

Macmillan Cancer Support

We provide services for people living with cancer at every stage of their cancer experience, including people receiving palliative and end of life care support.

Current state of palliative care services

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

Very 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

Public misconceptions around palliative care breeds a misunderstanding of palliative care services. The public associates palliative care with someone being close to death which isn't always the case, not only does this create anxiety and misconceptions for people with cancer and their loved ones, it may prevent people with cancer from accessing palliative care when they need or could benefit from it, this can include both early intervention in the cancer trajectory and at more advanced stages. We also risk people who are deemed as treatable but not curable, missing out on receiving palliative care support, and the opportunity to plan for their future care.

The biggest barrier is a lack of education and engagement with the general population. An educated and well informed public makes well thought out choices and engages in meaningful conversations around death and dying but this cannot be achieved via the Department of Health alone, this will take a cross-departmental approach with a significant commitment to change public perceptions of death.

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?

Inequity in palliative care is apparent from issues faced by the LGBTQIA+ community, refugees and asylum seekers, as well as issues around rurality, socio-economic deprivation, mental health and disproportionate service provision across Trust areas.

A basic example is the term palliative does not translate across various languages and we are aware of situations where a person is unaware they are dying which is truly abhorrent.

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

Yes

Community care is stretched, we know that many people with cancer who are at or approaching the end of their life find themselves unable to access the care and support they need out of hours, and so are left with no option but to access emergency care departments. Anecdotally people have told us when they contact out of hours GP lines they are being re-directed to hospital emergency departments as soon as they mention their cancer diagnosis, due to the lack of specialist advice and support available for those GP staff to enable them to make informed decisions about appropriate treatment and care, as well as the lack of access to patient records.

The problem is further exacerbated due to unmet need for specialist palliative and end of life cancer care in emergency departments across the UK. This means that many people living with cancer approaching the end of life are not able to access the care and support they need during an emergency admission, leading to worse outcomes and a negative impact on their quality of life. Without specialist support, people with cancer at the end of life are more likely to have multiple episodes of unplanned emergency care, stay longer in hospital, and experience a lack of continuity and personalisation in their care.

We also know that, since the pandemic, more people are dying at home, and systems have not been appropriately reconfigured and given the resource required to respond to this growing demand for their services within the community.

What additional services could/should be provided?

The fundamental challenge is access to workforce. Without an optimal workforce, people with non-curative cancer and those important to them will not receive timely and appropriate supportive interventions, information and coordinated care.

We know that integrated and well resourced community end of life care is one of the few interventions shown to be effective at improving experience of end of life care, and also in reducing reliance on emergency and acute care, largely through preventing avoidable emergency admissions and providing personalised care. For this to be achieved, there needs to be continued investment in both palliative care specialists and generalist health and social care professionals across the health system who have the knowledge, understanding and time to deliver high quality personalised care for people at the end of their lives.

Integration of Services

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

A siloed approach currently exists within some parts of the system due to a lack of integration across care settings. There are a number of reasons for this such as workforce not having the training and education to deliver palliative care, poor information sharing across settings and a lack of understanding of what palliative care is. The broader workforce challenges around recruitment, retention, staffing levels and skills mix also impact here,

and contribute to a lack of joined up working as often there isn't the staff in place to be provide an integrated pathway for people.

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

Yes

A regional service for palliative care helps address inequalities and inequities through a broader understanding and measurement of the needs of those accessing services. It will also better utilise the available workforce and allow for more streamlined reporting of data. We have recently seen breast cancer services move to a regional model on the basis that it will provide a better quality of service and we believe that this is achievable for palliative care with the correct interventions, action plans, funding and governance that should be designed through a National Palliative Care Strategy.

What can be done to improve integration?

Action is needed to ensure greater and earlier integration between cancer services and palliative medicine, including awareness training across oncology of the benefits of introducing palliative care alongside active treatment for people with cancer. We need to remove the misconception that palliative care means 'giving up' and change that to the access to the best healthcare for the current situation and safety netting going forward.

Advance care planning plays an important role in ensuring that end of life wishes are known, safeguarding against unwanted interventions as well as providing healthcare professionals and loved ones with the preferences of the person receiving palliative care mitigating uncertainty. Encompass needs to be utilised across primary, secondary, community and specialist care to have succinct access to the advanced care plan.

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?

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

No

Families and carers can experience a lot of pressure caring for someone at end of life, particularly when there is not the support available in the community to support them to care for their loved one at home. A complex and fragmented system means that many people do not know who or where to call to get the support they need, and calling emergency services remains their only option.

Pre-bereavement and bereavement services suffer from significant capacity issues in NI. At the statutory level capacity pressures are preventing Trust and primary care teams from offering greater levels in bereavement support including follow-up services with carers and loved ones. In the charity sector, providers are also under pressure to meet demand with some users experience longer than ideal waiting times for one to one support following referral. This can lead to psychological distress and physical health complications and may have a knock on impact on aligned services, including an already stretched mental health service.

Access to pre-bereavement and bereavement support is crucial to meeting the holistic needs of carers and loved ones of those with non-curative cancer. It is vital to adopt a wider approach to ensure that those important to the person living with cancer, including children, are not forgotten, both in terms of acknowledging younger mortality from cancer thus affecting more young people and also helping to provide support and advice.

Funding and Strategy

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

No

Other parts of the UK and Ireland have prioritised the funding for palliative care services and shows their commitment in supporting people to die well. Sadly, Northern Ireland continues to lack in terms of prioritising palliative care and that is evident through the provision of third-sector support to be able to deliver a level of care, that doesn't go far enough, to support people and their loved ones during a time when they are at their most vulnerable.

The continued budget cuts we have seen will alsoacerbate the inequities that exist within current provision, and will cumulatively have the greatest impact on the most vulnerable groups within society.

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

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

The Executive should recognise that the provision of palliative care needs to be a policy priority and that this requires a strategic approach. However, if a strategy is to be produced, it must also be accompanied by a fully funded implementation plan which sets out clear milestones for progress.