Southern Health and Social Care Trust

Do you currently work in palliative care services and if yes in what capacity?

General Adult Palliative Care

Southern Health and Social Care Trust provides **general adult palliative care** across many adult specialties both and as inpatient, outpatient and community based services including

- Across 2 acute (Craigavon Area Hospital and Daisy Hill Hospital) and 2 non-acute (Lurgan Hospital and South Tyrone Hospital) hospitals.

- Community-based services

Specialist Adult Palliative Care Services

Specialist Adult Palliative care services are provided by the Southern Health and Social Care Trust as follows

- Hospital based Palliative Care Team:
    - 9 - 5, Monday – Friday for Craigavon Area Hospital and Daisy Hill Hospital
    - Liaison team advising on the holistic management of inpatient and supporting ward staff in delivering palliative and 'last days' care
- Weekly Hospital based Palliative Medicine outpatient in 2 locations
- Community Specialist Palliative Care Team
    - 9 – 5, Monday – Friday for entire Southern Trust
    - Multidisciplinary team including Specialist Palliative Nurses delivering palliative and 'last days' care to people at home. Consultant, pharmacist, Nurses, AHPs, Social Workers
- Out of Hours 'Doctor to Doctor' telephone advice
    - Palliative Medicine Consultants (4 consultants) provide on call telephone advice to GPs and hospital doctors in the out of hours period.
- Inpatient Speciality Palliative Care Services are contracted for 12 beds from Southern Area Hospice Services (Newry).

Specific Comments

The provision of Community Specialist Palliative Care Services in the Southern Trust Area is different to other Trust areas of Northern Ireland. In the Southern Trust, the Community Specialist Palliative Care Team is multidisciplinary, Trust funded and Trust run community team. Professionals within the team consist of Consultant,

Pharmacist, Nurses, Physiotherapists, Occupational Therapists, Speech & Language Therapists, Dietitians, Social Workers and Admin support. In other parts of NI, the Community Specialist Palliative Care Teams services are contracted through charitable healthcare organisations (NI Hospice and Foyle Hospice).

- Approximately 3500 deaths in Southern Trust per year.
- Over 1500 referrals for Southern Trust in 2024. This increases yearly.
    - Growth of referrals is currently at approx. 33% from 2021.
    - As of March 2025, up 13% on last year alone.
- With increased referrals, the team have prioritised those with the greatest need and moved to an episodic care model (see and discharge model rather than keep reviewing for the remainder of the person's life). However now, due to the demand for the palliative services, use of a waiting list is being considered.
- The provision of Out of Hours 'Doctor to Doctor' Telephone advice is via Southern Area Palliative Medicine Consultants (4 consultants). (SET, BT and WT Out of Hours Medical Telephone Advice is contracted through a UK based company.)

In your view what is the current state of palliative care services in Northern Ireland? Excellent Good Neither Poor Very Poor Don't know

No answer as comments not requested to qualify the answer.

Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?

No

Published evidence shows the general public have a poor understanding of words such as 'palliative care'. In 2021, a Marie Curie Collaboration survived around 500 member of the general public and published their findings "Creating a Death Literate Society".

However, we also acknowledge and seek to support the role of unpaid carers, family, friends and the wider community in caring for patients who are palliative

The "95% rule" promotes the concept that seriously ill and dying people spend little more than 5% of their final year of life in the direct care of healthcare services; the other 95% relies upon relatives, friends or others without healthcare backgrounds to provide support. Viewed in this context, the people in our communities do support each other at times of physical deterioration, dying and bereavement. (Reference 'The social nature of dying and the social model of health' by Allan Kellehear.)

Barriers include

- Lack of clarity on words and phrases used - for example ‘general palliative care’ and ‘specialist palliative care’
- Promoting a ‘medical model’ rather than promoting a ‘Compassionate Communities’ model of public health
- Not encouraging, supporting and promoting individuals within our communities to care for each other during life-threatening illness, death and bereavement.

Are palliative care services equally accessible to all who need them?

No

From your experience where are the gaps in the provision of service?

<u>Southern Trust ‘gaps’</u>

We are aware of gaps to our Specialist Palliative Care services within the Southern Health and Social Care Trust but lack the funding to address these at present.

Acute Hospital gaps

- Monday to Friday in person service only. Aiming for 7 day in person service.
- Inadequate multidisciplinary team to support education of ward staff for Palliative and Last Days care. Aiming for a larger team to support our non-palliative care staff with education and training.
- No Mandatory ‘Last Days’ Training for non-specialist-palliative clinical staff

Community Specialist Palliative Care Team gaps

- Monday to Friday in person service only. Aiming for 7 day in person service.
- Service requires expansion to meet current and projected need

Additionally in the Southern Trust, there are 4 healthcare charities providing a range of services. On a practical level, it can be hard to keep up with changes to the various services as services/postcode availability change is based on the charities’ priorities. It is therefore also hard to clarify the gaps between services.

<u>Regional ‘gaps’</u>

- Lack of co-ordination and strategy
- Regional variations in NHS and charitable funding/services/staffing available in various regions.

Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

Yes

- Lack of NI Palliative Care Strategy
- Funding arrangements: ‘competition’ between charitable palliative healthcare providers. Essentially the current ‘system’ pitches charities against each other in fundraising and service provision often dictated by factors other than a needs assessment.
- Funding arrangements: lack of clarity and transparency on funding of Specialist Palliative Care services – both NHS and charitable organisations - in different Trust areas)
- Geographical barriers (road network, public transport, rural/urban)
- Community access to pharmacies stocking core palliative care drugs
- Social barriers
- Cultural/religious/language barriers

What additional services could/should be provided?

Specialist Palliative Services

Acute Hospital Services

a) 7 days a week (9 – 5) face to face service (ie a Specialist Palliative Nurse working Saturday and Sunday in the Acute Hospitals in every Trust)
b) Regional ‘Last Days Doctors Documentation’ Template and ‘Last Days Nursing Documentation’ template on Encompass to standardise last days care in hospitals and improve National Audit for Care at End of Life
c) Regional Mandatory ‘Last Days’ online training module for non-specialist-palliative clinical staff - Regional guidelines for ‘Last Days Care’ expanded

Community Specialist Palliative Care Services

a) 7 days a week (9 – 5) patients/relatives/District Nurses telephone advice service (ie a Specialist Palliative Nurse working Saturday and Sunday taking phone calls from patients/relatives/District Nurses in every Trust)
b) Financial review of Southern Trust Community Specialist Palliative Care Multidisciplinary Team to guide contract arrangements for Specialist Community Palliative Care in other Trusts
c) 7 day community pharmacy assess to core palliative drugs

Palliative inpatient units

a) Adequate palliative inpatient unit beds-per-head –of-population per Trust.
b) Clear, transparent and fair funding arrangements between Trusts and hospices

c) Financial review of Northern Trust ‘Macmillan’ Hospital-based Palliative Care ward to guide contract arrangements for palliative inpatient care in other Trusts.

A map (regularly updated and ‘live’) to show availability of palliative services in that area (for healthcare staff and patients/relatives)

How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

Specialist Palliative Care

- Specialist Palliative Care Teams in Acute Hospitals: well integrated
- Specialist Palliative Care Teams in Community: Southern Trust is well integrated as it is Trust run. We believe it should therefore be the model for Community Specialist Palliative Care in NI.
- Specialist Palliative Care inpatient beds: ‘Hospice’ inpatient services are not well integrated. Except Northern Trust ‘Macmillan’ Hospital-based Palliative Care ward which is NHS run and therefore well integrated.

Primary Care

- Palliative Care is a core part of GP Teams and District Nursing Teams practise.

Secondary Care

- Depending on the ward/specialty, Palliative Care is either a core or an occasional part of practise. Depending on the frequency and mode of dying.

Should palliative care be a regional service? Please outline your reasons in the box provided

There are pros and cons to development of a regional service.

There are clearly regional needs with potentially regional solutions:

- A Palliative Care (General and Specialist Palliative Care) Strategy
- Commissioned Specialist Palliative Care services
- Clear, transparent funding arrangements
- Regional ‘Last Days Doctors Documentation’ Template and ‘Last Days Nursing Documentation’ template on Encompass to standardise last days care in hospitals and improve National Audit for Care at End of Life
- Regional Mandatory ‘Last Days’ online training module for non-specialist-palliative clinical staff
- Regional guidelines for ‘Last Days Care’ expanded

- Regional roll out of the Advanced Care Planning and Respect documentation
- Regional electronic prescribing for GPs/Community patients

However,

- Palliative Care, dying and bereavement is not a 'regional' experience and patients/families should not have to travel for services.
- Additionally, our experience with 'regional' services tend to be that they are mainly located in the Belfast Trusts and funding is diverted from more peripheral Trusts.

What can be done to improve integration?

There is currently an insufficient understanding of Specialist Palliative Care Service provision across NI at present to make a recommendation on improving integration. We feel it would require:

- a clear understanding of the Specialist Palliative Care services provided across the region and the funding arrangements need clarified and understood.
- a population based needs assessment for those likely in their last year in NI
- a Regional Strategy
- a structure capable of delivering changes

There are certainly initial improvements that can be made before this is completed based on good practice and experience in the UK and ROI.

Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

Southern Trust

- The provision of Community Specialist Palliative Care Services is different to other parts of Northern Ireland. In the Southern Trust, the Community Specialist Palliative Care Team is Trust funded and Trust run. In other parts of NI, the Community Specialist Palliative Care Teams services are contracted through charitable healthcare organisations (NI Hospice and Foyle Hospice).
- The provision of Out of Hours 'Doctor to Doctor' Telephone advice is via Southern Area Palliative Medicine Consultants (4 consultants). (SET, BT and WT Out of Hours Medical Telephone Advice is contracted through a UK based company.)

Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

While this is an emotive concept, we are not clear what 'enough' support when accessing services would be. Not sure sufficient support will ever been given to all families all of the time.

The Southern Trust acknowledges once again the role of unpaid carers, family, friends, neighbours and our entire community in supporting those who are facing life-threatening illness, the dying and the bereaved. Dying is a social experience and while services can support individual and families, empowering use all to develop 'Compassion Communities' is hugely important.

- The "95% rule" promotes the concept that seriously ill and dying people spend little more than 5% of their final year of life in the direct care of healthcare services; the other 95% relies upon relatives, friends or others without healthcare backgrounds to provide support. (Allan Kellehear, "The social nature of dying and the social model of health").

We would agree there are insufficient Specialist Palliative Care services to meet current and projected needs.

Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

No

General Palliative Care through GPs

- Fair funding to recognise the time and expertise needed to care for patients with life threatening illness in their homes. These patients often have multiple health problems and complex social and medical needs requiring additional GP time.

Specialist Palliative Care Funding

- Independent charitable hospices providing inpatient and community Specialist Palliative Care services are contracted by Trusts. In Southern Trust, 12 inpatient palliative beds are contracted by the Trust through Southern Area Hospice Services.
- In is unclear the funding arrangements with Trusts and Hospices and how much additional fundraising a hospice requires for those inpatient beds.
- It is unrealistic to expect Trusts to fund a service 100% it has no oversight of. However funding the core services of a specialist palliative care ward would be reasonable and the model for the cost of this is the Northern Trust 'Macmillan' Hospital-based Palliative Inpatient ward with is NHS run and funded.

- Hospital-based Palliative Inpatient wards should be explored as an alternative to Hospice care. Increasing patient complexity and patient preference, the need for laboratory and imaging diagnostics, the need for specialist consults, and the need for NHS governance suggests that the Northern Trust model of Palliative Inpatient Care may be best suited to the further of Specialist Palliative Care.

Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

No

The current funding and service model in unsustainable to meet current and projected demand. Please see above response re: need to re-think Specialist Palliative Care Inpatient beds.

Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided

Yes

While a Strategy is generally considered helpful, it would be more important to bring accountability and responsibility to addressing the need. Potentially policy or making palliative care a legal right, as it is in England and Wales may have more impact.

Any other comments

1. Counting of 'general' palliative care unnecessary and time consuming
    - The Southern Trust has been made aware of the intention to commence a baseline audit of the totality of adult palliative care services (both generalist and specialist).
    - We would urge the Committee to reconsider and instruct the Department to conduct an audit of Specialist Palliative Care Services in depth
    - We feel 'general palliative care services' is essentially all adult healthcare services (hospital, community and GP services) as patients with life-threatening conditions and in the last days use the entire range of NHS healthcare services therefore counting these would be time consuming and unnecessary.

- The focus on resources, funding, staff and service provision is on Specialist Palliative Care Services and therefore an in depth assessment of these to allow for early decision making would be most helpful.
- The momentum created by the Health Committee risks being lost by a laborious counting of NHS general palliative care services which would not serve the people of this region well.

2. ED care not a failure, but needs to be more focused on supporting quality rather than quantity of life
    - Almost 50% of people die in our NI hospitals. While people may initially state they wish to die at home, when care needs and symptoms change, people often choose something different to originally planned. Often, this is a hospital.
    - Palliative patients have equal right to receiving care in ED and access the diagnostics, treatment options and specialist opinions that Acute Hospitals afford.
    - While the move toward the community is helpful in providing appropriate care, we do not want our language to give the impression that Palliative patients are in any way less deserving of active treatment options. However their options may be more focused on quality rather than quantity of life.
3. Regional caution
    - While there are certainly pieces of work which could and should be regional, Palliative Care, dying and bereavement is not a 'regional' experience and patients/families should not have to travel for services.
    - Additionally, our experience with 'regional' services tend to be that they are mainly located in the Belfast Trusts and funding is diverted from more peripheral Trusts.
4. Fair and clear funding arrangements
    - 'competition' between charitable palliative healthcare providers. Essentially the current 'system' pitches charities against each other in fundraising and service provision often dictated by factors other than a needs assessment.
    - lack of clarity and transparency on funding of Specialist Palliative Care services – both NHS and charitable organisations - in different Trust areas
5. 95% rule
    - Finally the Southern Trust wish to acknowledge and seek to support the role of unpaid carers, family, friends and the wider community in caring for patients who are 'palliative'.
    - The "95% rule" promotes the concept that seriously ill and dying people spend little more than 5% of their final year of life in the direct care of healthcare services; the other 95% relies upon relatives, friends or others without healthcare backgrounds to provide support. This is the underlying principle of a movement called Compassionate Communities.