

## **Teesside Hospice**

Established in 1982, Teesside Hospice is a charity working in partnership with the NHS and wider system delivering specialist palliative care, end of life care, wellbeing activities, lymphoedema care and grief and trauma counselling services for adults and children across Teesside and parts of North Yorkshire.

As others have developed their skill in delivering generalist care, our priority is to look after people, their families and carers who have complex or multiple needs and to provide Specialist Palliative Care and support and expertise in end of life care. In addition, we provide specialist advice and support to other professionals on palliative and end of life care, offer specialised education and training and undertake research across our areas of work.

Our Board of Trustees have close regard to our governing document to ensure our strategies and resources are focussed on helping people from all parts of our community, their wider family and continues into grief and trauma support when needed.

We employ 168 people in a variety of different roles and have over 300 volunteers in our hospice, retail and fundraising departments.

Our services are available free of charge to the people who need them. In 2023-24, our clinical services will cost just over £3.5M to deliver. About 50% of this comes from the NHS with the remainder coming primarily from fundraising activities across Teesside and local residents via retail sales in our shops.

### **Our Vision**

Our vision is that nobody in Teesside dies scared and in pain.

### **Our Mission Statement**

Our mission is to support people with a terminal illness by helping them to live as well as possible, for as long as possible.

### **Principles**

We recognise the added value which charitable endeavour can bring to essential healthcare. Our service delivery and development is led by the needs of our local population and system partners.

Teesside Hospice strives to integrate as closely as possible with local Hospital Trusts, Integrated Care Board, Macmillan Nurses, Community Nursing Teams and General Practitioners to deliver specialist palliative care services and expertise to patients, families and carers.

There is a skilled multidisciplinary team at the hospice, which offers patients holistic care, ensuring that their physical, emotional, social and spiritual needs are met. The

team includes: a Consultant in Palliative Medicine, Hospice Medical Team, Specialist Nurses, Occupational Therapists, Dietician, Social Worker, Physiotherapist, Complementary Therapist and Counselling Services.

Given the specialist nature of our work, referral into Teesside Hospice is generally through a GP, hospital team or social worker. Self-referrals are also possible and support is also available for family members and carers affected by a life-limiting illness.

Success is not achieved simply through the remission of symptoms and control of pain: those we work with are supported to engage with life to the best of their abilities. To do this they must feel empowered, and be afforded dignity and respect. We encourage people to take as much responsibility for themselves as they are able, and our staff are there to help them do this.

Our goal is to help our people face the world without fear or feelings of inadequacy arising from having been, or still being, unwell; to have attachments to others which have emotional meaning (to love and to feel loved); to be able to do things in the world which have a meaning and a purpose for them. In order to achieve this goal we include the development of communities within our services and where appropriate, a therapeutic community meeting appropriate quality standards.

## **Palliative Care**

Palliative care is treatment, care and support for people with a life-limiting illness, and their family and friends. It's sometimes called 'supportive care'.

The aim of palliative care is to help you to have a good quality of life – this includes being as well and active as possible in the time you have left. It can involve:

- managing physical symptoms such as pain
- emotional, spiritual and psychological support
- social care, including help with things like washing, dressing or eating
- support for your family and friends.

A life-limiting illness is an illness that can't be cured and that you're likely to die from. You might hear this type of illness called 'life-threatening' or 'terminal'. People might also use the terms 'progressive' (gets worse over time) or 'advanced' (is at a serious stage) to describe these illnesses. Examples of life-limiting illnesses include advanced cancer, motor neurone disease (MND) and dementia.

You can receive palliative care at any stage in your illness. Having palliative care doesn't necessarily mean that you're likely to die soon – some people receive palliative care for years. You can also have palliative care alongside treatments, therapies and medicines aimed at controlling your illness, such as chemotherapy or radiotherapy.

However, palliative care does include caring for people who are nearing the end of life – this is sometimes called end of life care.

## **End of Life Care**

Approximately 500,000 people die in in the UK each year.

People with advanced life-threatening illnesses and their families should expect good end of life care, whatever the cause of their condition. In addition to physical symptoms such as pain, breathlessness, nausea and increasing fatigue, people who are approaching the end of life may also experience anxiety, depression, social and spiritual difficulties. The proper management of these issues requires effective and collaborative, multidisciplinary working within and between generalist and specialist teams, whether the person is at home, in hospital or elsewhere.

Information about people approaching the end of life, and about their needs and preferences, is not always captured or shared effectively between different services involved in their care, including out of hours and ambulance services. Families, including children, close friends and informal carers, also experience a range of problems at this time. They play a crucial role and have needs of their own before, during and after the person's death: these too must be addressed.

### **What is Hospice Care?**

Bringing together Palliative and End of Life Care into a single, holistic environment Hospice care improves the lives of people who have a life-limiting or terminal illness.

It helps them to live as actively as they can to the end of their lives, however long that may be. It not only takes care of people's physical needs, but looks after their emotional, spiritual and social needs as well. Hospice care also supports carers, family members and close friends, both during a person's illness and during bereavement. Charities like Teesside Hospice offer a range of services, which may include the following: pain and symptom control; psychological and social support; rehabilitation – helping patients to stay independent and continue to live their lives as they have done before; complementary therapies, such as massage and aromatherapy; spiritual care; family care; practical and financial advice; bereavement care.

### **Standards of Care**

Teesside Hospice delivers high-quality Specialist Palliative care to the standard set by NICE (National Institute for Clinical Excellence) that, when delivered collectively, should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers. This is done in the following ways, regardless of condition or setting:

- Enhancing quality of life for people with long-term conditions.
- Ensuring that people have a positive experience of (health) care.
- Treating and caring for people in a safe environment and protecting them from avoidable (healthcare-related) harm.

The NICE standard requires Teesside Hospice to contribute to the following overarching outcome(s) for people approaching the end of life:

- The care that people approaching the end of life receive is aligned to their needs and preferences.
- Increased length of time spent in preferred place of care during the last year of life.
- Reduction in unscheduled care hospital admissions leading to death in hospital (where death in hospital is against their stated preference).
- Reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance.
- In addition, this quality standard should contribute to:
  - Enhancing quality of life for people with care and support needs.
  - Delaying and reducing the need for care and support.
  - Ensuring that people have a positive experience of (social) care and support.
  - Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm.

## **External Oversight and Regulation**

The core clinical activity at Teesside Hospice is delivered to the same standard, with the same regulation and oversight as that delivered within an acute hospital.

Teesside Hospice is required to register with the Care Quality Commission (CQC) and its current registration status is for the following activities:

- Treatment of disease, disorder or injury

The last unannounced routine inspection of Teesside Hospice took place on 16th March 2016. Our feedback was very positive and we received an overall rating of GOOD for our service. A small number of areas for improvement were highlighted e.g. a system to ensure that all fire points were tested as regularly as each other and these were easily and immediately addressed. No areas were rated as inadequate.

Teesside Hospice is inspected by CQC with all of the safeguarding, governance, compliance, patient experience and safety standards this brings.

CQC now operates a risk based assessment. Our most recent assessment in February 2023 indicated they had no concerns about our services that required further investigation.

Teesside Hospice is also regulated by the Charity Commission and Fundraising Regulator.

## **Internal Governance**

The Board of Trustees is made up of volunteer Trustees who meet at least four times per year to determine both the general and strategic direction and policy of the charity, and to review its overall management and control for which they are legally responsible. Trustees are recruited through a robust recruitment process designed to

ensure they are 'fit and proper people' with the specific skills and knowledge the charity requires in order to deliver its objectives.

Sub-committees (finance & facilities, fundraising, workforce development, quality & performance) meet quarterly to scrutinise performance, seek assurance and discuss relevant issues. All sub-committees report back to the full board and have trustee chairs and representation.

A Chief Executive is appointed by the Trustees to manage the day to day operations of the charity and responsibility for the provision of the services rests with the Chief Executive. A scheme of delegation is in place, ensuring that the charity delivers the services specified and the Chief Executive is aided in their duties by a Senior Management Team.

## **Teesside Hospice Services**

### **Inpatient Unit (IPU)**

Teesside Hospice's 10 bedded Inpatient Unit provides the only specialist inpatient beds for people requiring palliative or end of life care in the locality. A useful metaphor to describe the complexity and specialism within the unit is to consider the facility at Teesside Hospice as a High Dependency Unit for people with Palliative and End of Life Care needs.

With a target occupancy rate of 85% and average length of stay around 14 days, the Inpatient Unit focusses its work in the general areas:

- **End Stage Care:** Some patients choose to spend their last days in the unit, being admitted during the very late stages of their illness
- **Pain and Symptom Management:** for people experiencing pain and other symptoms that have not been controlled by generalist interventions.
- **Psychosocial and spiritual distress:** needs that cannot be met by the generalist referring team.

During 2022 there were 140 patients who received inpatient care (155 admissions) with a variety of complex needs. The average length of stay for patients is 19 days. 40% of patients were discharged to their homes or a care home. 58% of patients received end of life care and 2% were discharged to the hospital service.

During the covid crisis, we rapidly refocussed our clinical activities to support the needs of the local health system and residents. We introduced safe ways of continuing to offer wellbeing and psychological support and worked safety to care for people who needed inpatient care after testing positive for covid-19.

As we have moved on from the acute phase of the covid crisis we are now beginning to see the impact of delayed/reduced access to healthcare with young people needing our help – in both our wellbeing centre and specialist inpatient unit. We are also supporting people dealing with the psychological trauma the cause by the extraordinary circumstances in which they lost loved ones.

## **Wellbeing Centre**

This Centre offers professional advice and rehabilitation from our multidisciplinary team. The centre is open throughout the week, operates outreach sessions in the community and can offer remote support for those unable to visit in person. The centre operates a number of different services designed to help individuals manage their illness, stay independent, and meet other people in similar situations:

### Telephone Support

A nurse from our Wellbeing Centre is available for ongoing support for any problems including Specialist Palliative Care needs not met by the referring team. We also offer regular telephone calls and liaison with other Health Care Professionals who may draw on our expert knowledge.

### Peer Support Group

We run weekly support groups, led by our Wellbeing Centre nurses, enabling individuals to benefit from psychological and social support, whilst enabling them to connect with peers, expand their support network and answer any questions they might have.

### Anxiety and Breathless Management

Problems with anxiety and breathlessness are common in many life-limiting conditions. We offer a specialist 4-5 week course that teaches coping strategies and skills to help people live better with their illness and symptoms; focusing on relaxation and wellbeing. The meetings are led by a Wellbeing Centre nurse and include sessions from other members of the team, such as our Physiotherapist and Occupational Therapist.

### Cognitive Behavioural Therapy (CBT)

The psychological impact of a life-limited illness can be devastating. CBT is an evidence based talking therapy delivered by a trained therapist which can help reduce anxiety, panic attacks, low mood, depression, fatigue, and acceptance & adjustment issues.

### Carers Group

Caring for someone has huge demands that can impact their own health and wellbeing. If carers are struggling at home, or need practical advice to help look after your loved ones, this support group is for them. This group meets every week and offers practical, social and emotional support as well as connecting carers with peers who share their own experiences and knowledge.

During 2022 there were 227 new referrals into the service, 785 Wellbeing Centre sessions delivered and there were 1871 attendances by patients in the year.

## **Outpatient and Outreach Appointments**

Teesside Hospice offers outpatient appointments for individuals who need to access specialist medical support, follow up appointments for on discharge from our inpatient unit, medical assessments following referral to our Wellbeing Centre.

Although there is no commissioned Hospice at Home scheme in Teesside, we have secured charitable funds that allow us to employ an Outreach Nurses who carries out home visits, arranges assessments for referrals to the hospice and connects individuals into the district nursing and community teams.

Where resources allow, our doctors, specialist nurses and allied health professionals are able to carry out ad-hoc remote or face to face appointments.

## **Lymphoedema Service**

Teesside Hospice offers specialist care and symptom management for people living with lymphoedema - a condition where swollen limbs result from illness or treatment. The clinic at Teesside Hospice sees people with both primary and secondary lymphoedema. The clinic is run to instruct people how to manage their lymphoedema effectively, as there is no cure for the condition, although the earlier it is diagnosed, the more effectively the condition can be managed.

During 2022 the lymphoedema clinic received 594 referrals. There were 3767 patient interactions including clinic appointments, home visits, patient education groups, advice calls and IPU/Wellbeing Centre patients seen. 463 referrals were for new patients and 131 referrals were for new patients who were re-referrals. 248 appointments were for new patient assessments.

## **Bereavement Counselling Service**

Primarily staffed by qualified volunteer counsellors, the service provides support to both adults and children (via 'Forget-Me-Not' children's and young adults' bereavement counselling service) and enables people to work through their grief and accept what has happened helping them move forward in their lives.

Our online triage system enables people who come to us for support to be signposted to other generalist services/resources where they are more appropriate.

Our counselling service is being careful to avoid inadvertent medicalisation of grief and is focussing its resources on primarily supporting individuals who are experiencing complex grief or trauma. The team are still available to offer support and advice to colleagues across the wider hospice.

During 2022 the service received 211 referrals for counselling. Counselling referrals for children from the age of 7 and increasing and adults show no indication of decreasing. Referrals came in from a wide range of sources from within the community including GP's, self-referrals and referrals from other agencies. The counselling service provided 1307 counselling appointments.

## **Education and Campaigning**

In addition to its core clinical services, Teesside Hospice contributes to the training and education of both its own and partner staff in palliative and end of life care. With its own Consultant in Palliative Medicine, Teesside Hospice is able to offer Speciality training placements to doctors on the Regional scheme training to become Consultants and usually has two registrars working in the hospice at any one time.

We employ an experienced Clinical Practice Nurse with a dedicated focus on raising the knowledge, skill and confidence on our own team and people working in partner agencies around palliative and end of life care.

Raising public awareness about death, dying and the importance of advance care planning is an important aspect of Teesside Hospice's work. Still frequently viewed as a taboo subject, we know that early conversations and advance care planning can make a huge difference to people as they approach the end of their lives. We do this work though helping partners develop the skills they need to begin these difficult conversations and talking openly about these issues in the local media, our website and social channels.

## **Funding Teesside Hospice**

From its outset, Teesside Hospice, like 99% of hospices, has relied on community fundraising to support its activities. In our early years we were awarded an annual grant from the old Strategic Health Authority which rolled over into a grant from the PCT and eventually a contract with the CCG and now the ICB.

The value of this contract has never been properly reviewed and until 2020 there had been no cost of living increments in the memory of current hospice staff. Looking back, the value of this grant actually reduced over the years and was lower in 2020 than it was in 2012.

As the specialism of palliative and end of life care developed, the training, regulation and safeguarding around its care has grown. As Teesside Hospice has responded to local demand by supporting people with increasingly complex problems, the costs of that clinical care have increased. The impact of covid and the subsequent cost of living crisis has severely challenged our fundraising efforts despite the generosity and trust our community give us. One off funding from central government help get us through the initial covid crisis but that has ended with no sign of any further national support.

When I last attended scrutiny in December 2020 the financial position of the hospice was precarious with an ongoing structural deficit. The CCG spoke about the 'Exemplar' work it was undertaking that would lead to a fresh approach and sustainable commissioning from 21/22.

For a variety of reasons, that work has not been completed and we are still awaiting a clear plan for how local commissioners will ensure hospice, palliative and end of life care is sustainable and available for everybody who needs it.

In May 2022 an agreed amendment to the Health and Care Act placed specific responsibilities on Integrated Care Boards to make sure everybody had access to specialist palliative and end of life care. ([Amendment 52 to Health and Care Act 2022 to Health and Care Act 2022 - Parliamentary Bills - UK Parliament](#))

In September 2022, previously available draft guidance was reissued within statutory guidance to accompany the new law with clear commissioning and investment guidance indicating that **core** and **specialist** palliative and end of life care services should be **fully ICB funded** and that charitable funds should be directed towards '**enhanced**' services rather than propping up core provision. ([NHS England » Palliative and end of life care: Statutory guidance for integrated care boards \(ICBs\)](#))

The guidance is also clear that Palliative and End of Life Care services should be commissioned like any other hospital service: ([PEOLC Commissioning Investment Framework April 2022 - Palliative and End of Life Care Network - FutureNHS Collaboration Platform](#))

*“Following an amendment to the Health and Care Bill 2021, the role of integrated care boards in the commissioning of palliative care services (including specialist palliative care) to adequately meet their local population need is explicit and sits alongside the requirement to commission hospital services and other important core elements of health care. “*

This is **significant** and previously we have been told many times that ‘there is no money left’ after other services have been commissioned and funded.

In September 2022 Tees Valley ICB produced a new PEOCL strategy that recognised the new law and guidance and the need to retain the existing specialist palliative care services delivered at Teesside Hospice (and others).

We have been seeking a clear commitment and timescale from Tees Valley ICB that acknowledges the NHS guidance for full funding for specialist services and a timescale for how that will be implemented. We recognise this will take some time but without a timescale it is difficult to plan ahead to make best use of the charitable donations we receive.

With no clear progress in Tees Valley towards sustainable funding, alongside increasing costs and an incredibly difficult fundraising environment, we sought advice in the New Year from Hospice UK and MPs. At the end of January all five Tees Valley Hospices attended Parliament to share our story and ask MPs to help us secure the sustainable funding for palliative and end of life care services the law, the NHSE statutory guidance and the Tees Valley ICB PEOCL strategy says is needed. The NHS has responded on 7<sup>th</sup> March and told MPs we have been invited to join their partnership groups and we all need to work as a system to find a solution. We haven't seen an agenda or timetable to indicate what that looks like.

In March 2023, recognising the critical importance of our work to residents and families Teesside Hospice trustees agreed again to fund the deficit on our specialist palliative and end of life care services with £468K from our charitable reserves.

These reserves are finite and had originally been accrued to help pay for a new hospice building.

We are fortunate at Teesside Hospice that we have reserves. Other hospices are not so fortunate. We understand Alice House Hospice is predicting a significant deficit for 23/24, has few reserves and is now being forced to seriously consider closing its long-term inpatient unit. This is only long term specialist palliative care inpatient unit and its loss will impact Middlesbrough residents and Teesside Hospices ability to discharge people who need longer term care.

## **Recommendations**

1. The new **legislative framework** requiring the commissioning of specialist palliative and end of life care services, along with the **statutory guidance** on how that should be funded is noted.
2. This the **sustainability** of specialist palliative and end of life care in Teesside Hospice is noted.
3. Notes that charitable hospices cannot operate when insolvent and will inevitably **reduce services** or **close** once charitable reserves are depleted.
4. That HOSC seeks a clear commitment from the ICB to implementing the **Health and Care Act** requirements on commissioning specialist palliative and end of life care and that it will follow **NHSE commissioning guidance** in full (that it will fully fund core and specialist services) along with a **timescale for implementation**.

David Smith, Chief Executive, Teesside Hospice. 10<sup>th</sup> March 2023