Royal College of General Practitioners Northern Ireland

Current state of palliative care services

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

Good

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?

The public and often healthcare professionals can often believe that palliative care means only end of life care, and while this is an important component, palliative care can also help patients and families to 'live better' as patients can often live good and fulfilled lives with good palliative care.

There is key need to break down the barriers to understanding the needs of families seeking palliative care, such as better education, an open public discourse and improving the service for patients who are already receiving it. In particular, improving the planning and implementation of advanced care would support an earlier and more comprehensive discourse with individuals about their wishes, and also being realistic about what is available and can be put in place to support them.

Palliative Care is not just about cancer, it is for anyone who has symptoms of a condition from which they will not recover. In addition, palliative care is delivered up and down the region daily by General Practice and community teams (e.g. District Nurses), not just specialist Palliative Care services.

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?

District Nursing teams provide a majority of the day-day palliative care for patients at home, and they offer a remarkable responsive, adaptive and patient centred service- however they are among the most stretched teams in the Health and Social Care workforce. GPs provide much of the medical aspects of community palliative care, however the current crisis in GP services, with underinvestment, long-term workload and workforce issues has undoubtedly had a detrimental impact on the services we provide to our palliative care patients. Across community and specialist teams, workforce limitations have significant impact on the ability of these teams to provide such a service. A workforce that matches capacity to need in a more timely and responsive fashion would deliver better care and reduce the potentials for delay in response time to urgent need e.g. end of life medication or indeed capacity for inpatient and outpatient specialist services.

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

Yes

Current investment in community (district) nursing teams is wholly inadequate, and workforce/workload issues are leading to intolerable strains on these teams who provide the majority of palliative care. Much of the palliative care in the community is overseen by the patient's own GP, who due to chronic underinvestment face issues with recruitment, retention and major workload issues which impact the care GPs can provide. Where care is particularly complex and the need for specialist palliative care input is required, this can be limited by capacity and availability of such primary care teams. In a palliative care setting, capacity to react to need in the quickest and most effective way is integral to being able to deliver a quality service.

What additional services could/should be provided?

Improved availability for psychological services for patients and for their families, particularly grief support for families would extend a good palliative service to support bereaved families. It should also be noted there needs to be greater public awareness of current services, as often patients and their families are unaware of current services that are available to them.

Improving advanced care planning and the implementation of ReSPECT2 could contribute to improved understanding of and use of palliative care services across NI.

Integration of Services

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

From a primary care perspective, there seems to be a disconnect between the palliative care services provided between different geographical areas, as well as between primary and secondary care. It can be very challenging as a GP, to help a patient navigate through the journey. In some areas, 2 community palliative care services exist, some of the roles of the services are overlapping, some are unique to each service, but healthcare providers can be left unsure to which service, if any, they can refer. This creates the possibility that patients miss out on potentially life changing services, due to poor integration and lack of homogeneity throughout the region.

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

The entire population in NI should have access to the same services, and there should be a large degree of homogeneity across the province, to ensure equity of access and to allow healthcare providers to refer to the appropriate service easily via a fixed regional pathway. Such a pathway should deliver equity of access to services but also allow the delivery of

such service to reflect the needs of the individual and the community, given the significant differences geographically. Within Northern Ireland, there are substantial differences between our communities, e.g. rural and urban, and the fear would be that a regional service would lose the ability to be responsive to the unique needs of a local population.

What can be done to improve integration?

Geographically defined areas of cover, with all areas providing roughly the same services.

Increase resource to District Nursing and GP teams to allow more collaboration between teams on a day-day basis.

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?

In the Belfast Trust region, twilight nursing teams in Belfast Trust assist with palliative care at home. In the same region a pilot programme with Marie Curie allowed GPs to provide outreach in homes for complex palliative cases. Marie Curie hospices particularly have excellent outpatient clinics, such as day services helping with fatigue, anxiety or breathlessness.

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

No

Navigating a palliative journey with a loved one can be one of the most difficult things for a family to do. Support for the individual requiring palliative care is paramount but their families also need support during this difficult time, and the implications from lack of resources for healthcare teams mean that there often isn't enough time to consider these needs of the family, particularly where cases are complex. Unfortunately, these challenges often remain beyond the death of their loved one.

Funding and Strategy

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

No

Funding for all care in community is inadequate. Primary care teams are underfunded, in particular general practice is only allocated 5.4% of the total health budget. GPs play a key role within a community team delivering palliative care, and they need to have time and resource dedicated to doing so.

Protecting palliative care is becoming increasingly difficult with an ever-squeezed resource, practice instabilities, contract hand backs and recruitment and retention issues that prevail in general practice. Current palliative care provided by GPs is carried out as part of General Medical Services contract, thus strengthening palliative care should be achieved by an improved General Medical Service resource or at the very least a separately commissioned enhanced service.

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

With planned transformation and the shift of care from secondary care into the communities, the already inadequate funding for these services will be even more stretched. Hospice services provide amazing care to our patients, but large amounts of their funding is through charitable donations, and they are becoming increasingly unable to provide the care their patients need. Capacity for palliative care delivered by hospices needs a stable and sustainable funding model that is less reliant on charity for core services, and this needs to be accessible for all our citizens regardless of where they live.

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

A new Palliative Care Strategy for Northern Ireland which directed funding into care in the community, would mean that palliative care could be provided not only by specialist palliative care teams but also by primary care teams. Both an increase in funding and provision for inpatient care would reduce the reliance on charitable donations, as well as increase access to the services. Further integration and collaboration between all providers of palliative care, spanning both primary and secondary care, would also ensure the best patient-centred care.