

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 148 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 2020-21, our clinical services will cost just over £3M to deliver. About 43% of this comes from the local 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 we are there for everybody who needs us. We want to change the way our society and healthcare systems care for people with a life limiting illness and ensure that local people get the very best care at the end of their life

Our Mission Statement

Our Mission is to complement other services by leading the development of new ways of working and delivering hospice care that meets the needs of those at the end of their life today and those in the future, whatever their needs might be

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, Clinical Commission Groups, 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, Chaplaincy 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 England 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
- Diagnostic and screening procedures
- Transport services, triage and medical advice provided remotely.

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.

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 five 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 as appropriate to discuss relevant issues. All sub-committees report back to the Trustees and have Trustee 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 2019/20 there were 160 patients who received inpatient care with a variety of complex needs. The average length of stay for patients is 17 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.

As a result of Covid-19, the inpatient unit initially focussed its resources onto end of life care to support the predicted surge in the local system. From May, the IPU reintroduced symptom management and pain control and are currently delivering a full range of inpatient services. This includes people with suspected and confirmed Covid. Access and visiting arrangements are restricted to reduce covid risks but sensitive and flexible especially to the needs of those approaching end of life.

Perhaps as a result of other services focussing on covid, the dependency and levels of distress of people coming into the unit has been higher than we would have expected. We carry out regular 'dependency' checks to ensure we stay safe and at times have had to restrict admissions when required to do so. The additional

cleaning regime required by covid also means that post discharge, rooms are out of action for longer than usual and this is something we have factored into our anticipated occupancy levels.

Our staffing levels have held up well and we've maintained adequate levels of PPE throughout the pandemic crisis.

Wellbeing Centre

This Centre offers professional advice and rehabilitation from our multidisciplinary team. The centre is open throughout the week and is able to offer remote support for those unable to visit in person due to either illness or covid restrictions. 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 2019/20 there were 206 Wellbeing Centre sessions in 2019/20 and there were 2,056 attendances by patients in the year. The average length of attendance by patients was 13 weeks.

During covid, staffing levels have held up well and PPE hasn't been as issue as the work has predominately been done remotely. The majority of our support rapidly moved from face-to-face to remote support which will remain in place for the foreseeable future.

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 and specialist nurses are able to carry out ad-hoc remote or face to face appointments. Prior to covid we were in discussion with South Tees NHS to formalise this service and we hope to pick this conversation up soon in order to properly fund and integrate it within the wider specialist palliative care service.

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 2019/20 the lymphoedema clinic received 537 referrals over the course of 2019/2020. There were 4,562 patient interactions including clinic appointments, advice calls and IPU/Day Hospice patients seen. 458 clinic appointments were for new patients and 79 clinic appointments were for new patients who were re-referrals.

Our Teesside wide service has continued throughout covid with many regular reviews now being conducted by phone or Zoom and face-to-face appointments available where clinically required. The impact of covid on JCUH led to an increase in the number of people being referred into our service. Online group education classes are about to start soon.

Our Lymphoedema staffing has remained good throughout and we have had good stocks of PPE and equipment for the service.

Bereavement Counselling Service

Providing 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.

Primarily staffed by volunteers, on lockdown the service stopped taking new referrals and focussed on supporting the most vulnerable individuals to keep them safe throughout the first few weeks. All counselling has been done remotely and there are no plans to reintroduce face-to-face sessions for the foreseeable future.

A new online triage system is in development that will enable people who come to us for support to be signposted to other generalist services/resources where they are more appropriate. We expect the online system to be fully operational by January 2021. Volunteer counsellors are now returning to work which is allowing us to slowly start taking new adult referrals. Counsellors are booking their own appointments and the old 'assessment' appointments we used to have are now integrated into the main counselling process

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.

Staffing has been good throughout and there has been no need to access PPE as the work has been carried out remotely.

During 2019/20 the service received 450 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 average client received between 12 and 24 bereavement counselling sessions.

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.

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 current CCG.

The value of this grant has never been properly reviewed and until this year 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 is now lower 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.

As the NHS workforce has seen increments in pay (Agenda for Change, annual pay settlements) Teesside Hospice has had to follow some of those increments in order to recruit and retain the clinical staff it needs in order to deliver its services.

For many years the hospice was able to accommodate this increased expenditure through increased fundraising, charity shops and crucially, legacy donations that generated large lump sum donations that often balanced the books. Legacy donations could never be planned for but for many years, they arrived (sometimes just in time) to fill the budget gap. As a result of this, the hospice was able to build a reserve that gave it a measure of confidence it would be able to weather more challenging times.

For the hospice, those challenging times began arriving before coronavirus. As fewer people had the wealth to leave their house to charity and competition for those remaining legacies grew the hospice began 2019 with a structural deficit. The costs of regulation, compliance, competitive salaries, NHS and non-NHS pensions, increased running costs accumulated over the years and with no additional NHS funding available, the hospice trustees agreed to set a deficit budget of £468K for the financial year 2020-21.

And then coronavirus arrived. The closure of our charity shops and virtual ending of community and events fundraising increased our potential deficit this year to around £1.2M. After a few worrying weeks, we were fortunate that government announced a financial support package for hospices and that along with an emergency appeal, an unexpected legacy donation, business rate relief and income from the furlough scheme has meant we are now looking at balancing the budget this year.

Looking ahead to 2021-22 we are projecting a deficit budget of £750K. With £3M in free reserves this gives us 3-4 years until the reserves run out and the charity is forced to close.

In order to mitigate this our Board of Trustees instigated a transformation programme that has sought to seek savings and efficiencies in our work whilst working with partners and the wider system to increase the level of core statutory funding the hospice receives. We are encouraged by the warm words we have received and the confirmation that our specialist inpatient beds and Specialist Wellbeing and outpatient services are essential to the local system.

The next step in this transformation work will require senior decision maker engagement, a timely response and concrete actions to explore where resources within the system can be moved around, what further efficiencies the hospice might make and what we will do collectively to ensure the ongoing survival of the hospice as a specialist facility for people across Teesside.

Recommendations

Teesside Hospice takes an integrated approach working within the wider system using its charitable resources to meet needs and add value where possible. Whilst a separate review of Teesside Hospice could focus on its own position, a wider more strategic review like the one in 2011 would allow this to happen whilst following the journey residents and their families make at some of the most difficult times in their lives.

In order to achieve this we suggest:

1. That HOSC reviews progress towards delivery of its 2011 report into Palliative and End of Life Care
2. That HOSC reviews the availability, effectiveness and sustainability of current provision for local residents against the most current policy document agreed by NHS and Adult Social Care Directors: "Ambitions for Palliative and End of Life Care: the national framework for local action 2015-2020" and NHS England Specialist Level Palliative Care: Information for commissioners April 2016.

David Smith
Chief Executive, Teesside Hospice
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