

Life and Time Nursing Agency

Life and Time has a team of over 70 registered nurses and 8 Gps that provide on-call nursing care for patients in their home- at or near end of life from 22:00-08:00 365 days per year. Registered Nursing Agency providing care to patients at or near end of life. Our service provides on-call nursing care from 22:00-08:00 365 days per yr for patients referred by their GP and live in our catchment areas. Operational since 2018, Life and Time supports the communities of Warrenpoint, Rostrevor, Burren, Rathfriland, Hilltown, Mayobridge, Kilkeel, Annalong and Ballymartin.

CURRENT STATE OF PALLIATIVE CARE SERVICES

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

In our view palliative care services in NI is in a state of disparity. There is inequity in accessing services and the level of service/s which are accessible depends on where you live and what palliative care services may be available in that area. The population living in urban areas are better served than rural areas when it comes to palliative care services. Rural areas often identify the gaps and find innovative solutions to partially fill those gaps working in partnership with existing services.

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?

We think there is a limited but growing awareness of palliative care by the public in NI. Historically it would have been poorly understood if at all or totally misunderstood. Regional work on ACP and Public Health Approach, to palliative care Death Cafés has gone some way to engage the public and increase their awareness and understanding of palliative care. The main barriers to the public understanding is lack of interest, lack of opportunities, not seeing it as a priority area in their lives and palliative care not mattering to them until it does matter. The death denying society that we live in in NI has a long way to travel yet. Palliative care is often associated with end of life care, death and dying, last resort, nothing more we can do for you mindset which will take time patience and sustained effort by all to raise the profile of what palliative care has to offer those who need it and their families.

ACCESS TO SERVICES

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

No there is not equal access to palliative care services across NI. In the areas where access is good it is very good but in the areas less fortunate depending on where people chose to live it is sparse very patchy with poor limited access to services across all care services.

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

Yes there are gaps in provision of palliative care provision. It is difficult to identify and fill gaps in the absence of a key driver but based on experience we can identify some. Living Matters Dying Matters March 2010 offered a Palliative and End of Life Care Strategy for NI. A Palliative Care Policy is required in NI to support developments with a funded implementation Plan.

One gap is the absence of a regional central point of referral across NI . A pilot project is taking place in one of the largest HSCTs at local trust level so the outworkings from that should help inform way forward

Another gap is Out of Hours provision of palliative care services particularly across community services. This is a wide gap, (more wide in some areas which have poorer access than others which have better access) with some services, both statutory and voluntary trying to close the gap. Service demand often outweighs service provision/ staff availability. The rapid and widespread uptake of our organic model of care is proof of the absolute need in the Out of Hours period.

A third gap is information sharing across boundaries of patient 9 primary and secondary) care with IT systems not speaking to each other. It was hoped that Encompass would address that but I am not sure that this has been an output to date. NIECR not accessible to all care providers which is another gap when it comes to timely up to date information sharing / patient records.

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

Yes there are barriers to providing equitable access include

1. financial strain and funding disparities.
2. Demographic changes and rising costs.
3. Staff capacity and capabilities across the entire workforce.

What additional services could/should be provided?

We need to get in hours service provision equal and accessible as a first line but OOHs is also a priority

INTEGRATION OF SERVICES

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

Patchy/ partial integration of palliative care across primary secondary and specialist care. Depends on individuals driving the agenda on integration. Some good evidence of improved integration but much more work to do in this space.

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

Not sure. Regional service may be a better way to ensure equal access for NI population. Important that local need is not lost sight of if service is regionalised.

What can be done to improve integration?

More work required at local level to promote and drive forward integration . Existing networks at local and regional level through Palliative Care in Partnership ,an excellent model etc offers an already well established network to promote integration at all levels through PCIP regional workplan, Programme Board Members and Clinical Engagement

Group etc

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?

The Life and Time Nursing Agency is an example of good practice in meeting the needs of patients families and carers across South Down NI within SHSCT. It is a nursing agency regulated by RQIA and a Charity regulated by NI Charity Commission. A local response for the local population based on identified need offering a community nursing out of hours on call service 10pm -8am. This model was replicated by SAHs to offer a service to those living in areas of South Armagh within SHSCT we are not aware of any other area across NI offering this or a similar service.

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

Variable levels of support offered to patients depending on what level of palliative care provision is available / accessible to them in the area which they live in.

FUNDING AND STRATEGY

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

We think the current funding is inadequate and insufficient. A population based needs assessment review matched to a robust funding model and projection of future palliative care need across care settings in NI could influence this position much better.

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.

We do not believe the current funding of hospice is either sustainable or sufficient to meet population need now or into the future.

If the current financial pressures, funding disparities. dependency on fundraising to exist in the current economic climate, increasing demand due to increasing palliative care need, demographic changes, widening access to palliative care to those with life limiting conditions, growth despite adversity, recent bed closures in hospices or hospice closures, staffing challenges re increased staffing costs staff unavailability, staff turnover, staff retention and recruitment issues, are taken into account the current model will not address these very real and growing issues.

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

We would suggest there is an urgent need for a NI Palliative Care Strategy rather than a new

Palliative Care Policy A strategy specific to NI population palliative care needs tied to a timeframe with a fully funded implementation plan and an outcomes based evaluation framework built in from the beginning. The strategy should offer a broader plan outlining how long-term objectives can be met and by when. Evaluation of outcomes is a crucial component to consider in devising the strategy.

Living Matters Dying Matters 2010 (referred to as a strategy but in my view landed more as a policy) focussed attention on maintaining order ,which served the time it was created in well but we are in a very different space now 14 years later. A revised updated NI PC Strategy will provide the overall direction and approach to achieve palliative care for all at whatever level they require it no matter where they live.. It will also be a welcome addition for clinicians who will use it as a reference point for planning service provision and evaluating impact.

Any other comments

Thank you for the opportunity to respond to this NI Assembly inquiry into accessing Palliative Care services in NI. I hope our comments might go some way to informing this inquiry and the way forward