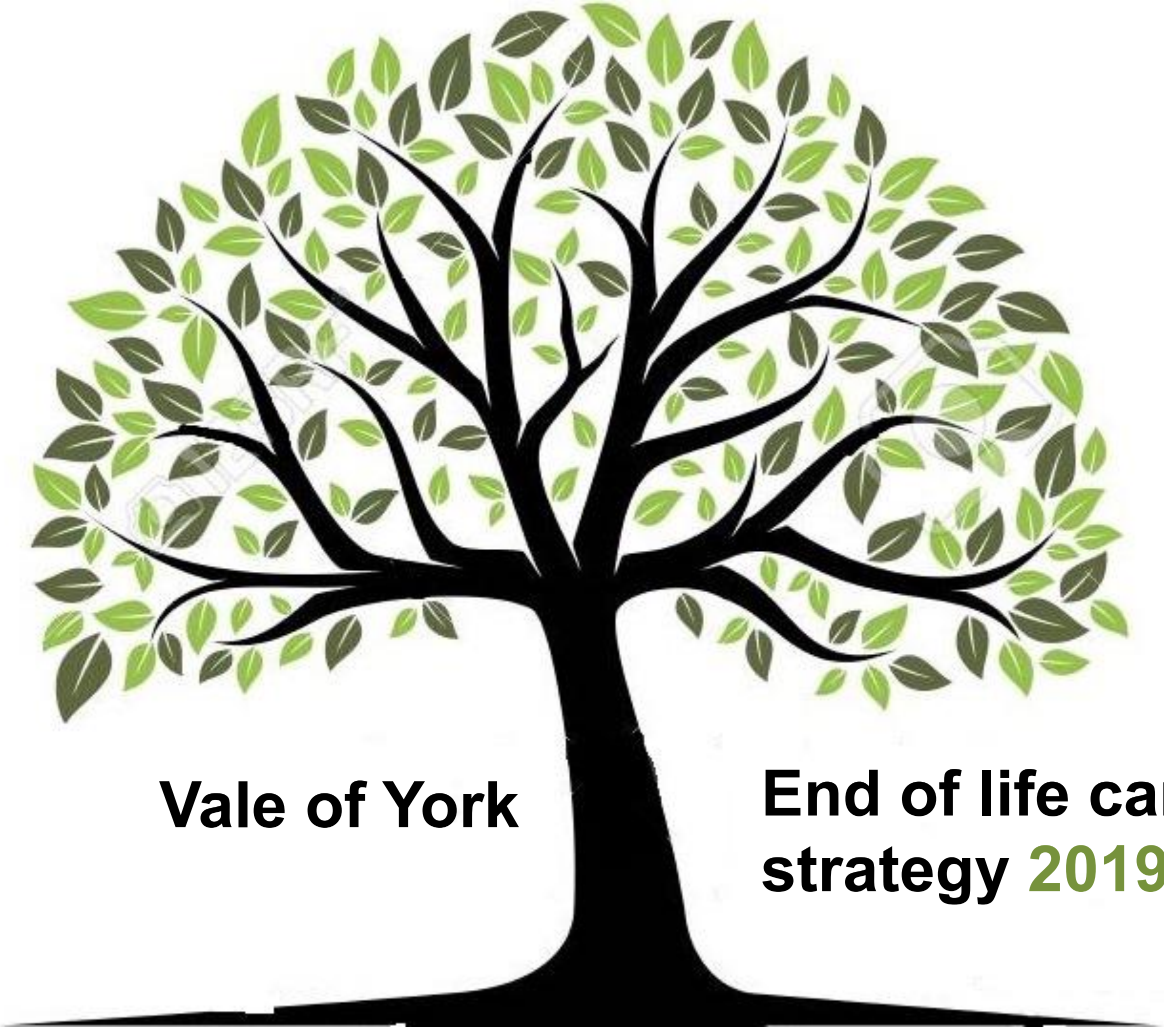

Vale of York

End of life care strategy 2019-24

Contents

Background

Dying is a process that affects everyone. Not only do we have to face our own mortality, but the majority of us will also be involved in supporting at least one friend, family member or service user at the end of their own life, and face bereavement after their death. We will all therefore experience end of life care in some form and appreciate the lasting impact that good (or poor) care can have. This strategy sets out the local health and care system's approach to making sure that our population across the Vale of York receives the best possible end of life care in the manner that is most appropriate for each individual.

In developing the strategy, we wanted to have a real understanding of what matters to our patients, our local communities, our staff and our partners. We developed a range of engagement and involvement opportunities to gather views and the information we received was rich in personal experience. This has helped shaped the framework for the strategy and could not have been achieved without the honest and open conversations held with our community.

What is end of life care?

People are 'approaching end of life' when they are likely to die within the next 12 months (General Medical Council).[i] This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions and are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events[1]

End of life care in the UK

End of life care in the UK has improved since the first national strategy was published in 2008. However, the latest *National Survey of Bereaved People (VOICES)* has highlighted that although the majority of carers felt the overall quality of end of life care provided

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[i] For more information on the differences between palliative and end of life care, see Marie Curie information page https://www.mariecurie.org.uk/help/support/diagnosed/recent-diagnosis/palliative-care-end-of-life-care

was good or better there were some areas still in need of improvement, such as getting hospital, GP and community services to work better together.[2]

The current national guidance for end of life care is set out in *Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*, which structures future improvements to end of life care provision around six key ‘ambitions’. The guidance emphasises the importance of locally-driven actions based on a person-centred approach and provides the underlying framework for the Vale of York strategy.

The NHS Long Term Plan identifies the development of personalised care planning (including personal health budgets) as a priority for end of life care. It also recognises the importance of children’s palliative and end of life care, with an increase in NHS funding expected over the next five years for areas who commit to increase their investment in local children’s palliative and end of life care services.[3] The development of new local and regional bodies such as Primary Care Networks and Integrated Care Systems also provide an opportunity to fully integrate end of life care into the emerging health and social care systems.[ii] Integration will mean that the care for patients and their families is delivered holistically and in a more person-centred, co-ordinated way, to deliver outcomes and services that meet their needs.

Not all people have equal access to care at the end of life. The 2016 Care Quality Commission report *A different ending: addressing inequalities in end of life care* identified people at risk of receiving poorer quality end of life care. These included people with conditions other than cancer; older people (including those with dementia); people from black and minority ethnic groups; lesbian, gay, bisexual and transgender people; people with a learning disability or mental health condition; people who are homeless; people who are in secure or detained settings; gypsies and travellers.[4] Issues such as the availability of local services for those living in urban versus rural populations also create inequalities in accessing care. These must be addressed in order to provide end of life care that is equitable for the entire Vale of York population.

A summary of key national guidance and resources for end of life care is provided in the *Atlas of variation for palliative and end of life care in England*.[5] There are additional resources available that focus on palliative and end of life care for children (including Together for short lives resources[6] and NICE guideline NG61[7]) and groups at risk of inequalities in care (Gypsies and Travellers, LGBT+ community and people and people experiencing homelessness)[8].

[ii] Please see the following for more information on Primary Care Networks (https://www.england.nhs.uk/gp/gpfv/redesign/primary-care-networks/) and Integrated Care Systems (https://www.england.nhs.uk/integratedcare/integrated-care-systems/).

End of life care in Vale of York

Around one per cent of the UK population will die each year. In Vale of York (population 357,000) this is around 3600 people.[iii] Currently 48% of deaths across Vale of York occur in people's usual place of residence.[9] Overall trends in recent years have seen a decline in the proportion of deaths in hospital, with an increasing proportion dying at home or in care homes.[10]

The Vale of York population is forecast to rise by 7.6% to 388,500 by 2040, which will increase the number of expected deaths per year by around 300 people. In addition, the proportion of people across both York and North Yorkshire local authorities over the age of 75 is expected to increase; people are likely to be more elderly when they die, and are therefore more likely to have multiple long term conditions and be in need of greater care and support at the end of life. This demographic change is also likely to affect where people die; based on current trends, care homes will become the most common place of death in the UK by 2040.[11] Infrastructure supporting end of life care in care homes and the community will therefore need to increase to prevent unnecessary hospitalisations at the end of life.

There are only a small number of children approaching the end of life at any given time across Vale of York. It is not uncommon for children to return to greater stability following a period of serious decline and some conditions are so unstable that the realisation that death is imminent is difficult to predict.[12] Both of these can make commissioning and providing end of life care for children challenging.

Recent research into the end of life care needs in North Yorkshire recommended seven key areas as commissioning priorities: providing access at all times for all people, integrating end of life care into existing/future care pathways, staff training, recognising patient wishes (e.g. preferred place of death), community engagement, providing the appropriate level of care, and supporting carers and relatives.[13]

In addition engagement with local stakeholders and service users (detail in Appendix A) identified areas that were particularly important to them to enable people to have a 'good death'. These included:

[iii] Latest published figures for NHS Vale of York CCG = 3292 registered deaths during 2016, or 0.92% of the population (ONS data).

	People wanted to be treated with dignity and respect, and helped to make their own choices and be in control of their own care		Including respite support and continued support after the death of a loved one
Ensure resources are available	There should be enough well-trained staff and funding available to provide high quality care, and individuals should be able to access services and products such as fast track care, mental health support and medications in good time	**Plan ahead**	Encouraging open discussions on death and dying, giving people time and support to arrange their affairs, and allowing individuals to express wishes and preferences for their care and how they wanted to live the remainder of their lives
Have supportive staff	Service users wanted staff to be caring, compassionate, respectful, and more open when discussion death and dying, and also to give them the time and right amount of information they needed	**Have co-ordinated care**	Importance of better joined up health, social and voluntary services including seven day working and improved IT systems, plus a single point of contact for accessing end of life services
Encourage the role of the community	The community can help promote wider awareness and discussion of death and dying, including through participation in local and national events, as well as providing support for individuals and their families and carers	**Treat everyone equally**	Making sure that groups that find it difficult to access care (e.g. people with dementia, LGBT+ community, people without family support) are particularly supported to get the care that they need.

Aim

Our vision is…for everyone requiring end of life care to have access to high quality, responsive services that meet their needs, at the time and place where they are needed.

In order to achieve this it is important that all people requiring end of life care are identified as early as possible, receive a timely prognosis and receive equitable access to end of life care.

Strategic vision

This section sets out our ambitions for improving end of life care for both adults and children across the Vale of York.

Foundations

We really value the feedback from those who shared their experiences with us. This information has been used to shape the strategy and a huge thank you goes to everyone that took part.

Information about our engagement and involvement work around this strategy is available on pages 16-19 of this document.

The main priorities and goals for Vale of York have been set out below in line with the six ambitions from the national framework. However, the *Ambitions* framework also sets out eight key foundations that the local health and social care system must provide in order for these ambitions to be achieved. The foundations are:

Personalised care planning	Everyone approaching the end of life should be given the opportunity to create a personalised care plan. This should cover their current and future preferences for care and should be made in conjunction with friends/family/carers where the individual chooses to do so.
Shared records	Local health record systems should allow for the a) recording and b) sharing of individual's preferences regarding end of life care.
Evidence and information	Services should provide qualitative and quantitative data for both local and national analysis that can be used to improve the quality, accessibility and effectiveness of services. Commissioners and services should make best use of the existing evidence base, and contribute to future research where possible.
Involving, supporting and caring for those important to the dying person	Whilst end of life care is centred around the dying person, it should also encompass their family, friends and carers both before and after their death.
Education and training	All professionals who provide any level of palliative and end of life care should have up to date knowledge and skills, as defined by a locally-recognised framework of training and development.
24-7 access	All people requiring end of life care should have access to appropriate support (e.g. urgent symptomatic relief) 24-7.
Co-design	Systems and services for end of life care should be designed with input from people who have personal and/or professional experience of palliative and end of life care.
Leadership	Good systems leadership is required to ensure organisations and staff know their roles and responsibilities in the system, and that the public know how to get access to care for themselves or for someone they care for. System leaders should champion a collaborative approach to commissioning services based on the needs of the population. Local providers should provide clear clinical leadership to ensure that the needs of service users are being met in the right way at the right time, delivering good quality care and support.

Ambitions

Our ambitions have been guided by national recommendations and feedback from the Vale of York community, including people providing and receiving end of life care support.

1. Each person is seen as an individual

We want	How we will do this
• Individuals to be treated with dignity and respect	• Produce a Citizen's Charter so people approaching the end of life know what they can expect from end of life care.
• To provide person-centred end of life care tailored to meet individual needs	• Make the best use of personalised health planning to tailor support to the needs of each individual
• Individuals to be at the centre of decision making, whilst also being able to involve those people who are important to them where they choose to do so	• Make sure everyone identified as being near the end of life has the opportunity to create a personal care plan
• People to have all the information they need to make informed choices	• Make sure that people have access to information, and that they are able, or helped, to understand it
• To recognise that decisions such as preferred place of death may change, particularly if someone is experiencing a crisis or deterioration	• Review individual's wishes to make sure documented preferences remain up to date
• To make sure that decisions are documented in a way that is accessible to everyone who may need to know about them	• Make sure that people who are approaching the end of life are appropriately identified in primary and secondary care records • Develop local IT systems so that all necessary partners can access each individual's end of life care records
• Everyone involved in, or receiving, end of life care feels able to have open, honest conversations about death and dying with professionals, friends, family members and carers • To enable these conversations to happen early, recognising that the right time may vary between individuals	• Staff have appropriate communications skills and feel confident discussing these important issues • Create an open culture across all care settings where both staff and service users feel comfortable initiating discussions around death and dying

2. Each person gets fair access to care

We want	How we will do this
• To reduce inequalities in accessing end of life care across the Vale of York	• Use local and national data to understand which parts of our population are at risk of not receiving good end of life care, and where there may be gaps in service • Specifically address the needs of populations known to be at risk of poor end of life care when commissioning, planning and delivering services
• To support people in vulnerable groups who may find it more challenging to access and navigate EOLC services	• Work in partnership with voluntary sector providers who support these populations to understand what their additional needs may be and how these could be addressed
• To make sure that information and services are provided in a range of accessible formats, including digital technology where appropriate	• Provide information on end of life care in a variety of formats, including those suitable for people with learning disabilities and sensory impairments • Use medical and communications technology to improve access to services

3. Maximising comfort and wellbeing

We want	How we will do this
• Effective symptom control to be available when it is needed	• Pre-empt the need for medication and equipment, and ensure these are accessible without delay
• Services and equipment to be available in a timely manner when required	
• People to be reassured that they know who to contact should they need advice, and are able to access someone whenever they need them	• Make sure individuals can always reach someone who will listen and respond at any time of day or night, every day of the week
• To support early access to palliative care whenever it is needed, not just in the final few hours of life	• Increase staff awareness of when to make early palliative care referrals
• Support to be available for family, friends and carers before and after the death of a loved one	• Support families and carers by providing respite, and working ahead to prepare for bereavement
• To recognise that people have other needs beyond medical and social care such as help with practical, everyday tasks or legal issues	• Educate staff so they are able to signpost to a full range of services that may be needed
• To provide holistic end of life care that considers the psychological, emotional, social and spiritual needs of an individual as well as their physical needs	• Staff will treat people as individuals, recognising people's priorities and wishes beyond just treating physical symptoms
• All staff to be able to recognise when individuals are experiencing distress, and to respond appropriately	• Make sure individuals are routinely reviewed for distress and other symptoms, and treated or referred on as appropriate
• To support people to identify what their goals and priorities are, and to work with staff, friends and family to achieve these	• Identify people's goals and priorities as part of their personal care plans

4. Care is coordinated

We want	How we will do this
• A single palliative and end of life care record that all services providing care can access	• Work together to implement an electronic palliative care record that can be accessed and updated by colleagues from all relevant health and social care organisations
• Care plans to have input from a range of professionals	
• Individuals to have a main point of contact for accessing coordinated care	• Make sure individuals have a single point of contact for accessing multidisciplinary specialists managing their care
• Routes into and between services to be clear and accessible	• Enable staff to provide clear signposting to relevant local and national services • Improve rapid access to needs based social care and fast track funding to prevent delays in accessing placements
• Good communication between services, and between services and service users	• Engage with families and carers when planning care • Promote integration and partnership working between relevant health, social and voluntary care services at local, city-wide, and system level
• To avoid people feeling overwhelmed by the involvement of multiple organisations, and having to co-ordinate between them	• Provide continuity of care where possible by engaging with nominated key staff member(s)

5. All staff are prepared to care

We want	**How we will do this**
• To recognise the wide variety of colleagues involved in end of life care, from domiciliary support to specialist palliative care teams	• Make sure that everyone who has any contact with people at the end of life or their carers feels confident to support their needs as appropriate
• To recognise that end of life care takes place in a variety of settings, and to provide high quality care in all locations	• Work with staff who take part in end of life care in hospitals, care homes, hospices, individual's own homes and in wider community settings to make sure they have the skills and resources available to provide high quality care.
• Everyone who provides end of life care to feel confident that they have the appropriate skills and expertise for their role, including communication skills	• Provide educational support for staff using the Yorkshire and Humber Learning Outcomes • Follow a joint educational and competency framework for end of life training to ensure all staff are competent to work at the appropriate level • Provide other relevant training to help support those with additional needs
• Staff to feel supported in their roles, allowing them to provide high quality, compassionate care	• Manage the health and social care workforce to ensure there are enough staff with enough time to provide high quality care
• Staff to recognise the limits of their own abilities, and to be able to refer people on to other sources of help when necessary	• Create an open culture where staff can seek help if they need support
• Staff to have access to care and support for themselves if they need it	

6. Each community is prepared to help

We want	How we will do this
• To encourage the wider community to be more open in discussing death and dying	• Participate in, and encourage communities to participate in, local and national events raising awareness of end of life issues • Actively encourage sharing ‘patient stories’ with a wider audience
• Communities to be part of the support network for people who are dying or people caring for those who are dying, including during bereavement	• Empower communities to provide emotional and practical support to people approaching the end of life and their carers • Continue to provide support for existing community activities run by specialist and non-specialist organisations • Recognise individuals as well as groups who may be helping someone at the end of life
• Voluntary sector partners to be involved in setting the agenda for future improvements to end of life care, including providing patient perspectives	• Include voluntary sector representatives in the Palliative Care and End of Life group
• To value and support volunteers already working with people approaching the end of life, and to encourage more people to get involved	• Help organisations to provide appropriate training and support around end of life for staff members and volunteers

Next steps

This strategy is the first of three linked documents setting out the priorities for end of life care in Vale of York 2019-2024 and how we will achieve them. The strategy will be used to produce two further documents to support delivery of our vision for end of life care:

1. Action plan

The action plan will include detail on specific actions for achieving the strategic vision described above. This will include setting out time scales, who is responsible for each action, and who holds overall responsibility.
The action plan will also include details of outcomes to be achieved and how these will be measured so that progress can be evaluated.

2. Citizen's charter

The citizen's charter will set out for members of the public what they can expect from end of life care in Vale of York in a brief, easy to read document. The charter will show how Vale of York allows them to meet the ideal set out in *Every moment counts – a narrative for person centred coordinated care for people near the end of life*:[14]

This strategy will be shared with system leaders and relevant stakeholders across health, social and voluntary care sectors. It will also be available to the public so that individuals and their families can see how the Vale of York system is working to meet their needs around end of life care.

> "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)."

Acknowledgements

Thank you to everyone who took the time to provide feedback at our engagement events. Your views matter and have a played a central role in the development of this document.

The strategy was written by Dr Victoria Turner, Public Health Specialty Registrar and NHS Vale of York Clinical Commissioning Group.

With thanks to members of the Palliative and End of Life Care Group from across the Vale of York for their comments and feedback on the strategy drafts. Thanks also to St. Leonard’s Hospice and NHS Vale of York CCG for hosting engagement sessions, and to staff and members of the public who attended these and/or completed the online engagement survey.

Appendices

a) Summary of engagement

Survey and focus groups

A survey was undertaken during August – September 2018 through patient and carers groups, stakeholder and internal e-newsletters, hospital e-newsletters and other professional channels (solicitors and funeral directors). 69 responses were received: 42 from clinical and professional colleagues, 19 from carers, family and friends and 8 from service users.

Key themes identified included the importance of individual choice, the desire for a 'good' death and encouraging advance conversations to support this, supporting family and friends after death, providing an adequate workforce, and ensuring the fast track service was available to all who needed it.

Focus groups were also held with clinicians (hospital, hospice, community services, GPs), care homes and carers groups. Feedback themes included:

- Availability and quality of carers
- Seven day working not fully supported
- Out of hours support for carers and care home managers
- Respite care: more needed for carers - especially when there can be long waits for care packages
- Mental Health support needed
- Increase capacity for community support: Joined up health and social care approach, Death Cafes, Dead Good Festival
- Improve communication with clinicians: needs to be easy to understand and respectful
- Treated as an individual, respect and dignity

Public engagement sessions

Public engagement sessions were held at St Leonard's Hospice (16 November 2018) and West Offices (22 November 2018).

Key themes from engagement at St Leonard's Hospice

- The importance of having a coordinated approach to care, and having a single point of contact
- Care and compassion of staff

- Support following a bereavement
- Companionship and sharing through the drop-in sessions
- Planning of affairs
- Ensuring that advanced care planning is in place
- Excellent work of St Leonard's hospice
- Dignity and respect
- Talking openly about dying and death
- Being given time by the staff
- Being treated as an individual

Key themes from the open public engagement session at West Offices

- Consider the needs of groups at risk of not receiving care: people with dementia (and their carers), people with diagnoses other than cancer, people with no children or family support, members of the LGBT+ community and people living in rural areas with reduced access to services.
- Factors that influence a 'good death': individuals being in control, timely access to services and products (e.g. continence, mobility beds), focus on preferred place of death (which may change over time and is not necessarily at home), advance care planning and integrated care.
- Communication: reluctance from professionals and public to discuss death directly (including issues around DNA CPR forms), individuals have different preferences on how and how much communication they receive, communication between services should be made easier (including more joined up IT services) and the need for wider public awareness of death and dying.
- Barriers to providing care: funding for services, lack of staff and lack of coordination.

b) Service overview

Currently, Palliative and End of Life Care services are provided to people in the Vale of York by the following organisations:

York Teaching Hospital NHS Foundation Trust (YTHFT)

YTHFT provides acute Specialist and General Palliative Care as well as Palliative Care in the community through district and community nursing teams. Team members primarily are either hospital or community based and are made up of consultants, clinical nurse specialists in palliative care, physiotherapists, an occupational therapist and a family support worker. YTHFT provides a seven-day palliative service (out of hospital: 8:30am-4.30pm; in hospital 8am-4pm).

The team has recently recruited three End of Life educators who will work collaboratively with the Specialist Palliative Care Team to deliver education and support. This will help to ensure that high standards of care are delivered in accordance with people's wishes where possible.

St Leonard's Hospice (York)

St Leonard's Hospice is an independent charity, providing specialist palliative care and support for local people with life limiting illnesses. Services include an inpatient unit (20 beds), The Sunflower Centre (providing a range of services including drop in sessions and art therapy), and the Hospice@Home service. The team at St Leonards includes highly experienced doctors and nurses, as well as specialists in a wide range of roles including complementary therapy, lymphoedema care, physiotherapy, social work, bereavement, occupational therapy and spiritual care.

Marie Curie

Marie Curie offers free nursing care to all people with a terminal illness, as well as providing support for family and friends. Nurses generally provide one-to-one nursing care and overnight support (eight to nine hours) in people's own homes or other usual place of residence.

Macmillan

Macmillan funded the City and Vale GP Alliance to have a Band 4 Community Cancer Care Coordinator on a fixed term contract for two years from 2017, based at Millfield Surgery, Easingwold.

NHS Vale of York CCG receives funding from Macmillan to support a 0.4WTE GP Cancer Lead as well as project funding for a recovery project across the York Teaching Hospital NHS Foundation Trust footprint.

St Catherine's Hospice (Scarborough)

Some individuals from the Ryedale area of Vale of York may access Palliative Care services at St Catherine's Hospice in Scarborough.

St Catherine’s Hospice provides services including an 18 bed inpatient unit offering 24-hour specialist symptom control and end of life care, a Hospice at Home nursing service, wellbeing services through the Wellbeing Centre and other specialist support including a care homes support team, lymphoedema clinic and Palcall, an out of hours nurse-led helpline.

The hospice team includes specialist nurses, doctors, physiotherapists, occupational therapists, bereavement counsellors, social workers, complementary therapists and spiritual care support. All areas of Saint Catherine’s work are supported by a dedicated team of volunteers.

Primary Care

GPs and other primary care staff routinely care for people approaching the end of life. Their role can include identifying when people are approaching end of life (and initiating relevant pathways), conducting home visits, prescribing appropriate medications and liaising with specialty care when needed.

Community care

Palliative care in the community is routinely delivered by district and community nursing teams provided by York Teaching Hospital NHS Foundation Trust. Community based palliative care services are also provided by Marie Curie and Macmillan as well as the as the St Leonard’s Hospice Hospice@Home team.

The York Integrated Care Team is a multidisciplinary team who are constantly looking at ways of working together across several agencies and refer patients to a variety of end of life care services including Hospice@Home, Macmillan and Marie Curie.

Additionally, Fast track Continuing Healthcare is delivered by a number of providers in both residential and own home settings.

Care Homes across the Vale of York support residents at the end of life care, Nursing homes deliver this care independently.

Children’s end of life care

Martin House Hospice (Boston Spa) provides planned care, emergency care, symptom control and end of life care, both in the hospice and at home, to children and families across Vale of York. They also offer bereavement support to families. Community support is provided seven days a week but not overnight unless in an emergency. However, professionals and families can contact Martin House at any time for medical and nursing advice.

Other community teams such as the community children’s nursing team and complex care nurses also provide community support.

Children with complex health problems will be under the care of a pediatrician. Leeds children’s palliative care team can also offer support.

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Clinical Commissioning Group

NHS
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UNIVERSITY of York
The Department of Health Sciences

CITY OF YORK COUNCIL

North Yorkshire
County Council

St Leonard's Hospice
Caring for Local People

Marie Curie
Care and support through terminal illness

MACMILLAN
CANCER SUPPORT

NHS
Yorkshire Ambulance Service
NHS Trust

Care Homes
Our Partners in Care
Care Homes and Domiciliary Care

NHS
Tees, Esk and Wear Valleys
NHS Foundation Trust

vocare
Quality care partners

Saint Catherine's
Caring for you at Hospice and Home

York Integrated Care Team

Martin House
hospice care for children and young people