

Southern Area Hospice Services

Current state of palliative care services

In your view what is the current state of palliative care services in Northern Ireland?

Poor

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

There is a lot of evidence to show that the public do not understand palliative care.

Life and times survey 2018 and 2022 Palliative Care Week surveys National Audit of Care at End of Life Survey. The public continue to associate palliative care services with cancer and end of life only. We need to educate the public on what palliative care is and what it can provide. we need a public health education programme on death and dying and normalise the conversation. There have been some initiatives to do this, but they have not gained the traction due to lack funding and resource. The compassionate communities' approach is a model that should be considered as it enables discussions and support networks in communities. Additionally Advanced Care planning is a clear opportunity to begin conversation around future planning and death and dying. Staff across health and social care can have a very limited knowledge of palliative care. There needs to be generalist training as a core competency for all non-palliative care staff. In addition, training to palliative care staff (especially specialist care) needs to be further enhanced. The language used to talk about palliative care is confusing to those in this area never mind more generalist staff and the public. This adds to the lack of understanding and creates misunderstanding. Language should be agreed in any new strategy or action plan produced and should be developed to ensure understanding of all stakeholders.

Access to services

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

No

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

Services are inequitable across the region, and it is a post code lottery and most are urban centric. They are seen only as a cancer service – i.e. cancer strategy yet no updated palliative care strategy. Patients can have palliative care needs emanating from a variety of conditions. There are patients in all areas of care (primary secondary and community) who are not being offered the right care and support at the right time. There are very significant gaps in palliative care services provided outside of the routine Monday – Friday 0900 – 1700. This results in patients ending up in settings which are not equipped to manage them

well (such as ED). Lack of packages of care (POC) in the community delays discharge from hospitals and hospices with palliative patients having to remain in hospital or hospices longer than necessary due to inability to be appropriately discharged. Lack of nursing home support for more complex patients who cannot be managed in community, however, do not need hospice care. There is a growth in overall demand; increasingly complex cases requiring more sophisticated and specialised clinical management. There is an increase in demand for psychological services as many of these patients and families are struggling to come to terms with their situation. If these needs are not met, they have an impact on the patient's and their family's ability to manage the clinical aspects of their condition.

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

Yes

Lack of funding is a considerable issue, services not properly resourced especially hospices. Model of financial support from Government is at best outdated. It is jeopardising the sustainability of hospices. Some palliative care beds in NI are 100% government funded whilst others are not even at the current stated benchmark of 50% (ourselves). Money allocated for short-term projects and not renewed (e.g. Cancer Charities monies see information on OOH service). No updated Palliative Care Strategy to guide the implementation of a better approach to palliative care across NI. Policies are developed which should see positive change to how we operate but their implementation is not resourced - The Advance Care Planning Policy launched in October 2022 and DoH are working to implement ReSPECT in 2023 to replace the existing DNACPR process. Encompass – the approach of a single record for each patient is to be commended. However, hospices are not included as mainstream providers and therefore will be outside the system for the foreseeable. Regional approach was to be developed towards Individualised EOL Care Plans. DOH statement shared on Sep 23 Regional Board meeting – this is not to be progressed at present. This is unacceptable and permits different working practices. Ensuring palliative care services are provided in an appropriate way for each person is challenging. Palliative Care services need to ensure they reflect that. As a provider we do our best but if this was more joined up, we could all do better.

What additional services could/should be provided?

Improvement in clinical care resource to ensure at least a minimum standard across the region.

- 24/7 Multi-disciplinary Team support in acute and community and hospice settings
- Out of hours support
- 24/7 hospice at home service
- More resources to community core teams (DN, Physio, OT etc) for generalist support palliative patients and their families
- Tailored Carer support
- More psychological/social and financial support for patients and their families

- Tailored education support programmes for core teams
- Fully funded training programs for specialist or dedicated palliative services (Acute and Community Specialised Palliative Care Teams and Hospice)

Integration of Services

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

In general, the provision of palliative care services is not in a great place. This is influenced by the fact there is no current regional strategy and is poorly resourced. Palliative care is not a priority in government evident by lack of policy direction and it not being a focus of the programme for government. Service development is mostly influenced by the ability of local providers to respond to the need that they identify within their areas rather than a population assessment and this then means that service provision ends up being a postcode lottery. These different supports in different areas creates a huge challenge for integration as there is a need to think of all the key services that feed into it. In general, it is disjointed, multiple levels of systems, teams, and services and while operations work very hard to integrate and work together but system does not allow for integration. Each Trust is even different. Hospices, community services and hospital services are all working with slightly different systems, different software packages, to different communication needs, and different goals and this creates difficulties. Funding is different in different areas and at times there is competition for same money. Multiple services with no integrated funding and no integrated communication.

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

Yes

There should be an agreed Integrated Palliative Care Model in NI which should be accessible, equitable, and adequately resourced which accompanies a palliative care strategy.

This will:

- Help to standardise services ensure all areas receiving equitable services
- Ensure safer practices
- Better sharing of knowledge and skills
- Limit competition for funding and resource
- Potentially better governance
- Joint up education and training
- Enable robust workforce planning and look for areas where workforces can work across Trust boundaries (e.g. medics)

However, there would need to be assurances that whilst there should be a regional service provision this needs to be close to patients and where they live and be flexible enough to adapt to localised matters. We need to work towards honouring where the person's preference is to receive care, and where possible to die at home, with the infrastructure in place to make such a choice real and viable.

What can be done to improve integration?

- Review strategy and policy or at least develop a detailed regional action plan.
- Prioritised in programme for government.
- Ensure resource for audit outcomes to develop best practice.
- Ensure resource for policy development and deliverance.
- Improve staffing resources - numbers but skills and expertise as well.
- Learning from excellence elsewhere – Ireland has a similar demographic and with a government prioritisation of palliative care services via a mixed economy of providers have a much more comprehensive service offering which is sustainable due to the funding position enshrined in law.

Example of services working well that could support integration, if further rolled out:

- Single point of contact. People have a number to call for the right person, right service, at the right time.
- Bring all organisations fully into Encompass.
- Frailty model - helping the community to provide services for the population.
- Joint workforce planning with regional population approach to needs. Workforce appropriate for population, not based on postcode lottery.
- Supporting uniformed data-based approach. Consistent collection of data across services. PCIP keen to look at this (minimum data collection).
- Out of Hours Nursing support at home for EOL

Best Practice

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 Area Hospice provision of holistic care to patients', their families and bereaved in the Southern Trust area is an example good practice. Our Hospice Team is a multi-disciplinary team working together to provide specialist palliative care and treatment to patients, their families/ carers and those bereaved. Our experienced team focus not only physical care but also on emotional, social, and spiritual wellbeing. We tailor our services to individual needs and those of the family. We provide wraparound services in their home, one of our hubs and when necessary, our inpatient unit. Additionally, SAH have developed an out-of-hours nursing support in the home at end of life to support patients who wish to die at home. The Service is available 365 night per year and between the hours of 22.00 and

08.00. The impact of the service has been extremely positive, and we have enabled all patients on the service to achieve their Preferred Place of Death (PPOD) and prevented patients dying in the acute hospital setting or needing to avail of emergency care in an acute setting. There is no recurrent funding for this project however we continue to fund the project at risk, due to its success and ongoing need in the community. There are many other examples of good practice and pilots across NI however due to funding they are under resourced, dependant on voluntary funding, and postcode lottery.

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

No

This is not always and depends on where they are receiving support. As outlined above services provided are impacted by postcode lottery and resource dependent. As already outlined before

- Too many patients die in pain
- Massive gaps in 24/7 community care
- Inadequate coordination of services
- Insufficient workforce (numbers and skills) capacity to meet demand
- Unsupported carers – excessive carer burden
- Not enough recognition and thereby services regarding the emotional and psychological impact on patient and families.

Funding and Strategy

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

No

Northern Ireland is an outlier in comparison to England, Scotland, Wales and Republic of Ireland. Further the approach in Ireland shows the prioritisation of palliative care for its citizens. The absence of strategy, the legal right to access palliative care and inadequate funding in NI is in stark contrast. Looking at NISRA, figures show that population is growing, people are living longer, co-morbidities and complex illness is highly prevalent and there is a younger cohort of patients with late diagnosis or advanced cancer. The pressures elsewhere on Health Trusts is well documented but it needs to be realised that hospices are struggling financially too. In 2023, Northern Ireland, with a population of 1.92 million, experienced 17,267 deaths. Of these, 46.9% occurred in hospitals, 17.5% in care homes, and 37.5% at home, in hospices, or other locations. It is estimated that approximately 8 out of 10 people who die would benefit from palliative care. Additionally, for every person who dies with palliative care needs, there are 12 others living with palliative care needs. NISRA estimated that by 2046 the population of Northern Ireland will be over 2 million and those aged 65+

will have practically double (49.2%). We are in a very vulnerable position moving forward into the future, services are not equipped to meet expected demands of the population.

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

Not sustainable too much reliance on public fundraising from local communities. A vital service reliant on local fundraising is not a secure funding model. Last year we received 34% of our income from SPPG – this % already excludes the costs we incur to generate our own income. On average our income from SPPG has increased by 2% each year. Our costs to deliver services is impacted by significantly increasing costs. This includes pay awards to staff to ensure parity with staff in the HSC, and other increasing running costs. One year budget allocation from Government means we are constantly working on a short-term approach. This impacts our ability to plan. We appreciate that Government is seeking to address this. Our financial revenue model means it is very difficult to address other issues such as infrastructure to appropriately deliver services in. 'Pots' of money become available every now and then. For example, for support worker for 18 months. Whilst this is to be welcomed it is not an approach that should be used to sustain services, rather it should be used to try, for example new ways of working or to enhance a service etc. If the Ireland model was adopted – that is 100% funding of hospices apart from their income generation costs, local fundraising could be used for innovation, additional services, comfort services, education and research. In fact this model in effect already exists in parts of NI which creates a very significant fairness and equity issue.

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

Northern Ireland's palliative care policy lags behind UK regions and Ireland. It has an outdated strategic approach with the most recent palliative care strategy, "Living Matters, Dying Matters," expired over a decade ago. The publication of the Irish Government's strategy starkly illustrates the disparity in approaches when our population issues are the same and demographic challenges are the same. Since that time the need for palliative care services among our population has soared and is expected to continue to increase dramatically while funding pressures on our services have never been higher. The long-term costs of ignoring the need for a strategic approach to ensuring that the dying (irrespective of postcode or financial status) can receive compassionate and professional end of life care is huge.

We support the implementation of a palliative care strategy, including the Integrated Palliative Care Model. This should outline the nature of palliative care, including an emphasis that palliative care be woven throughout the health care system and include the importance of advance care planning, and the importance of involving patients and

caregivers as experts. Palliative care should be a universal right and policy should indicate this. The Strategy needs to sit alongside a policy with a funding commitment and clear accountability.

Any other comments

We have been through similar reviews in the past 10-15 years ago. We have engaged in this process many times and are not at all sure of the impact that occurred. Frustration from palliative care staff at lack of progress. We are engaging in this process as we have an obligation to do so and in the premise that change will ensue. We would like to see a firm commitment to produce a palliative care strategy/policy, with committed funding, accountability and implementation plan for the next 3 years. The funding of hospices is robustly reviewed to ensure these services do not fail or diminish. All hospices in Northern Ireland to be brought into Encompass as soon as possible. Commitment to ensure the RESPECT implementation is taken forwards. One stop shop/ single point of contact. People can get access to good consistent, comprehensive information, good support, 24/7. Need to acknowledge failure to deliver and lack of progress from the last strategy; outline reasons for the pitfalls experienced in the last process, so this does not happen this time around. Level of inequity across the region in relation to what you can access and how you can access it (postcode lottery) must be addressed. Inequity starts at government level, inequity of support received from government in comparison to other regions.