

Minister of Health
Northern Ireland Assembly
Parliament Buildings
Belfast
BT4 3XX

14.03.2025

Dear Minister Nesbitt,

RE: Dying, Death and Bereavement Secured in Programme for Government

This letter is to acknowledge and pay thanks to you as member of the NI Executive for the commitment within the Programme for Government 2024-27 to improve support for those coping with death, dying and bereavement. As you will be aware the inclusion of this important issue was supported and campaigned for by over 10,000+ people in Northern Ireland before the last Assembly collapsed in 2022. We have ensured that our supporters, including those that wrote to their MLAs directly on this matter have been informed of this positive news. In achieving this important step, we pay special thanks to members of the APG Terminal Illness and Joanne Bunting MLA as Chair for their efforts to support our drive to ensure everyone at end of life gets the care and support they need.

We understand that this commitment in the PfG is a goal which will extend beyond the life of this Assembly Term. However, there is still much that we can do now- and we welcome the announcement that a palliative care needs assessment and service scoping exercise is being undertaken. Understanding need both now and into the future, alongside a review of both generalist and specialist services is critically important in developing a future proofed comprehensive roadmap for reform. It is vital that this work takes account of the projected increase in need and ensures that everyone with a terminal illness gets access to palliative care- sadly this is currently not the case. Whilst 90% of people could benefit from palliative care, 1 in 4 do not.

The Health Committee Inquiry into access to palliative care brings much needed visibility to this issue as an essential part of healthcare. As we shift left to more care in the community, it is also essential that we consider the wider system through a palliative care lens- to include equity of access to social care, social security support, appropriate housing etc. It is estimated that 3,000 people die in poverty each year in Northern Ireland- with more people being cared for in the community- these levels will increase if people aren't adequately supported practically and financially, as well as clinically, to be cared for and die at home.

In terms of healthcare specifically, the nature of palliative care means that patients need care from a myriad of services, including primary care (GP, District Nursing or Community Pharmacy), acute care (inpatient or outpatient), care homes or hospices. It is vital that a comprehensive plan is actioned to ensure a palliative approach to care is available wherever people are in the system, both in and out of hours.

Marie Curie invests considerable resource in research to develop evidence-based policy solutions and piloting and evaluating service innovations. In NI, Marie Curie is exploring initiatives to bolster community provision and reduce unnecessary Emergency Department admissions. This includes discussions with key partners in the Southern Trust to provide more seamless support to patients in this locality. We are also in discussion with the NI Ambulance Service about upskilling paramedics in palliative care to help stabilise and support patients in the home setting rather than conveyance to ED. We want to share our learning and will continue to engage in as much public consultation as possible. For example, we were very pleased to contribute to the recent consultation on hospital re-configuration. We would also welcome any additional opportunities to feed our ideas into the transformation workstreams happening across the wider health and social care system. We are aware that a recent event on winter pressures was held by the Department of Health - we very much welcome this earlier planning and collaborative approach and would be keen to be part of future events.

The Independent Hospice Sector is a key part the HSC system and are privileged to provide care to 11,000 people each year. As a sector, we want to be part of the solution that keeps palliative and end of life patients out of hospital or Emergency departments if they don't need to be there - many of them do not. Our focus is palliative patients, this is our area of expertise, we can help ensure that the needs of these patients are fully considered in all policy review and service re-design processes. Please do consider us as key partners in the transformation of palliative care- we care for the most vulnerable members of society- we want to make our health and social care system work for everyone- we can be part of the solution which ensures palliative and end of life patients get the care they need, where and when they need it.

Your Sincerely



Joan McEwan
Associate Director Policy and Public Affairs
Marie Curie NI

cc:
Joanne Bunting MLA - Chair of APG Terminal Illness
Philip McGuigan MLA- Chair Health Committee
Gearoid Cassidy- Director of Primary Care DoH with policy responsibility for adult palliative care and hospice services.

Ryan Wilson- Director of Secondary care DoH with policy responsibility for adult palliative care and hospice services.

Roger Kennedy- Commissioning of specialist adult palliative care and hospice services.
Permanent Secretary of Health