



Strategic Plan

2019 – 2024

"Outstanding Palliative Care"

St Cuthbert's Hospice





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Introduction

I am delighted to introduce our new Strategic Plan and to commend it to you.

The Plan does not anticipate any fundamental change in direction. However, it is now much more focussed on describing the people we serve and the difference we want to make in their lives.

At the heart of this Plan is the notion of a good death. This notion will mean different things to different people. Everyone is different and each person will need to determine what is appropriate for them and their family.

However, research evidence consistently demonstrates that most people expect that a good death will be made up of three elements: good pain control, feeling at peace and "ready to go", and the reassurance that the ones they love will be taken care of.

We believe that we can help more people experience a good death if we can encourage the general public to be more open to talking about care-giving, death, dying, grief and loss. We are already doing ground-breaking work in this area, and we want to do more.

We know that we can make a more significant impact if we can support

people from the time of their diagnosis with a life-limiting illness. We want to be in touch with the patients we support earlier in their journey through illness.

We want to do more to support the people who care for people with a life-limiting illness. We know this will benefit not only the carers themselves, but also the person they are caring for.

We want to provide excellent care at the very end of life for those who chose to die in the Hospice and to do what we can to support a good death for those who choose to die at home. We want to reduce the number of people who die in hospital when they have stated that they would prefer to die at home or in a hospice.

And we want to support those who are bereaved as a consequence of a life-limiting illness. Again, this will help them to adjust to life without



their loved-one but also assist with the experience of a good death for people, knowing that their loved ones will be supported through their bereavement.

Finally, we want to ensure that the best palliative care is available to everyone, including those who often feel excluded from services.

To achieve all of this, we know that we cannot manage on our own. We will need the continuing support of our local community who, through their volunteering and their financial support, help us to do so much more than we otherwise could. We will also need to work in partnership with the many groups and organisations that share our vision and want to make Durham a great place to live, right until the day you die.

Angela Lamb,
Chairman





Mission, Vision and Values

Our mission:

To make every day count for those affected by life-limiting illnesses.

Our vision:

To be a centre of excellence within our community and to provide all-embracing, compassionate and individualised care to all those affected by life-limiting illnesses, at a time and a place that is right for them.

Our values:



Our philosophy of care

At the heart of St Cuthbert's Hospice is the individual who is seen as a unique person deserving of respect and dignity. Our aim is to support each person and their family and friends, helping them to make informed choices and decisions affecting their lives.

Individual care is planned to support the total well-being of each person, taking into account their physical, psychological, social and spiritual needs.

We will work together to provide a warm and welcoming atmosphere that accommodates diverse cultures and lifestyles within a calm and compassionate environment. As a team, we will strive to provide care of the highest standard by ensuring staff are up to date with current research and training.

We are aware of the valuable work undertaken by individuals and agencies in the community and we will work in partnership with them

to provide excellent services for the people of Durham.

We see life – and death – as a journey to be made in the company of others. We are rooted in our local community and we approach life and death through a philosophy based on support and hospitality.

Strategic Goals

For people at end of life

Strategic Goal 1:

- To enable people at the very end of life to achieve a good death in the place of their choosing

Aims

- Improve availability of and access to end of life care at the Hospice
- Continually improve our understanding of how the management of complex symptoms and pain contributes to a sense of peace
- Share our specialist knowledge and skills with the wider community

We only have one chance to get care at the very end of life right.

As far as possible we want to ensure that we meet an individual's preference for where they want to die. We know that around 30% of people who state a preference would choose to die in a Hospice. In County Durham, around 5,300 people die every year from all causes (around 2/3 of these are aged over 75) and about 3% die in a hospice.

Wherever the actual place of death, people want a "good death". A number of research studies enable us to describe a good death with some certainty. It means that the person:

- Is able to make decisions about what is best for them

- Can be free of pain
- Is "at peace"

According to the Office of National Statistics the North East has the highest mortality rate in the country. In the North East, the mortality rate is 1098.9 per 100,000 population. This compares to London, which has the lowest mortality rate at 858.8 (these are based on 2016 figures). County Durham is 33rd out of 348 local authorities, with a mortality rate of 1118.5.

According to the same statistics, the percentage of people dying in a Hospice in County Durham was 4.7%. While this is higher than the regional average (3.8%) it is lower than the national average (5.7%).

There were 5,651 deaths in County Durham in 2016.

Achieving the preferred place of death is a challenge. According to the national Voices Survey, 8.2% of people would prefer to die in a Hospice. This suggests that, in County Durham, there are just under 200 people per year who would like to die in a Hospice but do not achieve this.

However, an important study from 1994 has suggested that that 100% of patients and carers expressed a preference for home care early on in their disease trajectory. However, as death approached, this fell steadily to 54% of patients and 45% of relatives.

Achieving a good death is a challenge. A good death is usually characterised as one in which key symptoms (especially pain) are controlled, the person is "at peace", their loved ones are supported, and they have a good measure of involvement in decisions about their care and treatment. Again the Voices survey suggests that 75% of people would rate the care their loved one received as outstanding, excellent or good. This means that 25% would rate it as fair or poor, with 10% rating it as poor.

The problems are well articulated in the NICE Guideline (NG31) on Care of Dying Adults in the Last Days of Life (first published 2015, updated 2017).

The root causes are:

- The inadequate availability of Hospice care
- Poor access to Hospice care
- Avoidable admissions to/delayed discharges from Hospital

If we achieve our aims, we expect to contribute to an increase in the percentage of people in County Durham who die in their preferred place of death and, for those we care for in the Hospice, to ensure that more than 90% achieve a good death.



"I didn't know what to think when the hospital recommended I come to St Cuthbert's, if I'm honest I thought the worst and was quite reluctant to come. I thought a Hospice was a place to die. Now I am here I can appreciate the level of care and how different it is."

- a patient at St Cuthbert's





For people with life-limiting illnesses

Strategic Goal 2:

- To enable people living with a life-limiting illness who use Hospice services to live well and make every day count

Aims

- Develop a culture of rehabilitative care across the Hospice
- Engage more volunteers in the delivery of palliative care
- Initiate new programmes to support people to live well with life-limiting conditions

The Hospice offers palliative care to those for whom no cure is available for their illness. Some people only live for a very short time with life-limiting illnesses, while others may live for many years.

The Hospice's aim is to help people with life-limiting illness make every day count, recognising that where it is not possible to add days to life, it is still possible to add life to days.

The needs of people with life-limiting illnesses are many and varied—they include; symptom control, learning new ways of coping with everyday activities, information about choices and services available to them, social, psychological, spiritual and emotional support, an opportunity to make preparations for their death.

It is generally recognised, that wherever possible, people with life-limiting illnesses should be able to be looked after in their preferred place of care.

The Government estimates that at any one time, on average, 1% of the population will be on the palliative care register (PCR) – i.e. a doctor or clinician would not be surprised if the person were to die in the next 12 months. In Durham Dales, Easington and Sedgfield Clinical Commissioning Group (DDES CCG), just under 0.8% of the population are on the PCR. In North Durham that figure is just under 0.7%. In total, there are 4,078 people on the PCR across County Durham, compared to the expected figure of around 5,221.

However, there are other people who have a life-limiting illness for whom there is no curative treatment but who would have a life expectancy beyond 12 months. A palliative care approach with this population will be the choice of some.

An average of 366 people per year will die prematurely in County Durham as a result of lung, breast, bowel, or prostate cancer. Cardiovascular disease, respiratory disease and liver disease remain significant causes of premature mortality in the County. These disease are all above the England average.

Estimates suggest that in 2011, over 6,600 people in the County who are over 65 are living with dementia. Projections suggest the figure will be double this in 2020.

Being faced with bad news is significant and disturbing experience creating stress and anxiety. This includes having to go on to break the news to family and friends.

There is difficult decision-making to be made about the types of treatment that may be available and their impacts. Different people react differently to whether they want to be involved in advanced care planning decisions. Treatments are sometimes distressing and can increase social isolation and reduce self-esteem. This often leads to a sense of loss.

The transition to palliative care can be difficult because, particularly in non-malignant conditions, the prognosis can be difficult to be definite about. This is often

compounded by an individual having more than one illness or condition.

The symptoms associated with the illness can be very debilitating and frightening. Common symptoms include dyspnoea (shortage of breath), pain, nausea, loss of appetite, constipation and low mood.

Even for those who prefer to be cared for at home, admissions for symptom control or for rehabilitation and resilience building are an important part of responding to the problems they face.

If we achieve our aims we expect to see a significant increase in the number of people who experience an improvement in their symptoms, experience an improvement in their quality of life and establish an Advanced Care Plan. We expect to be able to describe a baseline (how many people currently experience an improvement in their symptom load and an improvement in their quality of life) and also an improvement target in the first year of this plan.



For the carers of people with life-limiting illnesses

Strategic Goal 3:

- To provide the information and support that carers of people with life-limiting illnesses need to provide the care they want to provide

Aims:

- Implement a new carer strategy
- Forge new partnerships with carer support organisations
- Develop access to professional advice and support for carers

From its inception, the Hospice movement has been as much about caring for the family as it has been about caring for patients.

Research in 2013 identified the following 5 needs common to most carers of people with life-limiting illnesses:

- Recognition that carers have their own needs
- Respect for the fact that they are expert partners in care
- Support in every setting
- To be acknowledged into bereavement
- Caring shouldn't be a fight

Census results for 2011 show that there are approximately 59,000 adult carers living in County Durham, of which nearly 17,000 are providing 50hrs or more care a week.

There are 1,659 young carers aged between 5-17 years of age living in County Durham. There has been a 7.2% increase between 2001 and 2011 in the number of carers aged under 15 providing between 20 and 49 hours a week of unpaid care.

As at 31 March 2016 there were 13,339 carers registered with Durham County Carers Support, which is a 9% increase on the number registered as at 30 June 2015 (12,210).

Carers need support because:

- People are often suddenly in the role of carer without preparation or training
- Carers often feel side-lined by professionals
- Caring is not valued or appreciated

A Joseph Rowntree report, 'Characteristics of care providers and care receivers over time,' found:

- There were geographic variations in the proportion of the England and Wales population providing unpaid care for 20 hours or more per week in 2001. The likelihood of caregiving was highest in Wales and the North of England and lowest in the South East of England.
- Caregiving was associated with disadvantage. The proportion of the population providing unpaid care was higher in deprived areas and areas with higher levels of poor health. Carers were also relatively disadvantaged and more likely than others of the

same age to be in poor health themselves.

- Those from Bangladeshi and Pakistani ethnic groups were more likely to provide care than those from other ethnic groups, once age profile and gender were taken into account.
- Caregivers were less likely than others of the same age to be employed. Among those who were employed, women working in the public sector were more likely than those in the private sector to be carers. Women who had worked in a caring profession were more likely to become unpaid carers.
- Some 9 per cent of women and 4 per cent of men aged 65 and

over and living in the community in 1991 were in institutional care by 2001. These proportions were slightly lower than the equivalent between 1981 and 1991.

Characteristics associated with increased chances of moving into institutional care included older age, being unmarried, poorer health, being a tenant rather than an owner occupier and, among women, having no children.

If we achieve our aims, we expect to see more carers of people with life-limiting illnesses with improved well-being, improved support and improved resources.





For people who are bereaved following a life-limiting illness

Strategic Goal 4:

To support those who have been bereaved as a consequence of a life-limiting illness to adjust to life without their loved one

Aims:

- Actively promote pathways through bereavement
- Facilitate the development of peer support
- Promote the concept of compassionate communities

Many bereaved people need support to facilitate grieving and prevent some of the detrimental consequences of bereavement that can occur.

Bereaved people need to:

- Face the emotional consequences of loss with acceptance
- Achieve a revised sense of what can be changed/controlled
- Reach a sense of equilibrium, usually as a result of having good support, and acquiring a sense of meaning

People closely affected by a death may include other hospice patients and guests, staff and volunteers, staff from a variety of health and social care organisations, as well as family members and carers, including children. Children may need particular tailored support.

Bereavement support may not be limited to immediately after death, but may be required on a longer-term basis and, in some cases, may begin before death.

Needs include:

- Need for information e.g. registering a death, arranging a funeral
- Practical support – e.g. arranging a funeral, managing money, clearing a house
- General emotional and bereavement support
- More specialist support from trained bereavement counsellors

Bereavement often leads to:

- Forgetfulness-- missed appointments, keys locked in the car, purses left behind, work reports left at home, etc.



“We had reached a low. With your incredible care you turned us around. We can't thank you enough.”

- a patient's family

- Disorganisation – it takes longer to finish tasks. Time may not be managed as well.
- Inability to concentrate and retain information – it may be impossible to stay focused on a task. It may be difficult to read a book or even stick with a favourite TV programme.
- Preoccupation with the loss – this is a time when one's mind wanders and it is hard to stay on a task. Unplanned thoughts of the loss may enter the bereaved person's head at any time or at any place.
- Lack of interest or motivation – things just don't matter as much

now. It is difficult to be interested in anything. Life has taken on a temporarily different meaning.

- Lowered tolerance level – patience may not be what it used to be leading to minor irritations becoming bigger and more quarrelling with family, people at work or with friends.
- Chronic fatigue – grief is exhausting and in addition there may be difficulty sleeping, eating or exercising.

Research estimating aspects of the socioeconomic costs of bereavement in Scotland using 3 sets of data found that spousal bereavement was associated with increased mortality

and longer hospital stays, with additional annual costs of around £20 million. Cost of bereavement coded consultations in primary care was estimated at around £2.0 million annually. In addition, bereaved people were significantly less likely to be employed in the year of and 2 years after bereavement than non-bereaved matched controls.

If we achieve our aims we expect to see more bereaved people experience an improvement in their quality of life and feel more positive about the future.

For the general public

Strategic Goal 5:

- To break down the taboos associated with dying, death, loss and grief.

Aims

- Encourage more people to have "everything in place"
- Open new channels for conversations about dying, death, loss and grief, particularly with minority and under-represented groups
- Promote the value of palliative care

The general public need to be able to support their family, friends, neighbours and colleagues who are experiencing death, dying, grief or loss.

knowledge about how to request and access services, and a lack of awareness and openness between close family members when a person is dying.

They also need to be able to understand the options that are available to them if they were to be diagnosed with a life-limiting illness to make preparations for the end of life, whenever and however that might occur.

Some of the causes of the problem are:

- Deep seated fears – that talking about death can hasten death
- Death now a less public and more private event
- Focus on death as a medical event rather than as a social event

The population of County Durham is approximately 500,000. Everyone is likely to be affected by death, dying, grief and loss.

Consequences of the problem can include unresolved grief (leading to further complications) and lack of ability to make informed choices about good end of life care.

The End of Life Care Strategy for England notes that there appears to be a lack of public openness about death. This assumed lack of awareness and failure to discuss death as part of normal life may have a number of consequences, including fear of the process of dying, lack of

If we achieve our aims, we expect to see a greater awareness of, and willingness to talk about, death, dying, grief and loss, with more people making plans for the end of their life.



“Encourage more people to have everything in place”

Impact

If we achieve our aims, and reach our goals, the impact will be that more people will achieve a good death.

People at the end of life will achieve a good death because:

- They receive the end of life care they need and have the opportunity to die in their preferred place of death.
- During the time they are ill, they receive the palliative care they need and make the preparations they want for a good death.

- They know their carers are being supported and that carers are able to provide the care they want to.
- They know that the people they love will be cared for and supported after their death.
- Their neighbours, work colleagues, friends and family members are better able to support them during their illness and as they move towards the end of life.

This impact has consequences for:

- The health of carers and bereaved people
- The sense of community in County Durham, reducing social isolation
- The NHS, reducing the number of inappropriate admissions to hospital
- The economic well-being of the County, reducing days lost from work through stress and bereavement



Enablers

There are some key enablers which need to be in place if we are to achieve this impact.

These are:

- People (staff and volunteers) who share our values and are committed to the mission and vision of the Hospice
- Funding to enable us to increase our activity and thus our impact
- Governance to ensure that the Hospice remains accountable for the delivery of this Plan
- Technology to enable us to become more efficient and effective
- Community engagement so that our neighbourhoods become more aware of our role and how we can help
- Partnerships without which we cannot deliver this Plan
- Learning culture which helps us to innovate and to increase the impact of everything we do

Making it happen

All of the activity that will contribute towards the achievement of our goals will be subject to separate business planning exercises before implementation. We work to a planning cycle that ensures every member of staff and volunteer can see how what they do contributes to the achievement of this Strategic Plan.

Planning level	Who is responsible	Timescale
Vision and values	Trustees	Long-term
Strategic Plan	Trustees and Senior Management Team	5 years (rolling)
Operational Plan	Senior Management Team and Manager	3 years (rolling)
Annual Plan	Managers and Teams	1 year
Individual Objectives	Managers/Individual Staff and Volunteers	1 year

The Hospice's performance management processes are all focussed on enabling us to maximise the impact of our work.





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St Cuthbert's Hospice



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