



# Marie Curie Northern Ireland

*A whole society approach to end of life care*

Care and support  
through terminal illness

## The case for a whole society approach to end of life care

The population of Belfast is getting older, and there has been a steady rise in the prevalence of advanced and terminal illness in the city.

- The number of people in Belfast on registries for COPD, cancer and dementia has increased by over 70% since 2007. <sup>[1]</sup>
- Across Northern Ireland, the death rate is projected to increase by 32% by 2041 <sup>[2]</sup> – the highest proportional increase in the UK.

People with advanced and terminal illnesses, and their loved ones, are vulnerable to serious additional problems that are linked to their health conditions, including loneliness, social isolation, job loss, financial strain, stigma, depression, anxiety and fear. Problems of this nature can have a significant impact on the quality of life of those affected by terminal illness, and can be difficult to address through clinical health services alone.

**We need to recognise the limits to clinical care and service provision and consider the benefits of a whole society approach to end of life care – one that provides non-clinical support in a community setting and treats care as a civic responsibility, shared by everyone.**

In practice, this approach involves social efforts from across society to improve health in the face of terminal illness, caregiving and bereavement. This includes health promotion and awareness-raising, along with measures to change attitudes towards death and dying.

**Marie Curie is calling for Belfast City Council's People and Communities Committee to act as a partner in the provision of non-clinical, community-based support for local people affected by terminal illness.**

## What is involved?

A whole society approach to end of life care involves efforts from all the major sectors in the community – including **local government**, the business community, education, arts and cultural institutions and the housing sector – to support those affected by terminal illness and their loved ones.

At the heart of this approach is the recognition that care is not solely the task of HSC services – it is everyone's responsibility, and the issues associated with death and dying cannot be fully addressed without a whole-community approach.

<sup>1</sup> Northern Ireland Statistics and Research Agency. Disease Prevalence (Quality Outcomes Framework) (administrative geographies). Available at: <http://www.ninis2.nisra.gov.uk/public/PivotGrid.aspx?ds=8231&lh=73&yn=2007-2017&sk=134&sn=Health%20and%20Social%20Care&yearfilter=>

<sup>2</sup> Northern Ireland Statistics and Research Agency (2017). Statistical Bulletin: 2016-based Population Projections for Northern Ireland. Available at: <https://www.nisra.gov.uk/sites/nisra.gov.uk/files/publications/2016-based%20Population%20Projections%20-%20statistical%20bulletin.pdf>

The benefits of a whole society approach to end of life care are significant:

- Expands the reach of end of life care services by engaging the wider community.
- Addresses a greater range of needs (including social, psychological and spiritual) that may not always be met by clinical services.
- Mobilises untapped sources of social and spiritual care/support, as well as practical resources and expertise.
- Increases social networks and reduces social isolation.
- Helps to alleviate the significant burden on caregivers.
- Improves overall quality of life.
- Reduces the burden on frontline/clinical services, including unscheduled care.
- Provides care in a community setting, usually the place of choice for both patients and carers.

## Examples

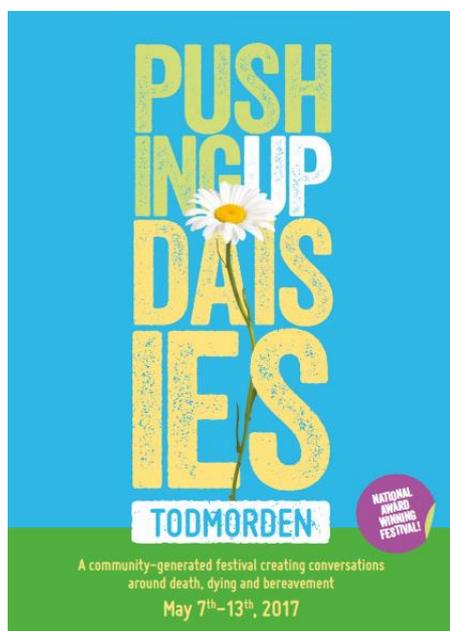
Below we have listed a number of examples of community-based initiatives that Belfast City Council could pursue to help support people affected by terminal illness. This is not a prescriptive list, but provides real examples of how local authorities, charities and voluntary groups across the UK have implemented community based approaches to end of life care.

*Belfast City Council could:*

- Establish a Carer Passport scheme to help identify staff who are caring for someone with a terminal illness;
- Introduce work-place resources to support staff affected by terminal illness and bereavement;
- Review council policies on sickness leave, compassionate leave and carers leave to ensure staff receive all the support they need when they are affected by terminal illness;
- Host a series of Death Cafés for staff and the public to raise awareness of the issues around death and dying and the support available for people affected by terminal illness. These could be organised in partnership with relevant organisations like Marie Curie or Cruse Bereavement Care;
- Host information pop-ups on issues relevant to death, dying and loss – for example, funeral planning, dealing with bereavement, balancing work and caring responsibilities etc;
- Support local art galleries and museums to run exhibitions exploring ideas of death, loss, grief, and remembrance.

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## Pushing Up Daisies festival



*Pushing Up Daisies* is an annual, volunteer-led festival held in Todmorden, West Yorkshire. The festival is designed to inspire public conversations about death and dying, with events including storytelling shows, art exhibitions, discussion groups, Death Cafés and writing workshops.

The 2017 festival included a children's workshop highlighting loss and bereavement through storytelling; a men's grief discussion group; and Death Cafés on funeral planning with advice from religious representative and grief counsellors (see attached).

“[T]aking time, giving space, having knowledge and being willing to sit with the ‘difficult stuff’ can radically improve the experience of end of life – and that that is an incredibly worthwhile thing to do.”

The People and Communities Committee could organise a one-day event with the following potential exhibitors:

- Cruse Bereavement Care
- Law Society NI
- Carers NI
- Macmillan Cancer Support
- National Association of Funeral Directors
- Men in Sheds

This would provide an opportunity to raise awareness of issues around death and dying and share information about available support services.

Alternatively, the Committee could organise a larger festival-type event. The programme for the event could potentially include the following (this is a draft for example purposes only):

Day One	
Activity	Potential Partners
<p><b><i>Have you made your will yet?</i></b> – Information pop-up on wills and estates</p> <p><i>Belfast City Hall</i></p>	Law Society NI
<p><b><i>Life can be a challenge, especially when it comes to death. Talking about it can sometimes help</i></b> – Death Café</p> <p><i>The Bobbin</i></p>	Cruse Bereavement Care Marie Curie
<p><b><i>Death from a different angle</i></b> – Painting and sculpture exhibition exploring death and dying</p>	The MAC Belfast
<p><b><i>Bringing death to life</i></b> – Story telling group on ageing and loss</p> <p><i>Linen Hall Library</i></p>	Libraries NI
Day Two	
<p><b>Presentation: balancing education and caring responsibilities</b></p>	Carers NI Queen’s University Belfast
<p><b>Discussion group on living with terminal illness</b></p>	Marie Curie Belfast Health and Social Care Trust
<p><b><i>Good Grief</i></b> – Practical and emotional advice session on coping with the loss of a loved one</p>	Cruse Bereavement Care
<p><b><i>A life well lived – bucket lists, creating memories and leaving legacies</i></b> – Death Café</p> <p><i>Marie Curie Belfast Hospice</i></p>	Marie Curie

These examples are not prescriptive or exhaustive, but demonstrate how whole society approaches to end of life care can be implemented in practice. The Committee could start with as many or as few of these initiatives as it sees fit, or come up with something different entirely.

## Our ask

We would ask the People and Communities Committee to:

- Formally endorse the benefits of a whole society approach to end of life care.
- Commit to a programme of activity to support people affected by terminal illnesses in Belfast City Council, with the support of Marie Curie and other relevant organisations.
- Create and publish an Action Plan for this programme of work.
- Submit the Action Plan for approval by the full Council.

## For more information, please contact:

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## About Marie Curie

Marie Curie is a leader in the provision of care to people with a terminal illness in Northern Ireland. We provide a range of bespoke services including the Marie Curie Hospice in Belfast, Nursing Service and Helper Service. Each year we provide care and support for around 4,000 people living with a terminal illness, their carers and loved ones.

[mariecurie.org.uk/northernireland](http://mariecurie.org.uk/northernireland)



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