportunities for people to interact with others. The activities encourage social interaction and, as people become more comfortable, they feel more able to share things with others. They become more open.

The creative activity sessions have also helped people build their confidence and take on coaching and teaching roles. Not only has this benefited the participants by giving them a sense of purpose and worth, they have also been able to share their creative talents and encourage others.

Taking part in creative activities at the Hospice has also led to some people picking up old hobbies again. One person, who because of the symptoms of their illness had lost confidence and stopped going to an art class, restarted after his interest was renewed and confidence built up by the creative activities he took part in at the Hospice.

This is just some of the artwork that has been created. The Hospice has kindly given us permission to use it in this year's report. Thank you!



STARTING THE CONVERSATION

'PASSING ON'

'AT REST'

'AT PEACE'

'DEPARTED'

'PASSING OVER'



Being able to talk about dying is essential when it comes to preparing ourselves for our own death. Yet, we often avoid even the word, preferring commonly used phrases to express when someone is dying.

It is often seen as an uncomfortable topic. But it is vital that both professionals and residents in Suffolk feel as comfortable as possible in talking about their wishes, their requests, their beliefs and discussing those with their families and friends.

That is what this year's report is all about.

INTRODUCTION

“ THE HAPPINESS OF THE DROP IS TO DIE IN THE RIVER. ”

Al-Ghazali

I was fortunate to have completed one of the five pillars of my faith, the Hajj in 2013. As my partner and I set out to plan this four-week journey of a lifetime, it became apparent that we had a huge responsibility to ensure that all our affairs were in order, including considerations of the guardianship of our young children. It was only at this point in our lives that both of us had time to pause, reflect and put in place our death plan arrangements in case either one of us died during the momentous journey. We had simply failed to have these conversations as a couple, and had not put measures in place or spoken with our family members about our wishes. We had our joint will witnessed by neighbours, and approaching them was a humbling experience. Needless to say, both of us came back alive but 'reborn' after the pilgrimage. I can truly say that I have planned for death.

End of life care is an important public health issue and is often overlooked. Everyone deserves to die with dignity, respect, free from pain and be comfortable, in their preferred place of care, whatever that looks like for them. It's about how we can age with self-respect, how we can die with grace and what legacy we leave behind.

The only certainty in life is that we will all die. What is less certain is where and what experience we and our families and carers will have when it happens. It's only by talking that we can agree what is really important to us and put plans in place to make that happen.

Ensuring excellent care at the end of life is a challenge that is not specific to the UK, but one that the world is facing. Death, dying, caring and bereavement touches everyone, and the care given to the dying is often seen as a barometer of a society's attitude towards their vulnerable and sick.

As many of the professionals working in this area will already know, having open and honest conversations about dying can be the first step towards having a 'good' death.

We also know that, all too often, people are not dying where they would like to, or in some cases, do not even know they can choose what happens around their final days.

Many of us face barriers that stop us talking about dying. Health and social care professionals, too, may be missing key opportunities to bring up the topic. In fact, around two in three people (64%) think that we do not talk about death enough in this country¹.

Being able to talk about dying is essential when it comes to preparing ourselves for our own mortality. While it's becoming more and more accepted that everyone should write a will, it's much less common to think about our future care needs. But we need to.

By putting plans in place earlier and thinking about what matters to us and our family, it may be possible to die 'well', and in the place of our choosing.

Improving the way that we die is a huge topic, and not one that we can fully address in one report. We all have the means to do this together, it is not the single responsibility of specialist teams or the hospice in isolation, but all providers of care and the community collectively.

This report considers the experiences 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 Suffolk residents and organisations to discuss and debate these issues and to improve the quality of death and end of life care.



Abdul Razag
Director of Public
Health and Protection

“ ...OUR LIVES HAVE NARRATIVE - WE ALL WANT TO BE THE AUTHORS OF OUR OWN STORIES, AND IN STORIES ENDINGS MATTER. ”

Dr Atul Gawande

Being mortal: Medicine & What Matters in the End



WHAT DO WE KNOW ABOUT END OF LIFE

The working definition of end of life care is usually considered to be the last year of life. However, the trajectory of different conditions means that for some, end of life care refers to the last few years of life, whereas for others, this could be a matter of months, weeks, days or hours, and into bereavement.

Improving services for people, their loved ones and carers at the end of life has been prioritised in several national policies, strategies and guidelines over recent years²⁻⁸.

The General Medical Council guidelines state that people can be considered 'End of Life' when they are likely to die within the next 12 months⁹. This also includes those 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; and life-threatening acute conditions caused by sudden catastrophic events.

The Age and Ageing commentary¹⁰, aimed to address issues of current significance in relation to death, identified three key points for consideration:

1. Current palliative care provision does not align with the needs of many older people dying with multiple morbidity and frailty.
2. Prevailing constructs of 'the good death' do not reflect patient and public values and experience and constrain rather than enable 'choice'.

3. New models of palliative care are required which accommodate diversity and are based on need rather than diagnosis.

These are all points we need to look at in more detail across Suffolk.

What makes 'good' end of life care and a 'good' death

Good end of life care allows a person to die with dignity, be pain free and as comfortable as possible, in their preferred place of care when the time arrives. It also ensures appropriate support is provided to families and carers before and after death.

Being able to talk about dying is essential when it comes to preparing ourselves for our own death. As mentioned in the introduction, while it's becoming more accepted that everyone should write a will, it is much less common to think about our future care needs. But we need to. Future care wishes, as well as wider wishes are crucial in creating lasting legacies.

By making it more natural to talk about death, it will be less difficult to have those essential conversations about what our final wishes are. If concerns and preferences about care are raised early enough, a lot can be done to make sure they are dealt with. Sometimes, we may not get a chance to do what we wish if nothing is said, written down or planned.

By putting plans in place earlier and thinking about what matters to us and our family, it may be possible to die 'well', and in the place of our choosing.

For beneficial conversations around planning to happen earlier and more regularly, we need to challenge existing perceptions that may be barriers: thinking or talking about death, and making plans for it, isn't giving up. In fact, it is taking control of a situation that is otherwise out of our control.

Research has identified that there is still considerable taboo around talking about death¹¹. It is also true that for those who are faced with illness, death may be a sensitive topic, and something that they do not want to face just yet. For others, it may seem far off and irrelevant to them – or, so inevitable and out of their control that there is no point thinking about it, let alone having conversations about it¹².

"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."¹³

Our reluctance to talk about death, dying and bereavement affects the way we experience death.

The 2016 Dying Matters survey found¹²:

73% of respondents believed that our culture in Britain meant that we are uncomfortable discussing dying and death.

However, 78% thought that if we were more comfortable, it would be easier to have our end of life wishes met.

64% of respondents said they did feel comfortable, talking about dying with their friends and family. However, this still means that nearly **1 in 3** people are not comfortable discussing dying with friends and family.

The survey also found that **35% had written a will and 33% had registered to become an organ donor or have a donor card.**

Only **30%** of respondents had let someone know about their funeral wishes, **25%** had talked to somebody about their own end of life wishes, **25%** had told 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.

Finally, only 19% of respondents were aware of the type of care and support their partner would want at the end of life.

ADVANCE CARE PLANNING

Advance care planning is the term used for planning ahead for a time when a person's health may change, and they lose capacity to make decisions and/or communicate these with others. It is a voluntary process to help guide individuals to anticipate how a condition may affect them in future.

Having a record of someone's preferences in advance of their death can significantly impact on their experience. These preferences can be changed at any time as the situation changes.

Putting an advance care plan in place for someone's end of life involves discussion between the individual and someone from their care team around their wishes and preferences. It can consider the individual's worries, values, personal goals,

and preferences for their care including: attempted resuscitation, preferred place of death, and tissue/organ donation.

Such planning can include legally binding advance decisions to refuse treatment, appointment of a lasting power of attorney, sharing of preferences, or letters between health professionals.

The benefits of this process are in providing greater control and input into a person's care. Individuals are more likely to consider alternatives to hospital admission at a time of deterioration if they have clearer plans and expectations. Proactive identification of needs can enable plans to be put in place in a timely manner, and avoid the need for crisis management.

According to NHS England's toolkit for Commissioning Person Centred End of Life Care¹⁴, approximately 1% of people on a GP registration list will die each year, equating to around 20 deaths per GP. It also estimates that 70-80% of those deaths are likely to benefit from planned end of life care - between 14 and 16 people per GP per year. All services, including primary care, community services and acute hospital trusts, must be equipped to provide excellent care to their patients who are at the end of life.

My goals and quality of life and death

The people who are important to me

PERSON CENTRED COORDINATED CARE NEAR THE END OF LIFE

"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)."

Honest discussion and planning

Responsive and timely support

My physical, emotional, spiritual and practical needs

'Every Moment Counts' - narrative of what 'person centred coordinated care' means in the context of end of life care

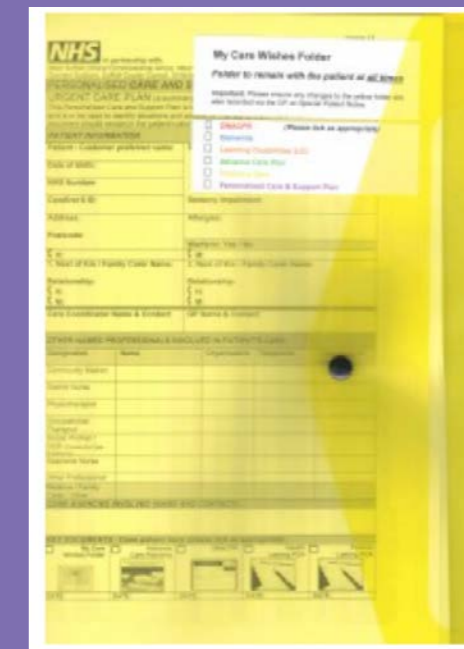
Thinking ahead – My Care Wishes in Suffolk

In Suffolk, people are encouraged to think ahead, even if they are not approaching the end of life. Thinking about the types of treatment they might want to avoid, where they want to die, ensuring that someone can make decisions for them, and putting a will in place, all support people to die where and how they want to.

When someone in Suffolk recognises, or is identified as approaching the end of life, a 'yellow folder - My Care Wishes' is available from the GP or other clinicians¹⁵. The folder holds key documents about the patient and prompts discussion on: advance care planning, personalised shared care and support arrangements, and resuscitation preferences in an emergency. The folder aims to support thinking ahead and choice for people at the end of life, their families and carers, and their 'care wishes'.

However, across Suffolk, it is recognised that My Care Wishes is not consistently completed, and difficult conversations are not always happening. Review of the process, and who should be taking responsibility at each stage, is ongoing across the county.

My Care Wishes folder used for advance care planning in Suffolk



Great Yarmouth and Waveney Clinical Commissioning Group is working within their Sustainability and Transformation Partnership (STP) footprint to promote advance care planning by rewriting the yellow folders to make them more user friendly. They have also set up the use of red bags for anticipatory medications for end of life and have written a Gold Standard Framework best practice guide for primary care.





PEOPLE LIVING IN SUFFOLK 2017

THE POPULATION IS FORECAST TO GROW **9%** by 2041

The population is estimated to grow to 831,400

LIFE EXPECTANCY FOR SUFFOLK RESIDENTS IS HIGHER THAN ENGLAND BOTH MEN AND WOMEN IN SUFFOLK **LIVE** statistically significantly LONGER COMPARED TO ENGLAND AS A WHOLE

LIFE EXPECTANCY IN SUFFOLK (2014-16)

80.8 YEARS (England 79.5 years)

84.2 YEARS (England 83.1 years)

THE POPULATION OF SUFFOLK IS AGEING

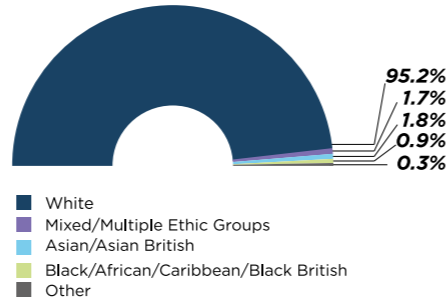
Suffolk has a high proportion of older people when compared to the rest of England



SUFFOLK IS LESS ETHNICALLY DIVERSE THAN ENGLAND

Although comparison of 2001 and 2011 census data show diversity is increasing

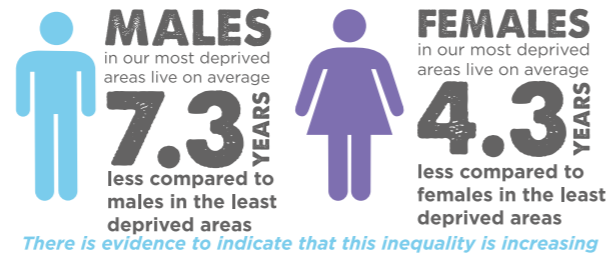
ETHNICITY IN SUFFOLK % 2011 CENSUS



OVERALL LIFE EXPECTANCY HEALTHY LIFE EXPECTANCY IS LOWER

This means that both male and female Suffolk residents are spending over 15 years in declining health

HEALTHY LIFE EXPECTANCY IN SUFFOLK:



7,864 LIVE BIRTHS IN SUFFOLK 2017

7,885 Deaths in Suffolk in 2017

ORGAN DONATION

In June 2018 over 600 people in Suffolk were alive thanks to organ donation

295,056 People are on the NHS organ donor register in Suffolk.

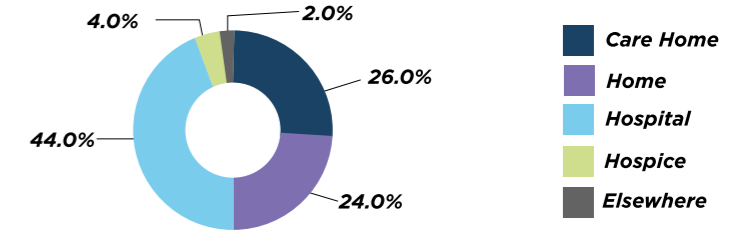
In Suffolk the number of people on the organ donor register has increased by **30%** from 2013-18

Data and intelligence

This report primarily focuses on deaths that are caused by chronic conditions like cancer, dementia, heart and respiratory diseases. The time that passes between receiving an initial diagnosis and death can be used to prepare, discuss and plan, if advance care planning has not been done before. This report doesn't focus on sudden deaths, such as those due to accidents or suicide. Of all deaths in Suffolk in 2017, one in 29 involved an accident or suicide.

WHERE A PERSON DIES CAN INFLUENCE THE EXPERIENCE FOR BOTH THE INDIVIDUAL AND THOSE CLOSE TO THEM

In Suffolk, four in every nine deaths occurred in hospital (3,457 people). A quarter of deaths occurred at home (1,908 people) and a further quarter occurred in a care home (2,005 people). The remainder of deaths occurred in a hospice (337 people) or elsewhere (178 people)



THE MOST COMMON CAUSES OF DEATH IN SUFFOLK ARE CANCER AND CIRCULATORY DISEASES. Each of these accounted for one in four deaths in 2017

2,171 deaths from cancer

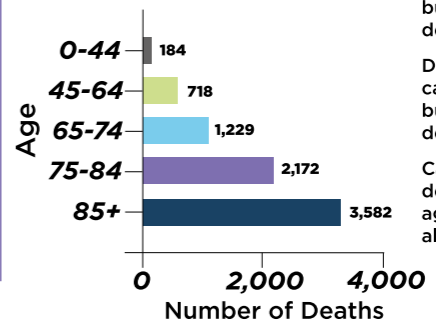
1,013 deaths from dementia

213 deaths from accidents

1,473 deaths from other causes

1,970 deaths from circulatory disease

986 deaths from respiratory disease



Causes of death change with age. Death from accidents and suicide account for one in three deaths among people aged under 45, but account for just one in 50 deaths among those aged 65+.

Dementia was not recorded as a cause of death in any under 65s, but accounts for 1 in every 5 deaths among those aged 85+.

Cancer affects all age groups but deaths are prevalent among those aged between 45-74, nearly half of all deaths are attributed to cancer.

PUBLIC HEALTH APPROACH TO END OF LIFE CARE:

COMPASSIONATE COMMUNITIES

The public health approach goes by many names: community engagement, participation, or development, social network approaches, and compassionate communities, to name a few. It views the community as an equal partner in providing quality healthcare at the end of life.

Compassionate communities are community development initiatives that actively involve citizens in their own end of life care; a holistic, population health approach to palliative care which goes beyond health and social care services.

They were first described in 1999²⁰⁻²³. A compassionate community is one which agrees to offer support, comfort and care to people who may be dying or suffering from a chronic condition such as dementia. A compassionate community recognises that we all experience loss and death. Given that these experiences are universal, there is a need for communities to help all their members to care for each other.

Compassionate communities advocate building partnerships between services and communities to build on the strengths and skills they possess, rather than replacing them. The basis of compassionate communities is their reciprocal relationships with services. The community is therefore supported by professionals such as palliative care staff, dementia nurses, and other health and social care workers.

Community nursing in Suffolk told this story:



"A lady lived alone in a remote house with no telephone and no family. She wanted to die at home and understood the risk of dying alone. A rota of neighbours, Marie Curie, community staff and local volunteers was drawn up, so she was never alone for more than two hours. She died peacefully at home in her preferred place of care."

St Nicholas Hospice Neighbours is a volunteer community project in west Suffolk with 150 volunteers providing companionship and practical support to people and their families. They establish what is most important to individuals and help build those supportive local networks around them.



One volunteer had this to say:
"This type of volunteer support enabled an isolated person to return home from hospital earlier than planned by encouraging engagement with neighbours and other community groups, building a network of homegrown local provision. Companionship and reassurance, along with shopping and transport all helped this individual remain at home and feel safe and supported"

St Elizabeth Hospice Home Sitting Service offers a volunteer led service that provides companionship and support to families and individuals.

The Good Neighbour Scheme is a voluntary initiative supported by Community Action Suffolk and run by groups of residents²⁴. They help people in their locality enjoy a better quality of life by offering them support with everyday tasks. This helps to build a stronger and more resilient community where people know and help each other.

Good neighbour schemes in Suffolk tell these stories about supporting people at the end of life:



"We had been regularly visiting a woman who lived on her own and helping in other ways when she was admitted to hospital. With the help of other volunteers, her neighbours who are part of our network were very much involved in supporting her as she reached the end of her life. She had no family nearby and her neighbours and our volunteers were really the closest people to her."

"We supported someone recently in the period leading up to death. We had provided transport when there were lots of hospital appointments and then helped recruit a carer for the return home after a hospital admission. When her health deteriorated the network and her immediate neighbours were very much involved in supporting her. Her nearest relative lived abroad and closest friend in another town. We were able to reassure them both that we were keeping an eye on her"

The examples above show how public health approaches can utilise community networks and assets. They expand the reach and

effectiveness of care into the community by providing better and more holistic end of life care. This can enable people to remain in the community setting if they prefer, and may also help to alleviate pressures on acute services.

Evidence indicates that individual learning, personal growth and developing community capacity can make a practical difference in end of life experiences. Further, community engagement in end of life care can lead to improved outcomes on carer support and wellbeing, community capacity, and social isolation. Increasing the size of caring networks and wider social networks can influence factors such as place of death and involvement of palliative care services. Studies have shown that public health approaches that build social networks provide strong support for people who are dying, their families and carers²⁵.

Initiatives at St Nicholas Hospice Care, such as **Gravetalk** and **Life's Questions** encourage adults and teenagers from all walks of life to think and talk about life, death, society, funerals and loss in an informal environment. Through open discussion, adults and teenagers can feel empowered to support themselves and others when times get tough.



A Gravetalk participant said:
"It has made me completely re-evaluate how I would like to be cared for later in life, so I can now include my family in end of life conversations"

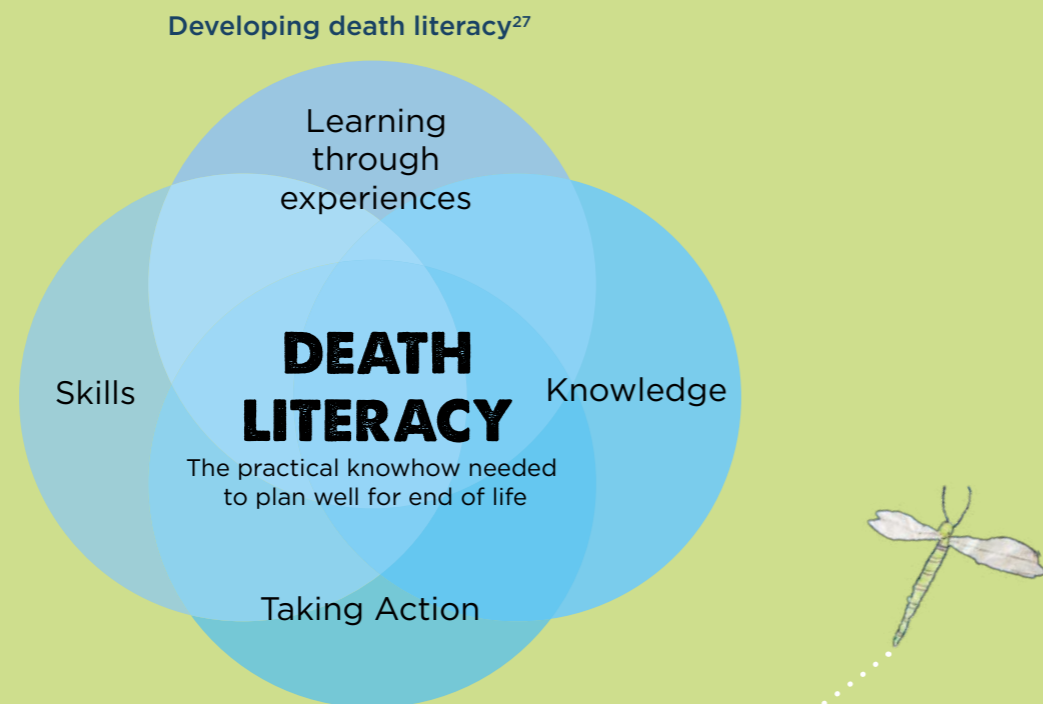
DEATH LITERACY

Death literacy is a relatively new concept in the UK but has been promoted across Australia for five years or more. Death literacy is the practical knowhow needed to plan well for the end of life. Experience of planning end of life care can be gained by participating in a network of people caring for someone who is dying.²⁶

By creating a more death literate society, where communities have the skills and knowledge to plan well for end of life, the focus shifts from 'talking about end of life' to transforming the conversation into one of networks, community, social action and empowerment.²⁷

Specific issues of death education that can help people adjust their health attitudes, behaviours and understanding of illness can be further explored in literature, film, music, art, social media and popular culture.

These sources can provide insights on existential and practical concerns that may arise in the face of life-threatening/limiting illness, caregiving and bereavement. These may include the role of death and dying in the human experience, social legacies, farewells, material preparations and funeral arrangements, life beyond death, spirituality and near-death experiences, loss and grief.



DIVERSITY, FAITH AND END OF LIFE

Every individual will have a view of what a 'good' death means to them. Recognising and meeting this aim should be the goal of all providers of palliative and end of life care.

There is growing evidence that ethnic and cultural differences can influence patterns of advanced disease, illness experience, healthcare seeking behaviour, and the use of healthcare services, including those for end of life care²⁸.

The approach of death can bring with it fears, anxieties and upsetting feelings about the possibility of suffering and being in pain; dying and death can be powerful sources of emotional turmoil, social isolation and spiritual or existential distress⁴.

Descriptions of 'spiritual suffering', 'pain', or 'distress' experienced by people nearing death refer to the fear of loneliness; the pain of separation from family, friends and community; the loss of identity and consciousness (including the deterioration and destruction of the physical body); existential struggles to understand the meanings of life and death, and to reconcile oneself with the nearness of death²⁹.

Every community has different ways of looking at death, and what a 'good death' means to them. Approaches to end of life must endeavour to be bespoke, and as individual as the person.

Community nursing told this story:



"An elderly person living with family on a Gypsy and Traveller site had a wood burner for heat and a camp bed to lay on. The family provided exceptional care day and night. Community nursing services supported the family until the person died in their preferred place of care".

Spiritual beliefs are an important source of hope and meaning for people facing life-limiting illnesses³⁰. Incorporating spiritual concerns in end of life care can help provide a context in which people can make sense of their lives, explain and cope with their experiences, and find and maintain a sense of hope, inner harmony and peacefulness in the midst of the existential challenges of life²⁹. Spiritual support can assist people approaching death to understand, make sense of, or find meaning in what is happening to them, and identify sources of strength they can draw on⁷.

A national case study ²⁹



“He developed a brain tumour at the age of 30. He was referred to the art therapist at the hospice after an episode of severe depression. His notes recorded that he was a Catholic, but he had angrily declined to see the priest when in hospital. However, one day, a few weeks before his death, he drew a picture of a man struggling to climb the steps of a church whose door was closed with a large key protruding. The art therapist guessed that he was experiencing barriers in his spiritual life and asked him to draw pictures to be able to draw on the resources of his faith. He eventually allowed the priest from the Church which he used to attend to visit him, received Holy Communion each week, and his drawings became more peaceful.”

Healthwatch Suffolk carried out a study of the provision of care in three care homes in Suffolk, focussing on the living environment and how an outstanding care home seeks to know its residents well enough to construct an environment, that meets its resident’s spiritual needs. As part of this study, Healthwatch Suffolk could access the ‘Emergency Planners Faith Card’ summarising religious beliefs and practices, and customs and rituals post-death of the major faiths, for use by health and social care professionals³¹. The Faith Card was originally compiled by Suffolk Inter-Faith Resource (SIFRE), and is now available from the East of England Faiths Agency.

Healthwatch Suffolk case studies found:



“One of the care homes in Suffolk organised a Bible reading group on Fridays and sessions of prayer during the week. Residents of the care home attended services at local churches, often accompanied by their relatives. The care home provides objects linked to the Christian faith such as prayer beads, crosses, and copies of the Bible. Residents can have these objects in their rooms. Another care home created a bereavement information pack to help relatives. It also offered objects that evoked spiritual feelings such as a pottery figure of two hands held in prayer.”

Unmet needs/disparities in access to palliative and end of life care for Black and Minority Ethnic (BAME) groups:

Evidence suggests that there is a lack of referrals to, and lower uptake of, palliative and end of life care compared to white majority groups; a general lack of knowledge of services; lack of knowledge about what hospice care involves; lack of cultural equivalents for words such as hospice; lack of sensitivity to cultural and religious issues; information not available in different languages/formats for those who do not speak English or cannot read²⁸.

There are sometimes assumptions by communities that care is neither available nor accessible; and care providers assume that family will provide care.

Palliative care can conflict with some religions. The idea of an end to life does not agree with some cultures that hold strong beliefs in life after death. In cultures where life is considered sacred and a high value is placed on it, the idea of an end to life, along with end of life care, may be considered taboo. The acceptance of a prognosis of terminal illness might be interpreted as giving up faith in the power of God to cure the person, which might conflict with religious beliefs to the contrary³².

Western values underpinning decisions at the end of life have been discussed in various studies²⁸. The idea of autonomy, and the right to self-determination and control over dying is not a universal value, and it is not shared in all parts of the world.

The concept of advance care planning is not universally accepted and might be seen as an ‘intrusive legal mechanism’ interfering with the family responsibility to care for their loved ones, a violation of one’s sense of identity and family. There could be avoidance of open disclosure due to religious and family values. In some cultures where the person is protected from hearing their diagnosis while the family receives the information, discussing advance care planning might actually harm the person and their family.

What could be done?

Research has emphasised the importance of cultural competency and communication skills training for healthcare professionals. Being sensitive and developing open, two-way conversations with people and families was also encouraged²⁸.

It is recommended that professionals caring for the dying and the bereaved acquire a reasonable, working knowledge of the specific practices and rituals prescribed by various faiths for the end of life but, equally, that they recognise the limits of their knowledge and seek advice and support, where necessary³².

Research has also described ‘best practices’ and initiatives to improve care, but it was not always reported how beneficial these were. Examples of best practice are understandably localised in areas with more ethnic diversity. However, this raises questions about whether minority ethnic groups living in less diverse areas would benefit from good practice shown to be working elsewhere²⁸.

Studies have also warned against assumptions and the use of stereotypes when providing care for different ethnic populations (for example, assuming that everyone from the same group behaves the same way or not being aware of their own values)²⁸.

END OF LIFE CARE FOR ADULTS IN SUFFOLK

Clinical Commissioning Groups (CCGs) are responsible for commissioning person centred end of life care as set out in the NHS Five Year Forward View and Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020⁴. Commissioning of services should encompass good bereavement care and support for children and young people. Individuals should be at the centre of service design and care, support and services¹⁴.

Person Centred Coordinated Care

PERSON CENTRED COORDINATED CARE

"I can plan my care with people who work together to understand me and my carer(s), allow me control and bring together services to achieve the outcomes important to me."

Care planning

My goals/
outcomes

Information

Transitions

Communications

Decision making

East Suffolk and North Essex NHS Foundation Trust (ESNEFT)

Led by ESNEFT, the Ipswich and East Suffolk end of life care strategy (2017 - 2020) has been developed to support patients, families and carers in their final stage of life. The strategy takes a whole system approach and its implementation is overseen by the End of Life Care Programme Board. The key strategy objective is to deliver a 50% reduction over five years in the number of deaths in hospital, and to support patients to die in their preferred place of death or care.

As part of improving end of life experiences in East Suffolk, ESNEFT gave a new look to the family area, visitors' room and garden in their mortuary. This is to provide relatives with a calm and reflective space in which to say goodbye to loved ones.

In ESNEFT :



"A person at the end of life was admitted to a surgical ward with no privacy, which was not an appropriate ward for them, and was stressful for the family. The hospital recognised this, and the patient was moved to a more appropriate ward in the hospital where they died peacefully."

Community nursing

The East Suffolk community nursing end of life care team has a strong focus on changing perceptions of dying at home and enabling that to happen where possible. They believe that links with the voluntary sector, and understanding the family support network, are essential to support families and patients at home. The team are looking beyond physical limitations of the home environment which will enable more patients to be discharged home without delay.

A community nurse told this story:



"A lady who lived in a nursing home was identified as dying and her family wanted her to die in her own home. She was transferred home with equipment and support provided. The community team provided all health care and the family provided all social care. She died at home in the preferred place of care."

Early Intervention Team (EIT) at West Suffolk Hospital Foundation Trust

The EIT works closely with other community services to support people towards the end of their life. The EIT supports individuals whose condition has rapidly declined leaving them requiring urgent assessment, which is particularly important if they have had little previous interaction with community services.

A local story from EIT:



"Social Services referred an individual to EIT for an urgent review of equipment needs. District nurses referred the same person to EIT for possibility of night visits. A home visit was completed by EIT and advised that needs were to be cared for in bed. Equipment was ordered and delivered within four hours. Care could not be increased for a few days, therefore EIT stepped in alongside the hospice to provide this. District nurses reviewed medications and EIT nurses visited during the night to provide additional pain relief. The person died at home in their preferred place of death."

James Paget University Hospital Trust

James Paget Hospital continually strives to provide excellent care to patients and their families as they near the end of their lives. The end of life care operational group meets monthly to look at service developments, and their work feeds into the Trust's end of life care strategic group. A 'plan of care for the last days of life' has been implemented in the hospital along with a new comprehensive palliative and end of life care resource folder, which includes palliative care guidelines and information on a wide range of topics within palliative and end of life care.

Training sessions on palliative and end of life care are regularly offered to all staff, including Sage and Thyme communications skills, communication skills for advance care planning, symptom control, syringe drivers and psychosocial support.

Future work includes establishing a specialist chaplain to work specifically with patients and their families at end of life, along with 'Friends to the end sitting service' to ensure patients in the last days of life are never left alone.

The specialist palliative care team at the hospital supports patients in their own homes and care homes to facilitate preferred place of care. The team provides support where complex symptom management and psychosocial issues are present, working alongside other services within the community.

A specialist nurse at James Paget says:



"A patient's preferred place of care was in his own home which was in a very remote setting. The specialist palliative care team worked alongside the district nurses,

GP and family carers to enable the patient to remain at home according to his wishes. There were many challenges to overcome, including a rota system to support the district nursing team with syringe driver management and regular support visits for the patient and family to minimise their feelings of isolation. The patient was able to spend his last few days at home with his family."

Louise Hamilton Centre

The Louise Hamilton Centre based at the James Paget University Hospital is a supportive and palliative care resource centre for anyone affected by a life limiting or progressive illness. The centre offers a wide range of services including advice

and information, family carer support, bereavement counselling and support groups. It is open seven days a week and is available for drop in or planned appointments and groups.

East of England Ambulance Service Trust

Just over a year ago the East of England Ambulance Service Trust (EEAST) adopted a three-year strategy to improve the care and experience for people who are at the end of their life and use the service.

Their strategy:

As an ambulance service we have a role to play in delivering high quality care at the end of life. We have a responsibility to ensure that patients receive a timely response and appropriate emergency care or transport. We must also ensure we are able to support patient choice regarding end of life care, including resuscitation decisions and place of death.

A local story from EIT about the ambulance service:



"A person had been unwell, and their family called an ambulance. The person wished to die at home and declined an admission to

hospital. Paramedics called the hospice for urgent review and asked the GP to go out to review and sign DNACPR (Do Not Attempt CPR) and review medications. The person died at home in their preferred place of death."

St Elizabeth Hospice

St Elizabeth Hospice in Ipswich is an independent healthcare provider and registered charity providing palliative care specialist services, support and training by a multidisciplinary team. There is an inpatient unit, day services, outpatients and community teams. The hospice provides a rehabilitative model to palliative care, providing weekly exercise groups and educational classes to patients and carers. The hospice is constantly developing to meet the needs of people in the local community and works in partnership with ESNEFT. Patients can benefit from talking therapies, and creative therapies such as art and music.

One person said:



"Talking honestly about how I felt had a huge effect on how I could cope. I cannot thank my therapist enough for their help and the effect this has had on improving my life."

St Elizabeth Hospice has recently launched its 'No Place Like Home' campaign aimed at helping people to die in their preferred place of death at end of life. The hospice wants to make sure patients are cared for by the right person at the right time.

St Elizabeth Hospice's Chief Executive says:



"Too many people who don't want to or need to die in hospital in Suffolk currently do. We are determined to help improve this situation."

St Nicholas Hospice Care

St Nicholas Hospice Care in Bury St Edmunds has actively moved services out of the building, to work in and with the community. The Hospice is currently responding to the increasing needs of the wider community by listening to people living with experiences of caring, dying, death and loss to inform the design of new sustainable ways of working. This challenges the myth that 'hospice' means a place or building where people 'go to die'.

The hospice manager said:



"We wanted to hear what was important to people rather than rely on what we think is important for them. In 2017 we began a service design initiative

called Listen, Learn, Adapt. Amongst many themes, we found that people wanted to help themselves through palliative care and end of life experiences, and they wanted information and support to do that."

During the listening exercise, one bereaved relative told the hospice:



"The healthcare professionals do not tell you what is coming down the line... We found that things that should have been made available were not."

Bereavement

Suffolk Family Carers provide information on bereavement services and support. Recognised challenges for bereaved carers in Suffolk after a patient has died include; isolation, loneliness, coming to terms with death and starting a new life.

St Nicholas Hospice Care, Stepping Forward is a walking group open to all who are bereaved. The group meet once a month, and for an hour walk and talk with other bereaved people and trained bereavement volunteers. This organised activity helps those people who have lost a loved one to meet others socially, and develop their confidence in picking up the threads of life again.



St Nicholas Hospice Care's most recent development is the **Bereavement Café**. People value the cafes for 'meeting others in the same situation', and for the 'understanding and empathy' they have encountered there.

Someone at the café said:



"You find that you can teach each other certain things, help each other, and you are able to get to know each other."

Open House drop-in sessions organised by St Nicholas Hospice Care offer the chance to meet others facing similar situations in a comfortable and relaxing space across West Suffolk.

Someone attending Open House said:



"I come to Open House, so I can meet people in the same situation as myself. When my wife died I became a recluse. I didn't want to leave the house and I couldn't seem to find the help I needed. I found it difficult to know who to get in touch with, but because Open House is local it has been easier."

Suffolk Cruse Bereavement Care provides information and support to anyone bereaved by death and is made up of four branches: Suffolk Coastal, Ipswich, North Suffolk and Great Yarmouth, and West Suffolk. Their volunteers have all been through the Cruse accredited training, are supervised, and undergo continuing development training.

One Cruse client said:



"I felt I was going mad until the volunteer showed me that everything I was feeling was normal."

St Elizabeth Hospice Emotional Wellbeing Support Enquiry Line answers general enquiries to support bereaved families. A new model of bereavement support is being developed, which includes information events, open and closed groups and one to one support to those recently bereaved.

END OF LIFE CARE FOR INFANTS, CHILDREN AND YOUNG PEOPLE IN SUFFOLK

When a person dies at an older age, there is often a level of acceptance that the individual has reached the end of their natural life. The death of an infant, child or young person is generally unexpected and difficult.

For children and young people, end of life care begins when a life-limiting condition is diagnosed (potentially before birth) and continues even if a child is having treatment for the underlying condition³³. In the event of the death of a child or young person, care extends to include the immediate bereavement support of their family. Young people may continue to have end of life care after they reach 18 years, and it may remain part of the transition to adult care.

Children, young people and their parents, families or carers may have varied and differing ideas about what represents good end of life care. They may also have differences of opinion with each other, including what is a priority for them, and their priorities may change over time. It is therefore even more vital that parents, siblings and carers have the support they need to address questions they may have.

Talking to the child about their death is of course a personal choice (and will be related to their age and level of understanding of their own health). However, being open and honest and having conversations can help families in calming fears and addressing questions the child may have³⁴.

Infants, children and young people's services in Suffolk

In Suffolk, paediatric end of life care combines a broad range of health and other care services, including hospitals, hospices, primary care and community professionals, ambulance services, dedicated palliative care teams, and other support providers. Because of this, good communication, care coordination and effective networking, are essential to providing good end of life care.

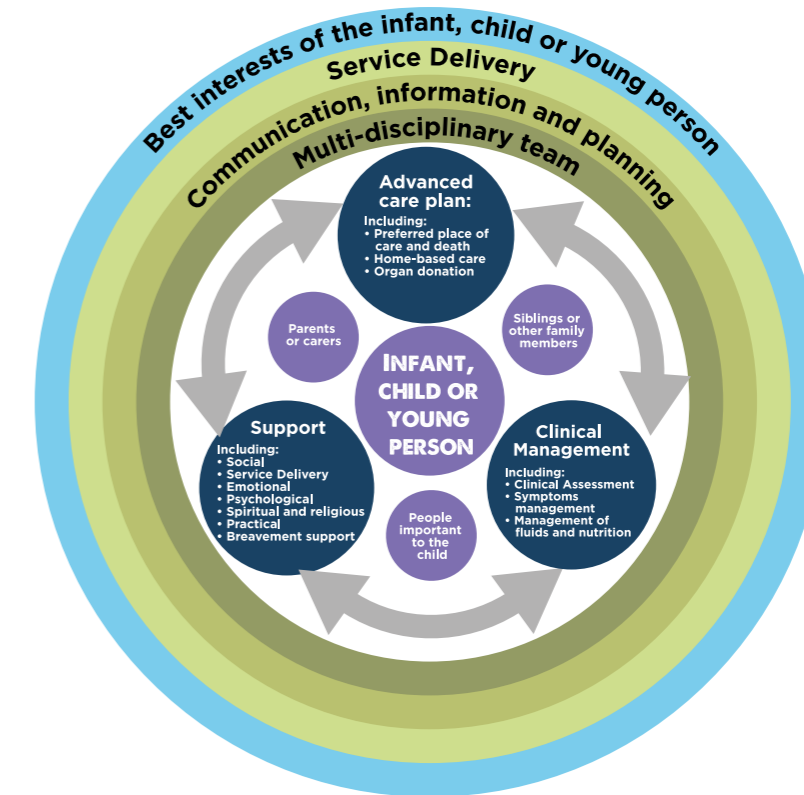
Suffolk Children's Palliative Care Forum (for East and West Suffolk) aims to improve the support for children with life limiting conditions and their parents through multi-agency effort. They provide services in line with National Institute for Health and Care Excellence (NICE) recommendations⁶.



Supportive framework developed by NICE guideline committee to represent the longitudinal nature of delivering end of life care for children.

LIVING WELL WITH A LIFE-LIMITING CONDITION

KEY MOMENTS OF CARE: Recognition of a life-limiting condition End of Life Bereavement



KEY LIFE TRANSITIONS: Birth Birthdays Social Transitions

Hospitals provide a medical palliative care service to local young people. This is mainly within paediatric cancer but also includes advice in the care of children with a non-cancer diagnosis and palliative care needs. These services are generally available 24 hours, seven days a week in varying forms.

Community Children's Nursing Team (CCNT) works across Ipswich and Bury St Edmunds

and supports families with children aged 0-19 years in the community setting who have complex and/or palliative care needs. This includes the delivery of complex nursing care, training, respite and supporting those who are dependent on technology. They offer a 24/7 service with visits where necessary, to deliver nursing care and symptom control during the end stages of life.

East Anglian Children's Hospice (EACH) offers a family centred, needs-led approach to care, ensuring all needs of a child are met – whether psychological, physical, emotional, social or spiritual. This service is provided across Cambridgeshire, Norfolk and Suffolk. The Tree House in Ipswich has five bedrooms for children and young people and accommodation for families to use for overnight stays³⁵.

St Elizabeth Hospice supports young adult care and transition using The Stepping Up Framework from Together for Short Lives³⁶ and NICE guidelines for transition^{37,38}. This provides recognised UK standards for transition of young adults with palliative care needs. Their services include: open events with children's and adult services to facilitate transitions, a monthly young adult group to offer professional and peer support, advice, discussion and information, clinical review every six months, complementary therapy, counselling, physiotherapy and day care facilities.

Support for bereaved children and young people

Children and young people can find it difficult to express their feelings about the loss of someone close to them, especially a parent or care giver.

St Elizabeth Hospice 'Dying to Talk' is a project running a series of training sessions to local high schools to upskill and respond to young peoples' grief earlier. After the training, each school can refer young people to attend bi-monthly **'Death Cafes'**. The aim of

the Death Café is to provide a safe and welcoming space for young people to talk about their experiences.

A children's specialist counsellor says:



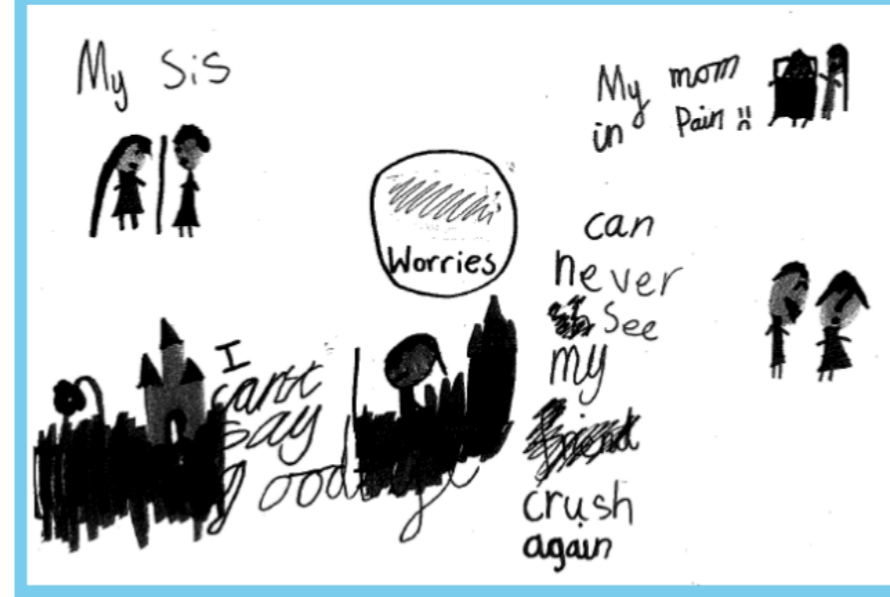
"Supporting young people in the earlier stages before someone dies can prevent crisis care and reduce future problems. We want to encourage preventative intervention rather than reactive."

Bereavement services at St Elizabeth Hospice also offer families of hospice patients access to counselling for children and young people aged from five-18. Bereavement packs on how to talk to children are available to support families. In addition to this they provide art and music therapy to support young people who have been bereaved.

Nicky's Way at St Nicholas Hospice Care

runs an open access service in West Suffolk for bereaved children, and young people grieving the death of a parent, carer or another significant person. This includes a group-based programme which runs twice yearly and casework with children and families. The service uses the 'Grief Recovery Method', an action-based education programme to help children and parents move beyond loss; empowering them with tools they can use to build resilience and dispelling myths about death and dying.

St Elizabeth Hospice, children's art therapy



Session 2 of work with an 8 year old. The image was completed as part of work on worries.

A parent said:



"Nicky's Way understands that children move through their journey of grief in many different ways, every child being unique in their own personal journey. It has enabled my daughter to move forward and move away from the problems she was having."

Individual work takes place in schools, in partnership with teaching and support staff. Therapeutic work is undertaken by a child art psychotherapist. A quarterly child bereavement forum offers more support.

Suffolk Cruse Bereavement Care can also offer support to children and young people.

One parent said:



"I wish to thank Cruse from the bottom of my heart for all the help given to my child after the tragic loss of her Dad. To say it saved us is to underestimate just how important the support has been."

Together for Short Lives Together for Families Helpline

– this national helpline is used by people locally and provides information and support for families with a child with a life-threatening illness and parents who are finding it hard to cope. It also provides information and support for carers and professionals who look after a child with a life-threatening illness³⁶.

Organ and tissue donation

Most people are in favour of organ and tissue donation, but unaware that they may still be able to donate something, even if dying of cancer or other illnesses.

Many people can donate their corneas, and a few can also donate other tissues, including bone, heart valves, tendons, and skin.

Organ donation is generally only an option for a minority of people, dying in intensive care units; where breathing and circulation is supported by a ventilator.

Local research with Suffolk individuals has shown that people prefer to be given the option to decide about organ and tissue donation for themselves, and do not find it distressing to be given this information.

St Nicholas Hospice Care has been recognised as an exemplar in cornea donation and was a British Medical Journal Awards finalist in 2017, where their good work in this area was recognised³⁹. Feedback indicates that everyone was either glad to be informed of cornea donation or had no strong feelings either way. No one said that they did not like talking about it at all.

One patient's son said:



"It's wonderful to think that someone out there is seeing the world through Dad's eyes."

Recommendations

1 *Talking about end of life and death should not be taboo. It is vital that residents in Suffolk feel comfortable talking about their wishes, requests, beliefs and plans, with professionals, and their families and friends.*

2 *Advance care planning and the 'Yellow folder - My Care Wishes' should be consistently completed by professionals and patients collectively having conversations. Ongoing training and development for this needs consideration.*

3 *Suffolk should embrace the public health approach and encourage compassionate communities that actively involve citizens in their own holistic end of life care, and a population health approach to palliative care which goes beyond health and social care services.*

4 *Suffolk should become a more death literate society, where people and communities have the skills, knowledge, learning and action needed to plan well and be prepared for the end of life.*

5 *Professionals caring for the dying and bereaved should be aware of practices and rituals prescribed by different groups, faiths and beliefs for the end of life but, equally, recognise the limits of their knowledge and seek advice and support where necessary.*

6 *People in Suffolk should make sure that their family and friends know about their organ and tissue donation decisions.*



FEEDBACK AND UPDATE FROM LAST YEAR'S REPORT

Suffolk's 2017 Public Health Report '*Working for Wellbeing*' won third place in the national Association of Directors of Public Health Annual Report Competition. The report was commended for its readability, accessibility and relevance.

The report focused on inclusive growth and the links between health and work. Inclusive growth can help people fulfil their potential and improve their quality of life. The report recognises the importance of local businesses and education institutions, which create opportunities for local residents to live, work and thrive, and make it easier to spend Suffolk money in Suffolk, thereby multiplying the local economic benefits of that spending.

It also recognised that the personal and fiscal costs of poverty are huge, and, with more lone parent and working families struggling, the negative impacts of failing to spread the benefits of economic growth may become entrenched and persistent.

Inclusive growth and high-quality work are vital for health and wellbeing but cannot be delivered by any single organisation – effective partnership understanding and working is key. Inclusive growth is one of three key priorities for Suffolk County Council over the next four years.

The main report was accompanied by an action plan and the final version was adopted by the Health and Wellbeing Board on 17 May 2018. The action plan built on system plans and priorities, and provides a framework for concerted action across the Suffolk system.

In 2017 the Suffolk Chamber of Commerce received the Annual Public Health Report grant. The grant helped to support and encourage local businesses to improve health and wellbeing. www.suffolkchamber.co.uk/initiatives/improving-workplace-health/

You can view the full report, the action plan and a video that asks Suffolk residents about their experiences of living and working in Suffolk, on the Healthy Suffolk website: www.healthysuffolk.org.uk/jsna/reports/annual-public-health-report

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