Fermanagh Community Transport Ltd

Fermanagh Community Transport is playing an increasing role in supporting and enabling patients and their families from County Fermanagh to make the journey to and from highly centralised and specialist palliative services in Belfast and at the North West Cancer Centre. For the people we transport, the option of public transport and private transport is imply not an option, especially within a deeply rural county such as County Fermanagh.

Current state of palliative care 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?

Yes

This question cannot be answered by a simple yes or no response. There are elements of the public who will have a understanding of what palliative care is, whilst others will have a lessor or no understanding.

In terms barriers to understanding:

1. The fragmented nature of palliative care and end of life services within and across sectors in NI;
2. The increasingly centralised nature and delivery of palliative care and end of life services - less understanding by virtue of less physical presence and
3. visibility within local communities, especially rural and highly rural communities;
4. Fear and reluctance linked to the cultural predisposition to avoid talking about and planning for our own death and those of our loved ones;
5. Language and terminology i.e., 'palliative'. Need to de-medicalise the language surrounding palliative and end of life care.

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?

Yes, there are gaps in the provision of services.

From the perspective of Fermanagh Community Transport, a key gap is more localised palliative and end of life care services and supports for patients and their families. Increasingly centralisation and specialisation has seen services increasingly concentrated within Belfast and L/Derry, meaning that those who reside outside of these metropolitan areas are seeing less local provision and more inconvenience and stress at a time when the system (ecosystem) should be working symbiotically to design out and minimise the

inconvenience and stress at such a profound and emotional time for patients and their families. Working within and across sub-systems within what should be a fully integrated ecosystem does not take place as it should.

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

This question specifies the term 'equitable' which is open to interpretation and often misunderstood and misapplied. It is important that the Health Committee in its Review of Access to Palliative Services gives due attention to this and how it relates to 'equality' and 'social justice'. Equity does not mean equality, and equality does not mean equity. Without equity, it is unlikely that we as a society can move to a more regionally balanced and accessible palliative care and end of life service ecosystem. Equality of access to the services does not exist and is heavily determined and impacted by where the patient and their family live (urban or rural) and the patient and families socio-economic circumstances.

Barriers preventing equitable access to palliative and end of life care for patients and their families:

1. Rural and Rural Proofing – The Importance of Geography, Demography and Economy

Rurality and deep rurality are major issues in terms of access to palliative care and end of life services, with those patients and families who live at the

greatest distances from our major regional health centres often experiencing the greatest challenges and complexities when it comes to accessing the

different elements which can make up the care offering.

2. Rural Transport

Rural transport, especially within the context of increasing regional specialisation and centralisation is undoubtedly one of the most pressing challenges for patients and families, especially those who cannot access Translink Public Transport due to poor and reducing coverage, lack of private transport and the increasingly expensive nature of taxis. Rural transport is an afterthought (if a thought at all) and it has developed within an uncoordinated historical policy, strategy and practice vacuum. As a result, you have a very disjointed, fragmented, often hidden and at times what can feel like a protected/reserved service (if you are in the know with the people or organisation who are running the palliative transport service then you might be fortunate enough to access it, if not, you might never hear of it). This is a phenomenon which I have observed in Fermanagh. I am not suggesting this is deliberate or intentional but it nonetheless exists.

Rural transport schemes to palliative care services for patients and their families cannot be solely dependent on the goodwill of the organisation and its volunteer drivers, as well as the goodwill and generosity of the general public. Transport is a critical element in the palliative care support ecosystem and as such it should be afforded the status and investment it merits based on the contribution and difference it makes.

3. Clarity on Support Available

Time and time again we hear of patients and their families trying (struggling) to discover what is available to them when they experience an end-of-life diagnosis. As they navigate from one health professional to the next, and from one organisation to the next, they hear a bit more but never quite getting the full picture, one which would have helped alleviate suffering and improve the quality and dignity of the end-of-life experience.

Given the nature of palliative services and the way many services emerge because of seeking to address a barrier faced by a loved one in their personal palliative journey (often after their passing) or seeking to secure their memory, this can make it difficult to get a firm handle on what is and isn't available as services organically emerge. Further, the desire to memorialise their loved one/ secure their legacy can lead to a fragmented, protectionist and at times competitive environment, with some charities/ support organisations determined to hold on to 'their' users. In our experience, most people don't care who provides the service or brings them to it, as long as they can get access to it, benefit from it and get relief from it.

4. Ageing Population and Palliative Care

We need a deliberate and thoughtful policy and strategy which sees the writing on the wall and endeavours to build a palliative ecosystem from the perspective of patients (present and future) and their families. Our ageing population is precipitating greater need for the volume and type of palliative services available. Given the highly ageing nature of our rural and deeply rural communities, this is an issue which will only stand to be exaggerated in terms of inequality of access and experience, so long as there is a lack of place specific understanding and a lack of equity based planning. Quality and dignity of death by postcode and along the rural urban continuum must experience greater fairness, justice and equity.

What additional services could/should be provided?

Greater policy, strategic and operational involvement of Community Transport operators in terms of the co-design and delivery of a future-proofed and patient centred service ecosystem, which sees all elements which are required to facilitate the access of patients and their families to the services. The very extent of the role and involvement of community transport in enabling patients and their families to access palliative and end of life care, speaks to the need and necessary involvement of this key stakeholder in ensuring greater integration and a more seamless and frictionless patient and family journey from the start to the end of their palliative and end of life journey.

Integration of Services

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

What we understand from our members is that integration could be substantially improved, especially in terms of communication and the sharing of information. Members often tell us of their having to relay over and over to different health care professionals within the

primary, secondary and specialist care sectors their symptoms, interactions and involvement with other professionals, the medications they are on etc.

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

No

Palliative Care is unique within the health landscape. It is a profoundly difficult, emotional and worrying time for patients and their families. Access, dignity and quality cannot diminish with distance from Derry and Belfast. Everyone must be entitled to access, dignity and quality as they personally draw to the end of their life, as should the family who support them on this journey.

What can be done to improve integration?

Deliberate application of Systems Thinking to visualise and design what the ideal system needs to look like in 5 to 10 years time. Once this has been established, look to understand the current system which is in place. Taking this approach which is consistent and in keeping with health and social care design best practice around the world, will ensure that improvements to the service and its integration are based on future needs, and that the tendency to try and affect change from the singular perspective of the current reality and likely reflexive and default back, are much reduced.

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?

Fermanagh Community Transport, CDM Community Transport, Easilink Community Transport and North Coast Community Transport are all piloting a Community Transport Out of Area Transport to Health Scheme which is being funded by the Motability Foundation and the Lottery Fund. This is short-term funding which is giving each of the organisations to text the nature and need for transport for patients and their families.

With a strategic and integrated approach and with the support of DoH, the model being deployed by the Community Transport Partnerships could be rolled out across NI, bringing a consistent and high quality, compassionate and reliable transport offering to meet the needs of those patients and families who can travel in a volunteer car.

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

No

Time and time again we hear of patients and their families trying (struggling) to discover what is available to them when they experience an end-of-life diagnosis. As they navigate

from one health professional to the next, and from one organisation to the next, they hear a bit more but never quite getting the full picture, one which would have helped alleviate suffering and improve the quality and dignity of the end-of-life experience.

Given the nature of palliative services and the way many services emerge because of seeking to address a barrier faced by a loved one in their personal palliative journey (often after their passing) or seeking to secure their memory, this can make it difficult to get a firm handle on what is and isn't available as services organically emerge. Further, the desire to memorialise their loved one/ secure their legacy can lead to a fragmented, protectionist and at times competitive environment, with some charities/ support organisations determined to hold on to 'their' users. In our experience, most people don't care who provides the service or brings them to it, as long as they can get access to it, benefit from it and get relief from it.

Funding and Strategy

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

No

Charitable organisations such as Community Transport Partnerships are being expected to step into the breach and deliver essential transport services on the basis of good will, the community in terms of fundraising, volunteer drivers in terms of their time and resources and staff in terms of woeful terms and conditions of employment when compared to their colleagues in Health and Social Care, the Education Authority and Translink.

The transport provided is critical to access palliative and end of life services by so many patients and their families, yet it is viewed outside of the palliative care ecosystem and seen as something which can operate on the basis of good will and short-term charitable funding. This does not sit comfortably with the principles of access, quality and dignity, with ones access subject to the potential fundraising capacity and volunteering propensity and availability within any given local community.

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.

Not sure

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

1. Rural and Rural Proofing - Rurality and deep rurality are major issues in terms of access to palliative care and end of life services, with those patients and families who live at the greatest distances from our major regional health centres often experiencing the

greatest challenges and complexities when it comes to accessing the different elements which can make up the care offering. There should be a specific rural dimension to the Strategy.

2. Rural Transport - Rural transport is an afterthought (if a thought at all) and it has developed within an uncoordinated historical policy, strategy and practice vacuum. Transport is a critical element in the palliative care support ecosystem and as such it should be afforded the status and investment it merits based on the contribution and difference it makes.
3. Clarity on Support Available - Giving as full a picture as possible, one which would have helped alleviate suffering and improve the quality and dignity of the end-of-life experience.
4. Ageing Population and Palliative Care - We need a deliberate and thoughtful policy and strategy which sees the writing on the wall and endeavours to build a palliative ecosystem from the perspective of patients (present and future) and their families. Our ageing population is precipitating greater need for the volume and type of palliative services available.