Middlesbrough moving forward

Legal and Governance

ADULT SOCIAL CARE AND SERVICES SCRUTINY PANEL

Date: **Wednesday 9th December, 2020**
Time: **1.30 pm**
Venue: **Virtual**

AGENDA

Please note: this is a virtual meeting.

The meeting will be live-streamed via the Council's Youtube channel at 1.30 pm on Wednesday 9th December, 2020

1. Apologies for Absence

2. Declarations of Interest

   To receive any declarations of interest.

3. Minutes- Adult Social Care and Services Scrutiny Panel - 11 November 2020 — 3 - 6

4. Palliative /End of Life Care- Setting the scene -NHS Tees Valley Clinical Commissioning Group (CCG) — 7 - 14

   Craig Blair, Director of Commissioning Strategy and Delivery, NHS Tees Valley Clinical Commissioning Group (CCG) will be in attendance to provide the Panel with information in respect Palliative / End of Life.

5. Palliative / End of Life Care- Setting the scene- Teesside Hospice — 15 - 24

   David Smith, Chief Executive will be in attendance to provide information on the work and support Teesside Hospice provide in respect to Palliative/ End of Life Care.

6. Chair's Overview and Scrutiny Board Update

The Chair will provide a verbal update from the Overview and Scrutiny Board help on 3 December 2020.

7. Any other urgent items which in the opinion of the Chair, may be considered.

Charlotte Benjamin
Director of Legal and Governance Services

Town Hall
Middlesbrough
Date Not Specified

MEMBERSHIP

Councillors J Platt (Chair), S Hill (Vice-Chair), J Goodchild, D Jones, G Purvis, D Rooney, J Walker and G Wilson

Assistance in accessing information

Should you have any queries on accessing the Agenda and associated information please contact Susie Blood, 01642 729645, susie_blood@middlesbrough.gov.uk

ADULT SOCIAL CARE AND SERVICES SCRUTINY PANEL

A meeting of the Adult Social Care and Services Scrutiny Panel was held on 11 November 2020.

PRESENT: Councillors S Hill, D Jones, J Platt, G Purvis, D Rooney, J A Walker and G Wilson

OFFICERS: S Blood, M Dawson (ABM) C Breheny, M Jackland, and E Scollay,

APOLOGIES FOR ABSENCE Councillor J Goodchild.

DECLARATIONS OF INTERESTS

None declared.

1 **MINUTES OF THE MEETING HELD ON 14 OCTOBER 2020**

The minutes of 14 October 2020 were submitted and approved as a true record.

2 **AGEING BETTER MIDDLESBROUGH (ABM) - UPDATE AND FUTURE/LEGACY PLANNING**

The Chair welcome Michelle Dawson, Manager of Aging Better Middlesbrough to provide an update regarding work undertaken to date, impact of Covid 19, together with plans for the future.

The Manager outlined that she worked for Middlesbrough and Stockton Mind and had worked there for the past 10 years. Aging Better Middlesbrough (ABM) was originally a 6 year funded programme of £6million over 6 years (April 2015- March 2021) to reduce loneliness and isolation for older people. The programme is a test and learn project co-designed with older people. The project gained evidence as at the time there was very little information about what worked. The project has gathered loads of Loads and loads of learning about loneliness, older people, communities, commissioning and partnerships, they have worked with thousands of older people.

The Panel learnt that the ABM website had a dedicated learning page, which contains information, not only from Middlesbrough but also from the 7 ABM projects across the Country to understand what works to reduce loneliness. Middlesbrough speciality, is around working with older people with complexity, mental health and chronic loneliness. The Manager outlined that chronic loneliness was different to transitional loneliness e.g. an impact from covid, whereby older people find themselves lonely in a transition of time.

Over the past 5 years, ABM has delivered a whole host of projects with older people; which has included long term intervention, asset based development, peer and befriending projects , projects within the BME community, digital support for older people, , projects with older woman from Pakistan, projects with asylum seekers and refugees, small grants projects and projects around dance and exercise. The Manager outlined that most projects which you could think of to engage with older people and reduce loneliness and isolation have been tried.

In March 2020 at the start of the Covid- 19 pandemic, like most, the way working for ABM had to change. The Director of Adult Social Care and Health Integration contacted the Manager due to the number of older people coming through Help BORO and the shielding HUB.

In response to a request from the council, Middlebrough and Stockton Mind became a ‘destination' point for people who were lonely or needed emotional support.
They undertook the following projects:
• Ageing Better formed a telephone support project for older people, bringing together staff from four different organisations. ABM also telephoned over 600 older people who they were in regular contact to check on their well being and to engage them in supplementary telephone support where they had additional need.
• ABM delivered wellbeing packs, activity packs to older people.

• They provided digital support and bought digital devices and data for older people to enable older people to use their devises and make the most of digital technology. They were also linked to a digital befriender.
• Middlesbrough and Stockton MIND carry out Social Prescribing, however ABM launched social prescribing on 1 April 2020 to support GP's who needed additional support to link them into social prescribing link workers.
• Age Friendly Middlesbrough connected people together, to enable the community groups to connect and find ways not to duplicate and share resources.

The Manager outlined that thankfully the lottery announced that they would not be ended funding in 2021, as they recognised that aging better played a crucial role in the recovery of covid. The County is not talking recovery now however still funding has been supplied for aging better Middlesbrough until March 2022. Funding for the year has been halved compared to the £1million originally received for the project on a year basis so the programme is currently prioritising what services they will deliver.

The services that they will be focusing on in the next 15- 18 months will be as follows:

• Telephone support plus- holistic support for lonely and isolated support. It has a link to improving physical activity for older people, so we are hoping to link them more robustly into programmes such as Falls prevention and physical activity.
• Digital support with expansion into BAME communities- providing Investing people and culture (IPC) digital support for BAME communities, as we are conscious the programme is not very diverse in its engagement.
• Funding the falls prevention strategy- aging better Middlesbrough funds an occupational therapist into the Falls Prevention Team in order to free up the Falls Prevention team to work on the Falls Prevention Strategy.
• Age Friendly Middlesbrough- we will continue to fund the officer to conduct the mapping, connection and capacity building work
• Mental health therapy- this service will be expanded as ABM currently has a waiting list.
• Development support to social prescribing

The Manager further outlined that the partnerships especially with the Health sector have improved over the past few years.

• The Manager advised that she chairs the Digital development steering group, which looks to conquer the digital divide. It is something she feels everyone should be investing in, but unfortunately this was not the case. They therefore created this partnership and attracted £20,000 funding to develop an online platform whereby businesses can donate devises, which will be upgraded by the private sector and they will keep 50% of these devises and donate 50% back into the platform. Organisations will then have an online login to apply for devises for service users and community groups. The group is also looking at online support for all an all age digital support group. This is being run with the Teesside combined authority to try and address what the connectivity issues will be in the future and what we might need to do to bridge the gap until this occurs.
• Falls prevention strategy - The Manager co- Chairs the Falls Prevention steering group which has put Middlesbrough and Stockton MIND and ABG in touch with health professionals.
• Supporting Older People through the winter (with You've Got This)- informal partnership and how we can share our resources to support older people.
The Manager further discussed the gaps in the system:
• There is a requirement for a single point of access for all the support available to older people. There is currently 100's of telephone numbers to access services and there needs to be a strategy to join services up, across public health, CCG and the Council.
• Better joining up between everyone - 72% of older people at the start of lock down had no access to the internet. Local GP services and Public health are trying to digital health support , whilst not investing in the required amount of support to get people onto the internet.
• Long term investment in digital development (72%) and telephone support- ABM are already in demand
• The gap that will be left when ABM has gone.
Whilst the Manager recognises that at the moment when support it required it defaults to ABM, there is that apprehension of what will be done to the work and partnerships when ABM

has gone.
A member queried how ABM support older people online? In response, the Manager outlined that they were there to help and reassure older people to protect themselves against online scammers and the police deliver training as well as google providing online support. The HOPE foundation support older people to get online under their own motivations, for example a zoom account.
Another member also queried whether addition resources would assist the work, and in response, the Manager advised that yes it does assist, however it is more looking at a ore joint up approach with the Council, Health, Public health and looking at ways of delivery. The befriending service has evidence to say that this is a fundamental part to reducing loneliness. This provides a voice, a friendly support. The Manager did however advise that they have been seeing older people face to face where possible, for example delivering activity packs and birthday cakes!

The Manager also stressed that providing information on activities whilst does help some older people engage, those who are lonely and isolated will not attend community events and without these bridging people are essential get getting people to events.

11am the panel paused for the 2 minute silence.

The Director of Social Care and Health Integration praised the work of Aging Better and advised that what they report is evidence based and the truth. He advised that there is discussion of a 5 year recover of covid, in terms of mental health, trauma which in turn may develop to isolation for some people. There is an additional legacy of ill health and therefore the role of Aging better is fundamental in this. The Director advised that the support of the panel on moving forward would be greatly appreciated.

Following a discussion, the panel agreed that they would like to receive an update in 9 months -time and from there look at putting forward recommendation of how further joint work could be undertaken to support some of the key services to continue past 2022.

AGREED-
That the information be noted
That the panel receive a further update on Aging Better Middlesbrough in 9 months time.

3 **REDUCING LONELINESS AND/ OR SOCIAL ISOLATION IN LATER LIFE- AN UPDATE IN RESPECT OF THE ADULT SOCIAL CARE AND SERVICES SCRUTINY PANEL'S 2018 REVIEW OF REDUCING LONELINESS AND/ OR SOCIAL ISOLATION IN LATER LIFE- TO CONSIDER AN UPDATE FROM THE DIRECTOR OF ADULT SOCIAL CARE AND HEALTH INTEGRATION ON THE PROGRESS MADE WITH THE IMPLEMENTATION OF THE AGREED RECOMMENDATIONS/ACTIONS.**

THE PANEL HAS ALSO REQUESTED AN UPDATE IN RELATION TO HOW COVID-19 HAS IMPACTED ON SOCIAL ISOLATION AND STEPS BEING TAKEN TO ADDRESS THIS.

In 2018, the Panel undertook a review into Reducing Loneliness and/ or social isolation in Later life. Part of the evidence, the Panel heard from Michelle Dawson, Manager of Aging Better Middlesbrough who support older people in this field. The Panel had received an updated action plan detailing updates on the recommendations and also asked for information relating to supporting older people curing Covid-19

Covid recovery
In terms of covid recovery, the Director outlined the work that TRUV are currently undertaking of how we respond to the mental health issues over the next 5 years. Covid 19 will have touched many peoples' lives through either personal or personal capacity.
The Director outlined that they have been the impact of Covid 19 in terms of service users

restriction of mobility, difficult to socialise with family and friends, ability to access services e.g. day care and difficulty of visiting loved ones in care homes.
It outlined as the Country enter the second lock down, most of the day care centres have remained open in a covid safe way. In terms of visiting care homes, there is a balance of Individual human rights and the duty to protect the collective and this will always be a fought decision to take.
The Director stated that the Director of Public Health and the Director of Social Care and Health Integration have to make a decision on visiting due to the number of infection rates in the region and it was decided to restrict visiting to essential only with the caveat of end of life.
The Panel learnt that the Social infection, protection and control grant fund was introduced to help care homes with the infection of Covid. In Middlesbrough, some of this money was put into a grant fund whereby care homes could bid for money to introduce visiting pods, or additional outdoor hand washing and it hoped that this would facilitate visiting. However with the new lockdown, the guidance issued means some of the pods do not meet the requirements, however the Council is working on a home by home basis to see if they can facilitate this, however saving lives in paramount and safety will always be put first.
The ABM Manager also added that in terms of isolation and loneliness all aspects are linked and need to be interlinked e.g. not being able to see their friends, family, catching covid and we shouldn't talk about one without the other.
A Board member queried whether there was support in place for home workers or are experiencing isolation. In response, the Manager advised that ABM hadn't done any specific work, as they generally work with those who have complex needs and who have been out of work for long periods and never been in steady work. But she hopes that organisations would offer services to support their workers during this period.

In terms of the recommendations, a panel member raised that the briefing session on loneliness and isolation should be repeated to ensure all members were aware of the issues. The Democratic services officer would arrange this in due course.

The Manager also outlined that in terms of isolation during Covid, there was evidence that this was displaying in young people. A panel member also added that this issue should be raised with the Children and Young people's care scrutiny panel for consideration.

AGREED-
That the information contained in the updated action plan be noted.
That a further member briefing on loneliness and isolation be arranged.

Tees Valley CCG – Palliative and End of Life (PEoL) Care

Craig Blair – Director of Commissioning Strategy and Delivery

NHS
Tees Valley
Clinical Commissioning Group

Context

Complex system - Tees Valley Integrated Health and Care Partnership (ICP)

Organisational change - CCG mergers have highlighted variation in care pathways, funding and contracting methods across PEoL care services and emphasised the need for one vision, co-produced with partners.

Our aim – Integrated, streamlined service delivery models that put the patient at the heart of decision making, enabled via innovative contracting and service provision to support delivery and sustainability.

Learning from the Covid pandemic – Co-ordinated, flexible and effective system responses. However the pandemic has had wider system impacts with Hospices especially in light of reduced charitable income.

Impetus for change - Review services and explore the development of a system wide approach to delivering integrated services through a new delivery model.

Innovation – Collaborative working to develop and deliver new and innovative pathway development and contracting solutions to deliver true integrated care that draws on the emerging 'Future Vision' work NHSE/I are currently supporting Hospice UK to produce, with the aim of re-imagining a more sustainable future for palliative and end of life care.

Our Aim

To make the last stage of people's lives as good as possible by aligning systems and processes so that everyone works together confidently, honestly and consistently to help the patient and the people important to them

An opportunity for the Tees Valley

Tees Valley CCG has been successful in bidding for NHS England support to undertake a commissioning pilot - £50,000

The funding will be used to;

- Support driving the agenda forward and create an environment where transformation can be achieved in a collaborative way across partners.
- Undertaking multi-agency engagement, patient/carer/parent consultation and engagement events to support development of a Tees-wide vision and strategy for PEoLC.
- Ensure the vision and strategy are owned by partners and are built from the 'bottom up', addressing local issues and building on good local practice.
- Enable the capacity to build relevant relationships across all key stakeholders that span the adults and children's agenda's and enables implementation of the key principles of the proposed service specification plus address local concern regarding service stability and cohesion.

NHS
Tees Valley
Clinical Commissioning Group

What we hope to achieve

This approach will support delivering the following key service developments and outputs;

- Scoping existing services against the national service specification and NICE Guidance
- Development of an ICP vision, key priorities and strategy for Palliative and End of Life Care spanning children and adult's services utilising the Ambitions for Palliative and End of Life Care and the CQC framework: Getting to Good
- Creating a cohesive pathway that spans all age ranges and offers equity of access for patients across all locality areas within the ICP, providing consistency across the following areas-
  - community support including primary care
  - specialist palliative care Acute/Community based support
  - Hospice provision
  - Children and Young People/adult transition, palliative and respite care
- Ensuring stability of service across the hospice market
- Reviewing and developing 24/7 access to specialist advice
- Reviewing and developing 24/7 community nursing services for both children and adults
- Increased implementation and utilisation of key aspects of the personalised care agenda to improve patient outcomes
- Co-ordinated care across organisations where money follows the person into the most appropriate setting and choice is supported for the person and family/carer where possible.

How we hope to go about this

We will;

- Undertake engagement with partners
- Baseline PEoLC services across the Tees Valley, using the commissioning and investment framework to classify key services into core, specialist and enhanced.
- Utilise service specification good practice templates to ensure revised service offerings meet the key requirements for good PEoLC.
- Ensure service specifications meet national standards, national policy and personalised care approaches, with amendments to meet each provider arrangement as appropriate.
- Test the guidance to develop meaningful integration across providers and organisations which may require non- traditional contracting methods.
- Explore alternative contracting methodologies such as delegated budgets or other innovative contracting approaches.
- Explore and develop further the relationships between specialised and local commissioning in order to improve the EOL journey for CYP and their families.

Next Steps

- Agree and sign off Memorandum of Understanding with NHSE for the pilot funds (December – Jan 2021)
- Recruit project support as per the requirements of the bid (circa Jan – March 2021)
- Agree a programme of extensive engagement with patients, carers and stakeholders to co-design a vision for EoL services across the Tees Valley early in the new year
- Translate the vision into new pathways and re-design service models with providers – supporting a collaborative approach
- Mobilise new pathways to support improved patient outcomes - spanning 2021/22

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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
27th November 2020