RESPONSE OF THE ASSISTED DYING AND EUTHANASIA TASK GROUP OF THE PRESBYTERIAN CHURCH IN IRELAND TO THE COMMITTEE FOR HEALTH ACCESS TO PALLIATIVE CARE INQUIRY

JANUARY 2025

Background

1. The Presbyterian Church in Ireland (PCI) has over 190,000 members belonging to over 500
2. congregations across 19 Presbyteries throughout Ireland, north and south. The Council for Public Affairs is authorised by the General Assembly of the Presbyterian Church in Ireland to speak on behalf of PCI on matters of public policy. The Assisted Suicide and Euthanasia Task Group was established in response to the proposed legislative change on assisted dying in GB and the Republic of Ireland. Membership of the Task Group includes medical professionals who work in the field of palliative care and their experience has informed this response.
3. PCI through its Council for Social Witness (CSW) provides services that meet the World Health Organisation's (WHO) description of palliative care through care homes for older people (residential and nursing). The CSW operates two residential homes for people with disabilities in NI, supporting people with life-limiting conditions. Additionally, PCI has five residential homes which cater for older adults and one nursing home providing care to those in the later days of their lives.
4. As part of the mission and ministry of the PCI there are 27 Chaplains working in hospitals across Ireland providing spiritual guidance and pastoral care to both patients and their families.

Current State of Palliative Care Services

5. There is a clear lack of understanding among both the public and healthcare workers about what palliative care is. This was evidenced during the recent Westminster debate on the proposed changes to the law on assisted dying in November 2024, where many MPs seemed to regard Palliative Care Medicine as 'handholding with morphine'. Additionally, there is a common misconception that palliative care inpatient units are places where a person's life is deliberately shortened. This is factually incorrect with evidence showing that palliative care often inadvertently extends life, and can improve quality of life.

    a. There are a number of possible reasons behind the lack understanding of palliative care:
    b. Lack of a clear definition of palliative care - there are a number of services providers, training, and approaches which are all described as 'palliative care.' Lack of regional ownership or leadership to define and clarify palliative care services in NI. This could be due to the perception that palliative care is delivered in discrete locations such as hospices, as opposed to the quality of end of life being strengthened by early identification, correct multi-disciplinary assessment and management of

pain and other problems whether physical, psychosocial or spiritual in a range of care and domestic settings

c. Cultural/Societal change- there is an unwillingness amongst the public to engage in issues surrounding morality, death and dying.

Access to Palliative Care

6. Access to Palliative Care is not equally accessible to everyone in NI and has been described by some as a 'postcode lottery'. PCI's CSW noted that in their experience, 'access to community supports that can enable a person requiring palliative care to remain in the place where they have been living is patchy and inconsistent across the region.'
7. One of the main gaps in the provision of services has been accredited to the lack of regional leadership and accountability from Stormont, to ensure that Palliative Care services are delivered in a joined up, equitable and accessible manner. This has resulted in consistent and repeated failures to address the needs of patients requiring generalist and specialist care.
8. Additionally, there has been a concerning lack of consistent funding for palliative care services, with around 70% of funding for these services requiring fundraising ventures such as cake sales and sponsored walks. The majority of Hospices and inpatient services are charitably funded.
9. A number of barriers exist which could prevent the equitable access to palliative care services, these include:

    a. **Palliative Care Services are delivered in a fragmented and non-integrated manner.** This is due to the differences amongst the Health Trusts delivering this service and a reliance on charitable hospices, each of which have a unique approach to service delivery. As a result of the inconsistencies in both the provision and delivery of this service, there is a risk that some patients are unable to access palliative care when they need it most.
    b. **No Legal Requirement for Palliative Care Commissioning.** In England and Wales the Health and Care Act 2022 requires the NHS in England to provide palliative care; the same legal provision does not exist in NI.
    c. **National Insurance increases:** The increased national insurance contributions
    announced in the autumn budget will adversely and disproportionally affect General Practitioners, the Hospice sector and nursing homes. PCI's Council for Public Affairs has written to the Chancellor expressing concerns regarding the negative impact this increase will have. (The recent announcement of a £100 million grant to Hospices made before Christmas only applies to Hospices in England and Wales leaving Northern Ireland strongly disadvantaged.)

Integration of Services

10. Palliative Care Services are poorly integrated across the health system with hospital doctors and GPs often unsure of when and how to use Palliative Care

services. This is due to the lack of clarity (referred to above) regarding what Palliative Care services provided; the continuing stigma associated with Palliative Care and the difficulties that some clinicians have in bringing up the topic of Palliative Care.

11. When considering how the integration of services could be improved, consideration should be given to reforming the distinctions between residential care homes and nursing homes. Stabilised and predictable funding for community based palliative services will allow for more dignified late life care in older people's homes of all types.

Best Practice

12. We commend the work carried out by hospices, palliative care inpatient units, hospital palliative care teams, and community palliative care teams and urge the health committee to look to them for best practice examples.
13. Through the work of the CSW, PCI are committed to supporting people near the end of their lives, and their families, in all possible circumstances. As a faith organisation, PCI's emphasis on meeting the spiritual needs of people at this time in their lives as had a meaningful impact. PCI has some great examples of this with the meaningful impact acknowledged by families. However due to a variety of challenges, this is not always the case.
14. The CSW care homes (when required) are dependent on Trusts agreeing funding for additional staff, or on availability of community nursing staff, or on flexibility from RQIA to permit care outside a category of care (sometimes care could be delivered in a person's own home). Unfortunately, staff members' experience indicates this is also not always the case in all residential and nursing homes in NI.
15. Due to the inconsistencies in the delivery of palliative care outlined above, we are concerned that families are not receiving the appropriate support when a loved one is receiving palliative care. However, we also acknowledge that this is due to fund constraints and a lack of resources.

Funding and Strategy

16. The current palliative care funding model relies largely on charitable donations and fundraising, with the Northern Ireland Hospice reporting that 30% of its service costs are covered by government, relying on the generosity of voluntary donations and other fundraising activities for the majority of their income.
17. This funding model is unsustainable, insufficient and inequitable; it fails to provide financial stability and prevents hospices from maintaining services, retaining skilled staff, and fostering innovation. It also forces unnecessary competition for limited funds, fragmenting care and hindering collaboration. Without multi-year budgets, long-term planning and meaningful service development are impossible, leaving clinical needs unmet and communities underserved.
18. There is a need to ensure stability of long-term funding to allow planning service developments and alignment of resources with community profiles to ensure best distribution of resources. This will also enable enduring partnerships with other care providers regionally.

19. There is an urgent need for a Palliative Care Strategy in NI, however this needs to be
underpinned by a Palliative Care policy.
20. The policy could introduce the necessary legislation change, placing the provision of palliative care in NI on a statutory footing providing the necessary accountability, with a strategy providing a road map for delivery. It is essential that any strategy should include measurable milestones and be subject to yearly reviews to ensure that it is delivering the desired policy objectives.
21. A Palliative Care policy should address all of the gaps outlined above including: Regionalisation of Palliative Care services; Integration of services; Workforce planning for the next 20 years; Data collection of services to demonstrate impact; Funding strategy for charitable services delivering Palliative Care; Ease of access; and Out of Hours services involving clinicians and pharmacy.
22. This should include a review of regulatory arrangements for varying types of care provision, and involve extensive consultation with carers and patient's groups. Consultation with independent sector care providers, statutory bodies and representatives of churches and other faith communities should also be included to advise on the importance of meeting spiritual needs at this time of life – something that is currently recognised by NHS England.

Additional Comments

23. PCI remain concerned about the proposal of an assisted dying law in Westminster and the Dail, and that the introduction of such legislation may result in necessary resources and funding being redirected from palliative care.
24. PCI would like to commend the valuable work of health care chaplains, ministers and church leaders (including PCI ministers and chaplains) for the spiritual, pastoral and religious care that they offer to patients, their families and friends.