Title: Enhancing Palliative Care Access in Rural Northern Ireland

Introduction

Palliative care is essential for improving the quality of life for individuals with terminal illnesses by addressing their physical, emotional, and spiritual needs. However, rural communities in Northern Ireland face significant challenges in accessing these services due to limited public transport, workforce shortages, geographic isolation, and uneven distribution of hospice services.

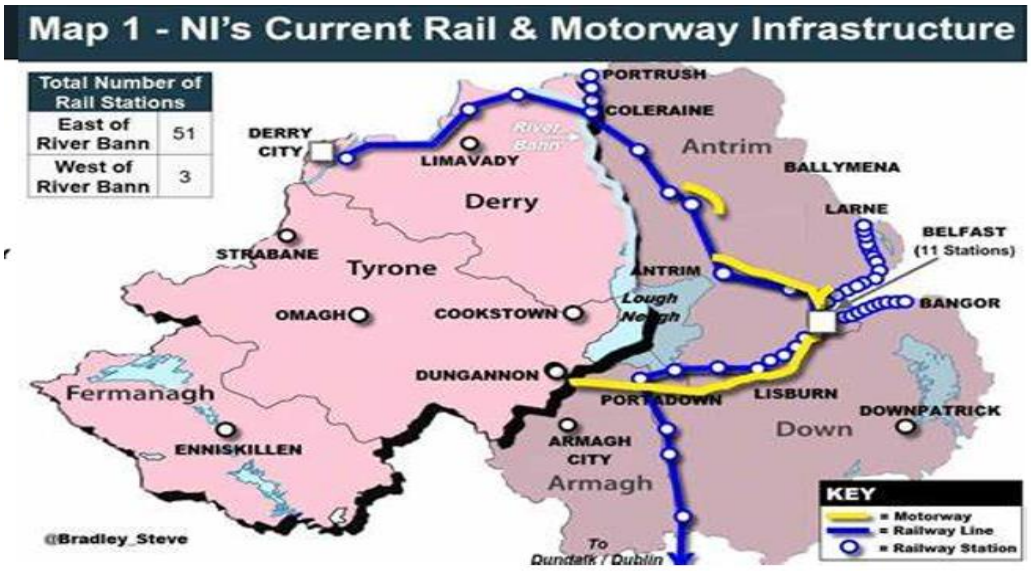
The Department of Health's proposals for the reconfiguration of hospital services, combined with the Rural Needs Act and the Rural Proofing for Health Toolkit, present a unique opportunity to address these challenges.

In this speech, we will explore the current state of palliative care, the barriers faced by rural patients, and recommendations for leveraging these proposals to improve service access and equity. We will also reference findings from Brendan O'Hara's study and surveys by Marie Curie and Macmillan, as well as insights from Scotland's "A Road Less Lonely" initiative.

PART 1: Key Challenges in Rural Palliative Care Access:

a) Limited Transport and Hospice Access:

Issue: Rural patients face long travel times and limited public transport options to reach hospice and hospital services. Reduced bus routes and infrequent services exacerbate the problem.



Finding: According to Marie Curie, many rural patients experience delays or forgo care due to travel challenges. A report by Community Transport Northern Ireland showed that 80% of rural patients rely on community transport for medical appointments. Report from Cancer Connected Communities West Project service users concluded that transport was one of their key concerns in terms of accessing this type of care.

Impact: Travel burdens deter timely access to end-of-life care and complicate visits from family and carers.

Lived Experience Voices from patients accessing Cancer Services via Easilink and Fermanagh Rural Community Transport as part of Cancer Connected Communities West Project:

"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."

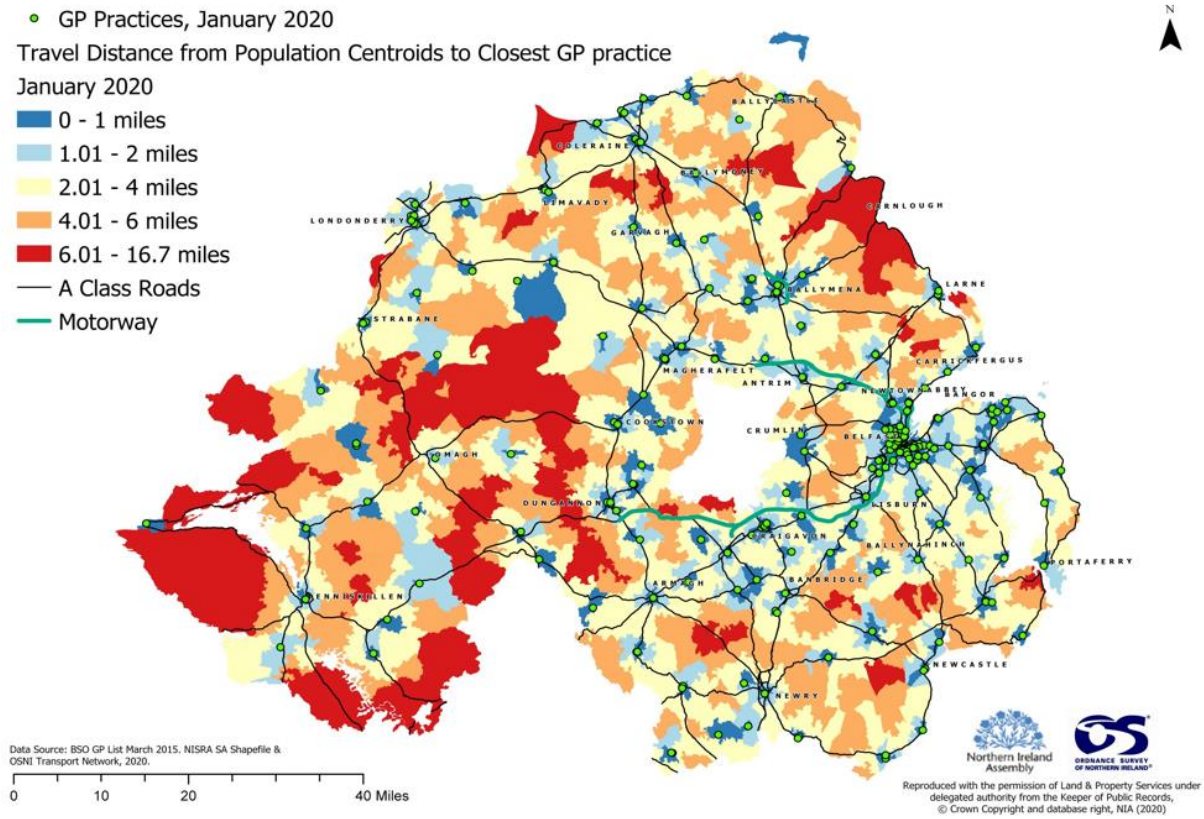
"Assumptions are unrealistic, that friends and family can take time off work to drive patient to their hospital appointments"

"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."

b) Workforce Shortages:

Issue: Rural Northern Ireland suffers from a shortage of palliative care specialists, GPs, and community nurses due to limited career development opportunities, professional isolation, and insufficient financial incentives. Below is a map of GP locations across Northern Ireland:

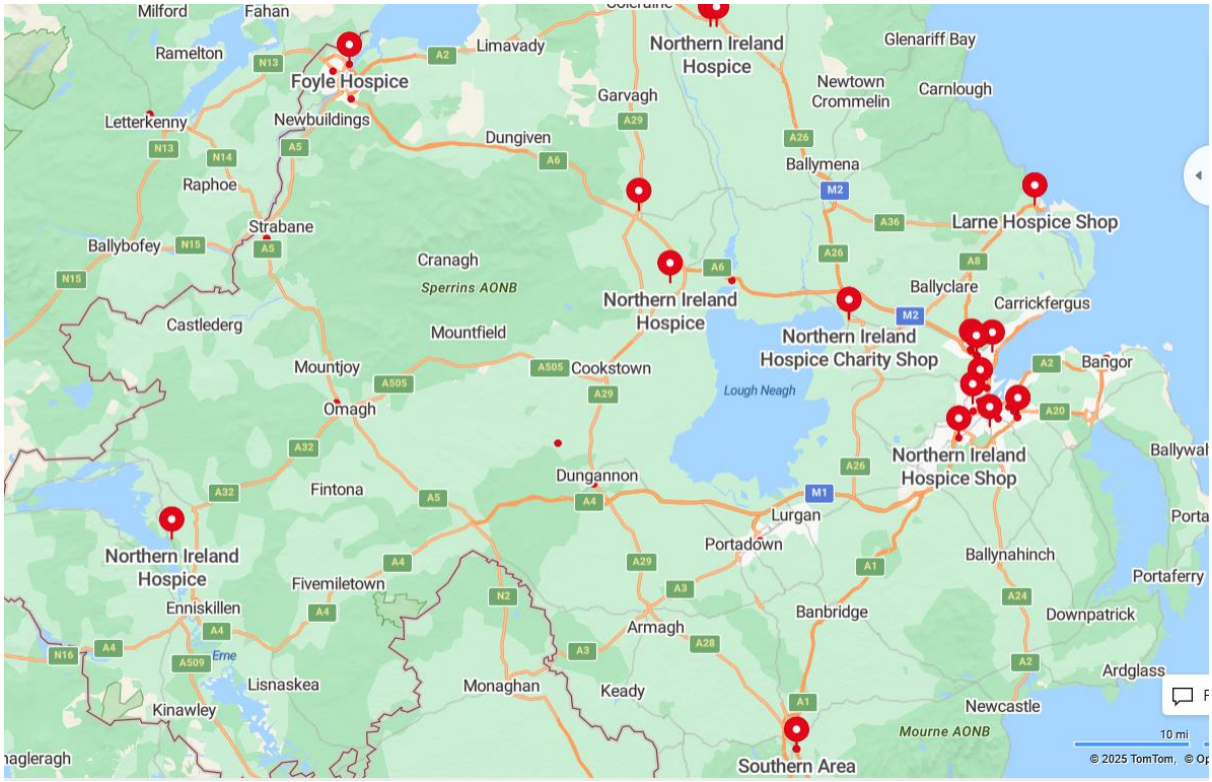


Finding: Brendan O'Hara's study emphasized the variability in service delivery based on location rather than patient need. Marie Curie Survey Response January 2025 Health Committee Inquiry into Access to Palliative Care Services in NI concluded there was fragmented and inconsistent Service Provision including **v**ariability in service access depending on geographical location and Health Trust funding as well as poor coordination between generalist and specialist care providers leading to patients falling through the gaps.

Impact: Patients experience longer waiting times, limited access to specialist care, and inconsistent home care services. A Macmillan report highlighted that rural patients are twice as likely to report difficulties accessing community nursing services compared to urban patients.

c) Inequitable Service Distribution:

Issue: Hospice services are largely concentrated in urban areas, making access difficult for remote and rural communities:



It can also lead to disjointed approaches in terms of the provision of complimentary therapies or additional support

Impact: Rural patients receive delayed or fragmented care, undermining their quality of life. The sheer distance rural dwellers are required to travel, whilst in pain, puts many off using it as an option.

A rural advice organisation assisting in applications for Personal Independence Payment in Fermanagh advise us that there appears to be no pain clinic at SWAH and patients are required to travel to Omagh. Patients are in so much pain trying to make their way to the service, they often decide not to go at all.

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in addition to the foregoing, Scotland's "A Road Less Lonely" initiative offers valuable insights for Northern Ireland:

(a) Compassionate Workplaces:

Challenge: Many rural patients and carers struggle to balance work and care responsibilities due to a lack of employer support.

Recommendation: Encourage local businesses to adopt flexible work policies for employees managing terminal illnesses or caregiving duties.

(b) Death Literacy and Media Awareness:

Challenge: Limited understanding of palliative care leads to late referrals. There is also a lack of awareness of the support available through other supporting organisations.

Recommendation: Implement targeted media campaigns using local radio and community newsletters to raise awareness about palliative care options. Stakeholder engagement to collate information of local service provision with community and voluntary sector who are plugging the service provision gap especially in relation to complementary therapies and additional supports.

(c) Supporting Socio-Economically Disadvantaged Communities:

Challenge: High levels of poverty in rural areas make it harder for patients to access care.

Poverty in rural Northern Ireland significantly hinders access to palliative care, impacting patients' quality of life during critical times.

Key factors include:

(i) Limited Healthcare Facilities and Travel Required: Rural areas often lack specialized palliative care centres, requiring patients to travel long distances to urban facilities. This travel is both time-consuming and costly, posing challenges for those with limited financial resources. It also causes challenges for patients who are unwell after treatment. Sickness and distance from centres can leave them feeling unwilling or unlikely to travel.

We also need to consider the cost to families and carers who travel to be with their loved ones for support. Recently a student of RCN was required to travel from Fermanagh to Derry for treatment – her family rented an Air B and B to be near at hand as she went through treatment. The distance was too much for the family to undertake each day. This is particular true for the one Children's Centre which is located in Belfast.

(ii) Financial Constraints or Rural Premium to Access Services from Rural Areas: The costs associated with traveling for care, including transportation, accommodation, and lost wages, can be prohibitive for low-income families, discouraging them from seeking necessary palliative services.

Help with Healthcare is not sufficient to address rural access. Family Support NI help page[i] indicates that the help with travel costs 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. Our rural advice

sector colleagues advise us that this has been an ongoing issue. Within this issue, we have three serious concerns:

- The lack of dignity for the patient, to be reimbursed the price of a bus fare when they are too ill and in too much pain to take public transport.
- The lack of understanding that not all of Northern Ireland has access to a suitable form of public transport.
- Rural Complexities in navigating Universal Credit as a passporting benefit to Help with Healthcare costs including the issues around the two child limit as reported by Cliff Edge Coalition[ii] (of which we are members) and self-employment rules associated with the benefit as reported by NISRA in their Report entitled: Non-Movers from Tax Credits to Universal Credit[iii]

(iii) Awareness and Education: Economic disadvantages often correlate with lower health literacy. This can result in limited awareness of available palliative care options, causing delays in seeking appropriate support.

(iv) Workforce Shortages: Marie Curie Survey Response January 2025 states that rural areas frequently experience shortages of healthcare professionals trained in palliative care, leading to reduced service availability and increased burdens on existing staff.

Recommendation: Provide transport subsidies and options as well as expand home-based palliative care services to reduce financial and logistical barriers.

Enhance Community-Based Services: Develop mobile palliative care units and telehealth services to bring care directly to rural patients, minimizing the need for travel.

Subsidize Transportation: Provide sufficient and rural proofed financial assistance for travel as well as community transport programs that are securely funded, to ensure patients can attend necessary medical appointments without undue financial strain.

Increase Funding to

- train and retain healthcare professionals in rural areas, ensuring consistent and accessible palliative care services
- Rural Community Transport thus giving equity of access to services from rural areas

Raise Awareness: Implement educational campaigns to inform rural populations about palliative care options, encouraging timely utilization of available services.

Addressing these challenges requires a comprehensive approach, integrating community support, policy interventions, and targeted funding to ensure equitable access to palliative care for all individuals, regardless of their economic status or geographic location.

Part 2: Potential Solutions and Evidence-Based Approaches

Leveraging the Department of Health's Reconfiguration Proposals

Proposal: The Department of Health's plan to reconfigure hospital services in Northern Ireland (Feb 2025) aims to create a more integrated and regionalized healthcare system by optimizing hospital locations and infrastructure, enhancing community care, and expanding digital health services.

Impact: As part of the consultation process for Hospitals- Creating a Network for Better Outcomes our members advised they were happy to travel "a reasonable distance" to access specialist treatment where it was not detrimental to their health outcomes to do so or where it was not too painful to do so.

We sought evidence from the Department that a network approach to health would/does actually improve outcomes. We have asked on multiple occasions and to date, we have not received any correspondence or evidence. Evidence based decision making on topics such as access to palliative care is essential.

A Report by Nuffield Trust entitled *Rural Health Care: A rapid review of the impact of rurality on the costs of delivery health care dated 20th January 2019*[iv] states that "*the conclusion of the most recent scoping review is that centralization itself may not improve outcomes and that attempt to centralize for specific populations – particularly in rural areas- may in fact make your outcomes worse because the distance that the patients have to travel is substantially longer and there are all sorts of secondary impacts on the patients and their family*" whilst we are not confusing a network with centralization, it is difficult to argue on the contrary when one considers the Map highlighting Hospice Provision in NI.

In addition, SIREN in Republic of Ireland[v] concluded there was no evidence that HSE reconfiguration has improved outcomes. The evidence here shows that they key driver of health outcomes is deprivation (which is often higher and more hidden in rural areas) It also states *"drivers of reconfiguration in Ireland are based on safety and efficiency claims which are highly contestable. Reconfiguration was not associated with improvements in*

safety or efficiency and may have exacerbated the growing capacity challenges for acute hospitals."

Recommendation: Department and Individual Trusts to engage with Rural Community Network in relation to their Rural Health Toolkit to build on this network approach alongside evidence to be provided by the Department on a network approach improving outcomes to ensure transparency in decision making

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Leverage the Department of Health's Help with Health Costs Scheme

Proposal: Leverage the Department of Health proposals in terms of reviewing the Help with Health Costs Scheme in particular in relation to travel costs with an aim to provide those people on low-incomes, in receipt of Universal Credit, assistance with travel

Impact: the Rural Premium (the additional cost to access services from rural areas) has a crippling impact on people with ill health on low incomes. This assistance is vital for them to be able to better afford to travel to receive treatment

Recommendation: a review of how UC, as a passporting benefit to access help with Health Care Costs, is required and a robust rural proofing exercise on the travel component of this scheme

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Optimizing Hospice Locations including a review of Cross Border Healthcare:

Proposal: Establish satellite hospice units linked to central hubs in reconfigured rural hospitals and expanding use of cross border healthcare where location allows

A family from Belleek in Co. Fermanagh required a Hospice for a very ill family member. Her nearest Hospice is 5 miles away in Ballyshannon, Co. Donegal ROI, but she is required to go to Omagh because it is in Northern Ireland some 36 miles away

Impact: Reduces travel times for rural patients and their families in a bid to reduce isolation and improve access to specialist palliative care services.

Recommendation: Prioritize placement of satellite units in areas identified as "*palliative care deserts"* by Marie Curie and Macmillan studies.

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Integrated Transport Solutions:

Proposal: Leverage hospital reconfiguration to integrate community transport services into the healthcare network and fund accordingly

Impact: Coordinated transport services would ensure reliable access to appointments and hospice care.

Recommendation: Establish transport hubs at reconfigured hospitals and subsidize travel costs for low-income patients with a robust Help with Healthcare Costs Scheme. Expand volunteer driver programs with secure funding.

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Regional Staffing Models:

Proposal: Implement a regional staffing model to rotate palliative care specialists between urban and rural hospitals.

Impact: Helps mitigate workforce shortages and ensures consistent care for rural patients.

Recommendation: Introduce financial incentives and professional development for healthcare workers in rural areas, including relocation allowances and housing support.

Expanding Community-Based Palliative Care

a) Home-Based Palliative Care Teams:

Proposal: Establish mobile palliative care teams operating from regional hospital hubs.

Impact: Ensures that remote patients receive pain management, symptom control, and emotional support at home. Farming Community Network, who are currently running an

awareness campaign around cancer and relevant support services, advise us that social isolation of patients is a real concern especially when patients are required to stay as an inpatient for treatment so far away from home. They spoke to the son of a man who was receiving palliative care as an inpatient and he told them of how his father would often not be fully honest with the family in terms of how he was feeling as he did not want to "burden" his family with having to travel so far to visit him.

Recommendation: Secure funding through the Rural Needs Act to support mobile services.

b) Telehealth and Digital Support:

Proposal: Integrate telehealth capabilities into reconfigured hospitals to support virtual consultations for rural patients.

Impact: Reduces the need for travel and enables continuous symptom monitoring.

Recommendation: Invest in broadband infrastructure and provide digital literacy training for patients and carers.

Leveraging the Rural Needs Act and Rural Proofing for Health Toolkit

a) Rural Needs Act Compliance:

Proposal: Ensure that hospital service reconfiguration aligns with the Rural Needs Act by conducting comprehensive rural impact assessments.

Impact: Reduces disparities in palliative care access by identifying rural-specific needs.

Recommendation: Include rural representatives in decision-making bodies overseeing hospital service changes.

b) Rural Proofing for Health Toolkit:

Proposal: Use the toolkit to develop policies focusing on transport, workforce distribution, and digital access.

Impact: A structured approach to rural proofing would directly address the challenges faced by rural patients.

Recommendation: Establish a Rural Health Task Force to oversee toolkit implementation and monitor progress.

Recommendations for Effective Implementation

Funding Reallocation: Advocate for targeted funding to support hospice satellites, transport services, and workforce incentives in rural areas.

Partnership with NGOs: Collaborate with Marie Curie, Macmillan, and Community Transport Northern Ireland to expand services and share expertise.

Community Engagement: Conduct consultations with rural communities to identify priorities and tailor palliative care services accordingly.

Conclusion

The reconfiguration of hospital services, guided by the Rural Needs Act and insights from Scotland's "A Road Less Lonely" initiative, presents a unique opportunity to transform palliative care in rural Northern Ireland.

By strategically locating hospice services, enhancing community-based care, and addressing transport, rural premium, rural poverty and workforce challenges, we can ensure that all patients, regardless of location, receive compassionate and timely end-of-life care.

A collaborative approach involving policymakers, healthcare providers, and community organizations will be essential to achieving these goals.

Let us seize this opportunity to build a palliative care system that really does leave no one behind.

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