Rural Community Network

Consultation Response: Review of Access to Palliative Care Services - Organisations/Health Professionals

We refer to your above consultation and thank you for giving us the opportunity to respond publicly to the review of Access to Palliative Care Services. For us the key word in your consultation is “access” and we hope you find our response helpful and informative.

Rural Community Network (RCN) is a regional membership-based organisation supporting rural communities across Northern Ireland. RCN works with rural communities to address issues relating to poverty, inequality, community and good relations and strives to develop the capacity and skills of groups to articulate their voice at a policy influence level.[i]

RCN has over 200 member groups across rural Northern Ireland. Its Board is also representative of its membership base. RCN’s aims are:

- to empower the voice of rural communities
- to champion excellence in rural community development practice
- to develop civic leadership in rural communities
- to actively work towards an equitable and peaceful society
- to promote the sustainable development of rural communities

To help inform this response we have consulted with a variety of rurally based community groups and people living rurally who have been impacted by having a family member with an end of life diagnosis and needing to use Palliative Care Services. We have also used our knowledge and expertise from conversations with various groups looking to rural proof how they provide either direct or indirect services for those using Palliative Care Services.

One of your first questions in your online survey is to ask if we do not work in healthcare, what interest do we have in Palliative Care Services. Therein, lies the first issue we have in providing a response to your questionnaire and therefore, we have opted to email a Consultation Response.

To clarify, our interest as an organisation relates to rural provision of Palliative Care Treatment and Services with a particular emphasis on the additional needs and complexities that arise out of this rurality for the person accessing the care/treatment and for their families. It is disappointing to note that this questionnaire has been worded in this manner and shows a narrow lens when reviewing health care provisions. Health care provisions are linked directly to economics, poverty, accessibility in terms of journey time, quality of roads and transport options. Rurally our biggest issue in relation to health care provision of any kind, including that of Palliative Care Services, is access.

Multiple Deprivation Measures 2017[ii] indicates that the top 10 areas of deprivation linked to access to services are all rural and five out of the top ten are all in the Southern Part of the Western Trust Area. You also have to consider the additional cost of the access, the addition burden of travelling long distances whilst in pain, the time off work for family members both to attend the appointment and to help with travel to the appointment, the state of our road infrastructure, the poor bus options and the lack of rail network.

RCN recommend a wider lens when reviewing Access to Palliative Care Services and thus we have taken this opportunity to address some key rural issues in this response and link it to the questions you posed in your online Questionnaire.

Do the public understand what is meant by the term "Palliative Care"?

In rural communities, there is often a reluctance to discuss end of life care, treatment options or legal scenarios. It is taboo for some. People may or may not understand the term, but they also may or may not wish to talk about it. Rural advice providers assisting people with social security applications following end of life diagnosis advise that it is often something people do not think about until it comes to their door and so there is a real risk of them not fully understanding the term. In addition, for those who do understand the term, Easilink [iii] advise us that some people may also not wish to share their struggles with their families out of fear of being a burden on them. Easilink describe that their volunteer drivers, who are driving people long distances to receive end of life treatment, often end up becoming the confidant for that vulnerable, unwell person. Whilst the sense of community in rural areas can be strong and people come together to support others, people can also be very private and stoic, not wanting to bother people and so, not asking for help or support.

Further to this, obtaining and understanding information on Palliative Care Services becomes more difficult rurally. RCN were involved in 5G New Thinking Project [iv] in recent years due to the lack of sufficient broadband provision rurally. Without access to information easily for example from digital sources, access to digital technologies, access to libraries, access to information and the ability to read and understand said information, then it can also become more difficult to fully understand what is meant by the term. Health literacy is closely linked to general literacy and the Patient and Client Council Scoping Paper on Health Literacy in Northern Ireland 2021 indicates that 18% of working age people in NI operate at the lower literacy levels. [v] Furthermore, 13% of UK population have "ultra-low" digital skills. [vi] Within that group, there are concerns for older people as two thirds of this group labelled as having ultra-low digital skills were over 70 years old. One look at the Census Data for 2021 shows us that there are high numbers of people over the age of 65+ living rurally- for example in Causeway Coast and Glens Council Area [vii] 19% of the population living there are aged 65+. In addition, Rural Local Independent Advice Providers have indicated their concern for males, over the age of 55 regarding their digital literacy. Community Advice Fermanagh in their study into "The Move to Universal Credit" highlighted this demographic of people were concerned about managing their business and social security online due to a lack of digital skills. [viii]

In relation to access to digital devises, a study from NICVA 2022 advises that there are many issues contributing to digital poverty in Northern Ireland and “the digital divide cannot be fully addressed by policies purely focused on broadband infrastructure, when multiple causes evidencing digital exclusion exist” [ix]. This is something we urge the Department to be mindful of when engaging on complex medical topics.

Are Palliative Care Services equally accessible to all who need them and what are the barriers to equitable access?

For there to be equal accessibility, that would suggest that each geographical area in NI has access to Palliative Care Services. We know from our consultations with Rural Community Groups in Fermanagh for example that this is not the case. Indeed, one Rural Community Group kindly showed us a letter to one of their services users (with express consent). The letter was from the Western Health and Social Care Trust, sent to them as a service user of Palliative Care Services. The letter stated that Palliative Care Services were being transferred within the WSHCT to Foyle Hospice in Derry/Londonderry. It stated there was going to be a “seamless transition “of services over to Foyle Hospice in Derry City to cover right across the Western Trust (Northern and Southern sector) to include “Omagh and Fermanagh Council areas”. The reality of this change in provision was felt first hand by this service user and their family when they found out that there was no longer a Hospital Specialist Palliative Care in South West Acute Hospital and they would now be required to travel to Altnagelvin. In addition, the patient no longer had an option to die in a hospital in Fermanagh, if they wanted to die in Fermanagh, they had to be supported by a local charity providing care in the community, otherwise they would be required to die in either Foyle Hospice or Omagh Hospital. The reality herein is when it comes to a patient needing that Hospice Care towards the end of their lives, they may be too ill to make the arduous journey to Derry City or Omagh from Fermanagh. Transparency, consistency and good communication is required when dealing with such emotive and serious health services.

Rurality is a major issue in terms of access to palliative care and end of life services with those living in rurally isolated areas required to travel further to access the various health services that form each patient’s individual care offering. We also need to consider the Rural Premium i.e. The additional cost of this travel to the patient and to the family, who may require time off work to enable the accessibility of a much-needed medical service. Even with financial assistance towards travel costs via Hospital Travel Costs Scheme, the true cost of rural travel is hidden. One look at Family Support NI help page [x] indicates that the scheme will pay the cheapest form of travel, for example, if you choose to travel by car but the cheapest option was to take a bus, you are reimbursed the price of a bus fare. Within this, there are two issues: `

1. The lack of dignity for the patient receiving end of life care, to be reimbursed the price of a bus fare when they are too ill and in too much pain to take public transport.

2. the lack of understanding that not all of Northern Ireland has access to a suitable form of public transport. For example, there are areas of Fermanagh such as Garrison Village with only one bus route to Enniskillen per day at 12.35pm. [xi] Much of the West of Northern Ireland also has no train network. [xii]

You have asked for our opinion on the current state of Palliative Care Services in NI and we believe it is fair to say that it is not up to scratch for rural communities in terms of access. Rural transport is undoubtedly one of the most pressing challenges for patients and families. Easilink and Fermanagh Community Transport were recently involved in a project called Cancer Connected Communities West [xiii]. Transport was highlighted as one of the top priorities for people accessing this type of care. Some of the comments made by patients travelling to receive cancer treatment at Altnagelvin included:

"No consideration for how [a] patient gets to and from appointments. Must rely on family and friends and then worry about them during the wait period."

"Assumptions are unrealistic, that friends and family can take time off work to drive patient to their hospital appointments"

"2 hour wait in Omagh for a connecting bus to Derry" and " Bus once per week from Kesh to Omagh."

"There are no direct buses from Enniskillen to Derry for treatment. Logistics are a nightmare as connecting buses from Omagh do not run regularly. There are no toilet facilities in the Enniskillen bus centre at certain time periods. Taking public transport is not ideal for someone who has a compromised immune system. This is additional stress for someone who is vulnerable and ill."

These are comments from real rural people and the same symptoms and issues would arise from end of life treatment.

Access to Palliative Care also requires a look at the pathways to access the services in a timely and dignified manner. Advice Services in rural areas are advising that their service users indicate serious issues with getting a GP Appointment and with closures of rural GP surgeries thus increasing the catchment area for small rural GP Practices. These service users were keen to point out that this was in no way a reflection of poor GP care but more that the system itself is broken and GP surgeries rurally are having to take on huge number of patients over large geographical spreads with limited resources.

In addition to this, RCN had a service user contact us to describe the issues she was having when her GP surgery in Carnlough closed. She advised that at the age of 72 and as a non-driver, she was now required to travel to the next village over, Glenarm, to see a new GP. In order to do so, her options were limited because there is no direct bus route from Carnlough to Glenarm. The only bus leaves at 9.35am and returns at 3.58pm at a cost is £11- £14. If she were to take a taxi, it would cost £25 plus waiting times and there is no community transport service at present for the

area. 25% of residents in Carnlough do not have access to a vehicle. If a patient is very ill, in a lot of pain and in need of an urgent GP appointment, this becomes very difficult to manage logistically and financially. Palliative care relies on safe and timely access to GPs for referral pathways. It also needs a holistic approach in relation to, not just the Palliative Care service, but how and where it is located and access to same.

The centralising of services has become a concern for our Rural Community Groups. Rural Communities do not expect every service on their doorstop, but they also have a right to a medical treatment in an end-of-life scenario in a timely and dignified manner, given solace to them and to their family at a time of immense grief and pain. Services linked to the relief of pain such as pain clinics for example need to be able to be accessed more equitably. Our members are advising us for example that a much-needed pain clinic which used to be situated at South West Acute Hospital is now located in Omagh or Derry City. Patients are required to travel on poorly maintained roads from Fermanagh, on the border with Republic of Ireland, all the way to Omagh or Altnagelvin to receive services for pain. The roads they are travelling on are not well maintained, indeed they are not even considered a “main road”. Department of Health need to work more closely with Department for Infrastructure to ensure that patient safety, wellbeing and human rights are protected when travelling to access services.

Members are also advising us that the service is disjointed, and communication is poor. For example, Easilink advise us that people in south west Fermanagh are being provided with hospital appointments in Belfast or Altnagelvin Area Hospital for 9am to access end of life treatment. People from Fermanagh and Omagh are also being provided with appointments for bloods or scans in Belfast/Altnagelvin, which could easily be done locally in their GP practice or at a local hospital. In addition, short five-to-ten-minute review appointments are being offered face to face when digital could be an option.

The fact that the travel consequences have not been included in decisions about vital services to a rurally isolated area is simply not good enough. It is this siloed mentality that is causing distress and pain for rural people.

Easilink produced a findings report following their involvement in Cancer Connected Communities West and within same, there was a strong feeling that Fermanagh and Tyrone feel left out of the decision-making process in the Western Trust. There were, what are described in the report as, “genuine fears” regarding the maintenance of services at SWAH following the removal or reduction of a number of key services in the last few years including Emergency General Surgery and Pain Clinics. Their service users are struggling to make their way safely to regional centres, citing access to transport, finances, pain and health issues as well as feeling a burden on family as barriers to being able to make their way to receive treatment.

Gaps in provision, what can be done to improve integration and is having one regional service a solution?

In rural areas, at home palliative care is an essential service and tends to be provided by charities such as Marie Curie. Even where the Trust is providing Hospital Specialist Palliative Care, in most cases it is a 9-5 service [xiv]. It should not be the case that NHS are reliant on charities to fulfil their role considering the funding model most charities rely upon.

It should also not be the case that a persons geographical position means they are more likely to suffer in pain for longer to access Palliative Care Services. Consideration should be given to how services are allocated to ensure a sufficient geographical spread across NI reaching out into rural areas. There is infrastructure already in place for example GP buildings, health centres and Community Halls which could be used to bring care to the people or as a service point to enable a floating service to be provided in a larger geographical area. This approach will require appropriate staffing levels, multiyear budgets and plans, as well as interdepartmental working to ensure safe and sufficient funding of services and safe and timely access to same.

Charities supporting people to access Palliative Care Treatment in the manner in which Marie Curie or Easilink do, should not be reliant on annual funding- their staff should be sufficiently paid and resourced. Whilst the format of charitable fundraising might work well in cities or larger towns where fundraising is more easily achieved, in rural areas it is much harder to fundraise as well as to hire staff to take up positions.

In addition to this, rotas, outside of hours care and access to medication have been an issue rurally. Easilink described a scenario where a service user was dying and suffering in significant pain. This person urgently needed specific, prescribed, pain relief medication but the only pharmacy open was miles away at the other end of the County- as such, this family spent the last few hours of their dying relatives life, travelling in a car to access medication to make the death less painful, instead of having easy access to medication and more time to say goodbye to their loved one. This is the reality of rural provision.

Easylink and Rural Community Transport Fermanagh advise that Rural Transport Schemes to Palliative Care Services for patients and their families should not 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. Easilink received money from Lottery to enable them to bring people to regionally based hospital appointments from rural areas. In one year, they facilitated 6,000 journeys and over the course of their 5 year funding, facilitated 25,000 hospital appointments. This is serious evidence of need and yet their funding was from a charitable source and is due to end soon.

In addition to the foregoing, the job of an end-of-life carer is not an easy one, it is physically and emotionally demanding. Staff working rurally are required to travel longer distances, often unpaid for the travel between patients and they feel isolated. Staff need support and good working terms and conditions. At the very least they deserve the Real Living Wage and RCN welcome the Ministers Comments at the Emergency Health Committee Meeting on 7th January 2025 indicating that he intends to bring this forward. In addition to this, Department of Health need to look at regional balance and rural proofing service provision to ensure it is tailored to the needs of geographical areas eg enough staff to reasonably cover rotas in larger geographical or isolated areas or a rural premium to attract staff to the role.

We have addressed issues above wherein our members advise us that Palliative Care Services are disjointed. Indeed, Fermanagh Community Transport [xv] went on to advise us that “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 end-of-life experience.” More communication and a joined-up approach with a seamless information sharing system between services would be required to plug this gap. Our concern is if this cannot be achieved within one Trust Area, how likely is it to be achieved by having one regional centre. 37% of people in Northern Ireland live in rural areas and over a large geographical spread. For your convenience we have attached a map of what Rural Northern Ireland looks like highlighting the vast nature of this spread. The risk that a regional model might be a Belfast centric model or have a city based mentality is also a concern.

Notwithstanding these concerns, there is, of course, real potential that better communication and seamless transitions between services could be achieved by having one regional centre and to be absolutely clear, RCN are not against centralising a service or creating regional based services as long as this regionality is not confused with urban or to the detriment of rural communities. In addition, making a service regional, does not require it to be based in Belfast. Making a service regional also means that the service has to be able to understand and accommodate everyone in that region – both urban and rural. With a mixture of Trust and Community and Voluntary Sector involvement, better communication also needs to be achieved between the two strands. Multiyear budgets and interdepartmental communication will also be required.

No one should get left behind because of their postcode and that would require from the outset a sufficiently rural proofed service that maintains this equitable lens throughout the life span of the service.

Another consideration is the position of the border in relation to Palliative Care Service provision. There are patients who live closer to hospices in Republic of Ireland but cannot access same. For example, patients living in Belleek, Co. Fermanagh could access the Hospice in Ballyshannon Co. Donegal, but instead are required to travel to Derry City. You might also like to consider opening conversation

with ROI counterparts to remove the border barrier in relation to accessing Palliative Care Treatment.

Rural Health Toolkit

It is our conclusion that the Department of Health need to more effectively rural proof and border proof access to Palliative Care Services. We point to our Rural Health Toolkit [xvi] for guidance on same and RCN are happy to engage with you at any time in relation to the implementation of this Toolkit. We thank you again for allowing us the opportunity to respond.

i Home - Rural Community Network

ii NIMDM17- with ns.pdf

iii Easilink community transport

iv 5G New Thinking Archives - Rural Community Network

v https://pcc-ni.net/media/54ipa1z5/pcc-scoping-paper-on-health-literacy-2021.pdf

vi Digital Inclusion News - November 2023 | Digital Inclusion Toolkit

vii Causeway Coast and Glens Census Data

viii 2024 Conference Presentations – All-Island Social Security Network

ix The Digital Divide in Northern Ireland: Horizon scan of digital policies | NICVA

x Hospital Travel Costs Scheme - Northern Ireland - Directory Listing

xi Timetables

xii Northern Ireland Rail Network Map

xiii Cancer Connected Communities West | Western Health & Social Care Trust

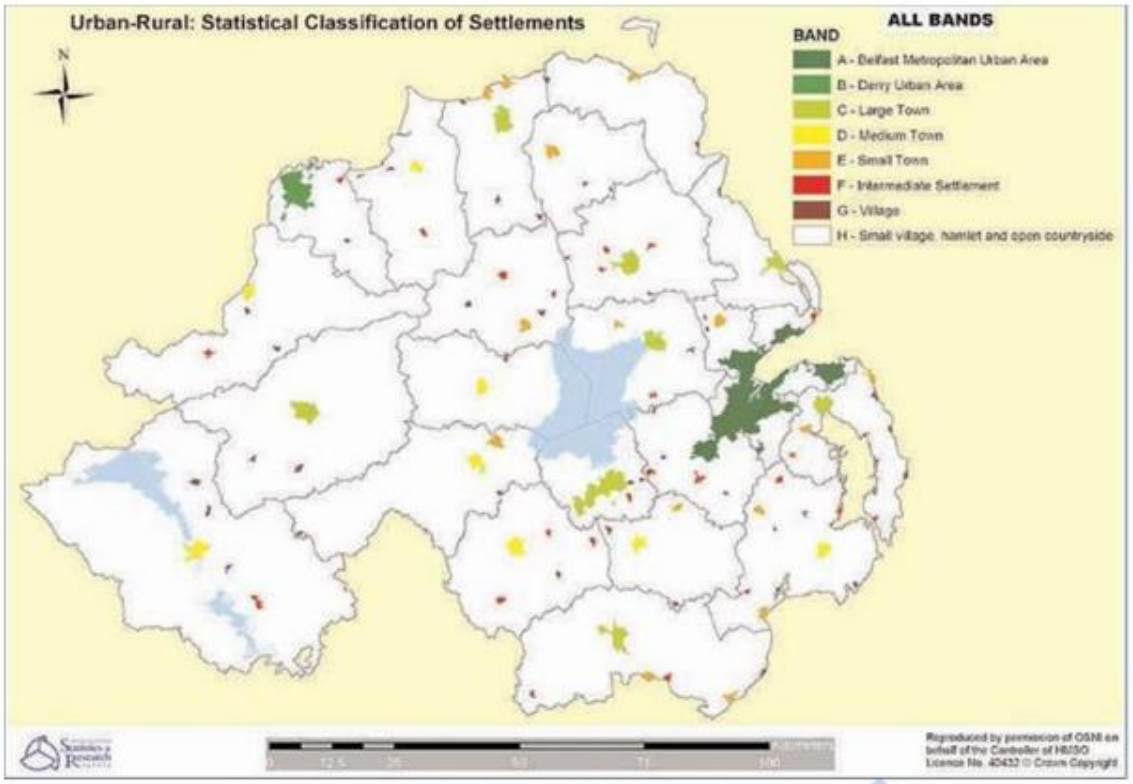
xiv Specialist Palliative Care | Western Health & Social Care Trust

xv Transport | Fermanagh Community Transport | Northern Ireland

xvi Rural Needs Toolkit for Health and Social Care - Rural Community Network

Appendix one

Map of Rural Northern Ireland (Urban - Rural Classification | Northern Ireland Statistics and Research Agency)



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