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Research on loneliness in advanced life-threatening illness: A focus on what we can do in our local communities

11th March 2026

QUEEN'S UNIVERSITY BELFAST

UCL

MAIN Mental health and wellbeing in Advanced Illness Network

Speakers:

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Dr Lisa Graham-Wisener

Panellist:

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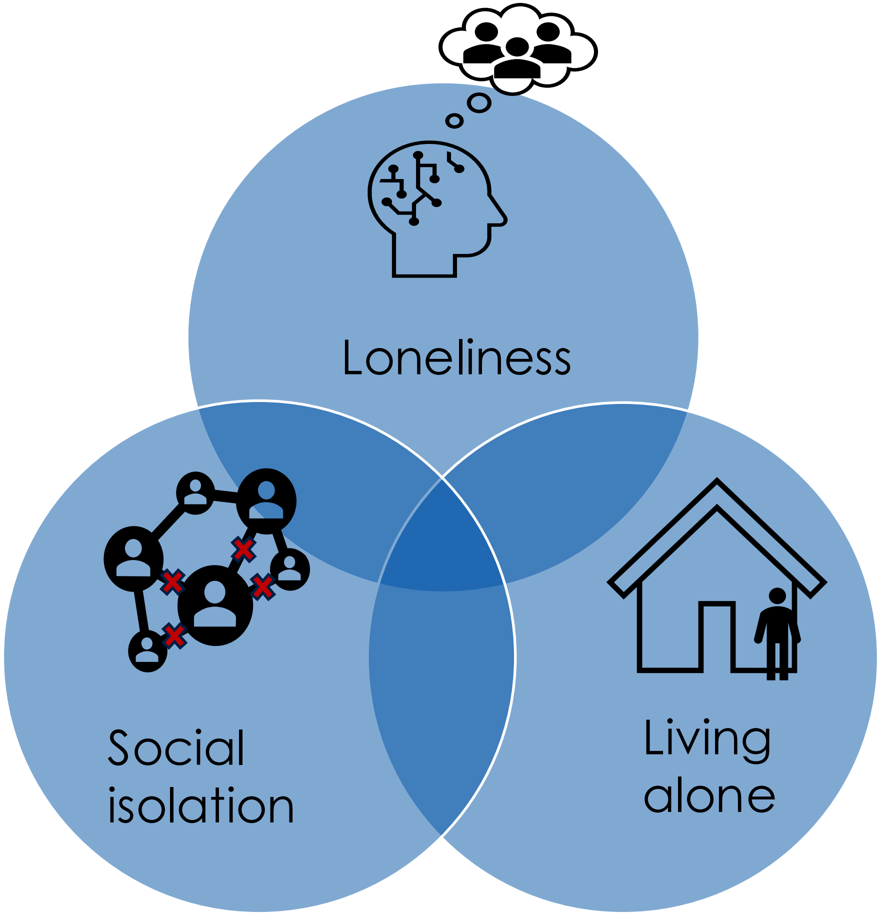
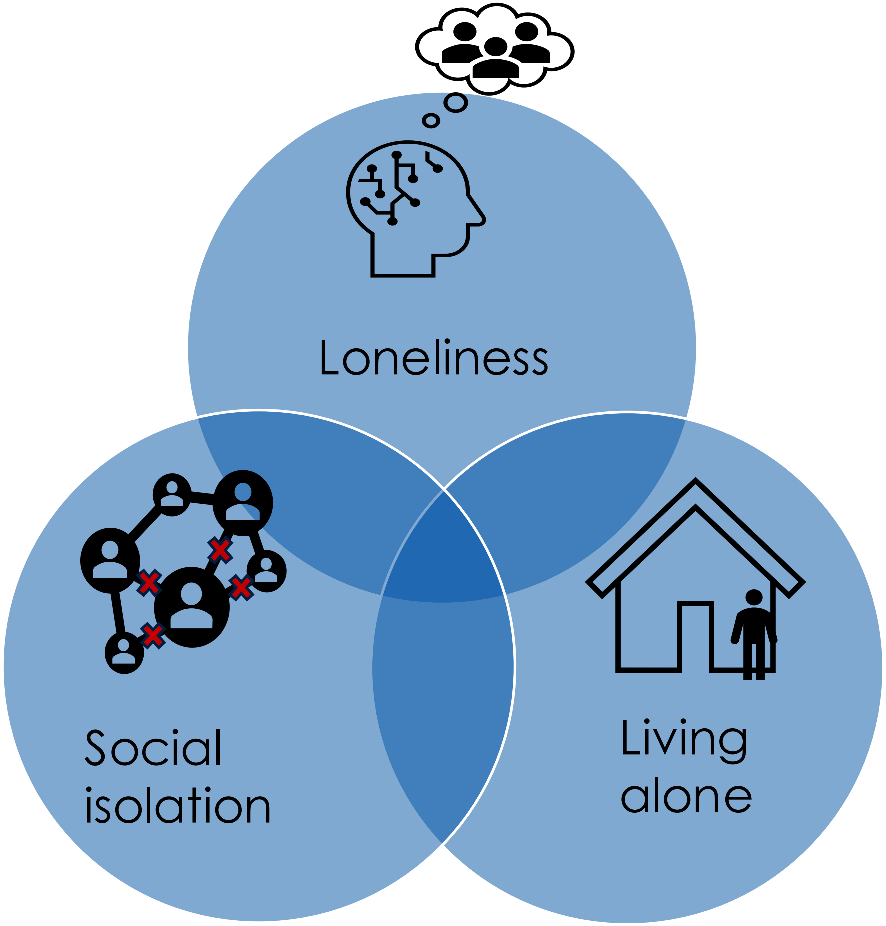
Chair:

Dr Natasha Bradley

Loneliness, social isolation and living alone



Loneliness, social isolation and living alone



Loneliness

Social isolation

Living alone

> *"One of the loneliest people I've ever met is a gentleman who's living with a terminal illness and he's in a nursing home. He doesn't have very many family visitors. And the care staff, he knows they care and they come in and they do their tasks. But he'd just like, at some point, one of them to take five minutes and sit down and say: 'how are you?' and just have a chat with him. They just don't have time. He understands that. But he's very, very lonely."*

Marie Curie Patient and Family Support Team Member[1]

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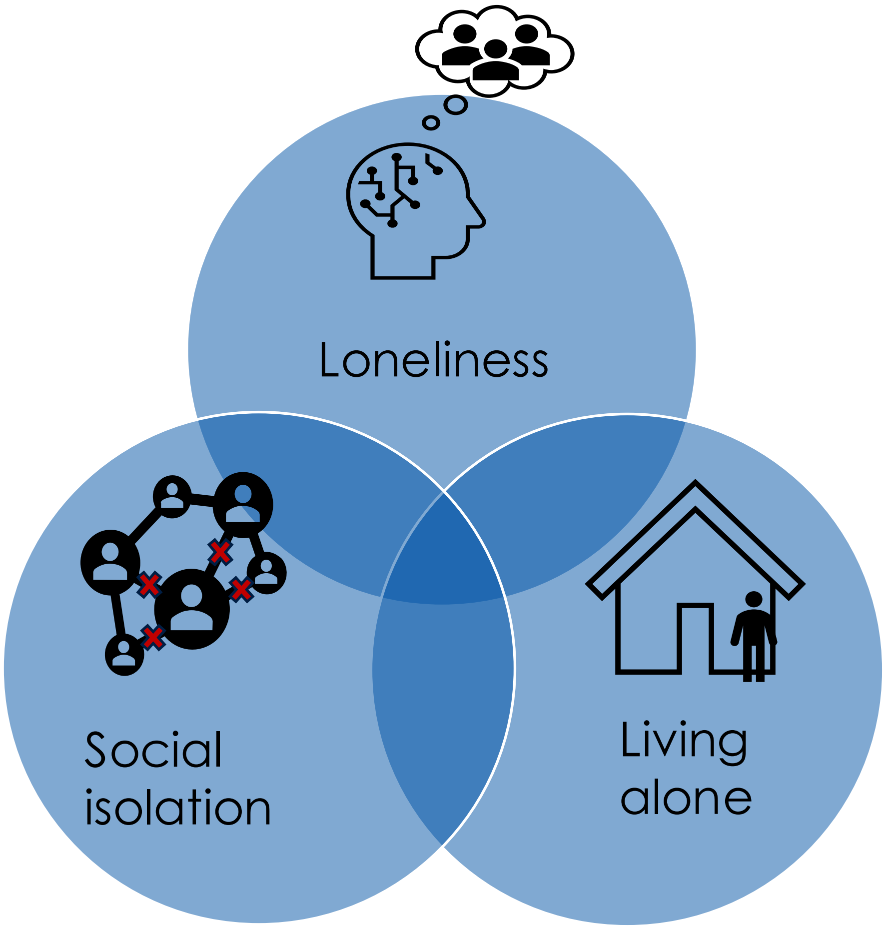
[1] Marie Curie and Queen's University Belfast (2022) **"You're the first person who's sat on that sofa in 12 months"** Experiences of loneliness among people at the end of life and their carers in Northern Ireland

Loneliness, social isolation and living alone



Research priorities for palliative and end of life care

Identified and prioritised by people with lived and/or professional experience

PARTNERED WITH

In 2025 Marie Curie, in partnership with the James Lind Alliance and other charities and research funders completed a priority setting partnership to agree on the top priorities for future palliative and end of life care research. These priorities were identified and prioritised by people affected by serious life-limiting illness.

What did we do?

We followed the James Lind Alliance Priority Setting process to consult people affected by serious life-limiting illness across the UK. This involved the following stages:

- An online survey to ask people affected by serious life-limiting illness (patients, families, friends and health and social care professionals) what they thought future research should focus on. 1032 people completed this survey.
- A second survey to prioritise the issues identified in the first survey, which was completed by 626 people.
- An in-person workshop where 20 people affected by serious life-limiting illness agreed on the ranking of the prioritised issues, and a top 10.

How did we involve pe
life-limiting illness?

Twenty people affected by ser
group. The group met regularly
was grounded in lived experier
findings as accessible as possi

10 How can palliative and end of life care better meet the needs of people **who live alone, or are socially isolated?**

Measuring loneliness

Feel isolated from others?

Lack communication?

Indirect

Feel lonely?

Direct

?

Existential loneliness

Dying person?

Family or friend?

Health professional?

Perspective?

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Professional perceptions

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How much has changed since 1952?

70 years of
end of life care
in the community

Supported by
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Original Article

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'There's something about admitting that you are lonely' – prevalence, impact and solutions to loneliness in terminal illness: An explanatory sequential multi-methods study

Jeffrey R Hanna[1], Tracey McConnell[2], Craig Harrison[2],
Katarzyna A Patynowska[2], Anne M Finucane[3], Briony Hudson[4],
Sharon Paradine[4], Angela McCullagh[4] and Joanne Reid[1]

Abstract

Background: Loneliness is a prevalent societal issue and can impact on a person's physical and mental health. It is unclear how loneliness impacts on end of life experiences or how such feelings can be alleviated.

Aim: To explore the perceived prevalence, impact and possible solutions to loneliness among people who are terminally ill and their carers in Northern Ireland through the lens of health and social care professionals.

Design: An explanatory multi-method study.

Setting/participants: An online survey ($n = 68$, response rate 30%) followed by three online focus groups with palliative and end of life care health and social care professionals ($n = 14$). Data were analysed using descriptive statistics and thematic analysis.

Results: Loneliness was perceived by professionals as highly prevalent for people with a terminal illness (92.6%) and their carers (86.8%). Loneliness was considered a taboo subject and impacts on symptoms including pain and breathlessness and overall wellbeing at end of life. Social support was viewed as central towards alleviating feelings of loneliness and promoting connectedness at end of life. Four themes were identified: (1) the stigma of loneliness, (2) COVID-19: The loneliness pandemic (3) impact of loneliness across physical and mental health domains and (4) the power of social networks.

Conclusion: There is a need for greater investment for social support initiatives to tackle experiences of loneliness at end of life. These services must be co-produced with people impacted by terminal illness to ensure they meet the needs of this population.

Keywords

Loneliness, terminal illness, carers, end of life, palliative care, healthcare professionals, social care professionals

What is already known about the topic?

- Experiences of loneliness are heightened for people impacted by terminal illness.
- Individuals who experience loneliness are at risk of a variety of physical and mental conditions including heart disease, obesity, a weakened immune system, anxiety or depression.
- Loneliness is a global public health issue that has become more prevalent during the COVID-19 pandemic.

What this paper adds?

- Loneliness is perceived by healthcare professionals as a common experience for patients and carers at the end of life which has become more commonplace during the COVID-19 pandemic.

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Marie Curie
Care and support through terminal illness

"You're the first person who's sat on that sofa in 12 months"

Experiences of loneliness among people at the end of life and their carers in Northern Ireland

In partnership with QUEEN'S UNIVERSITY BELFAST

February 2022

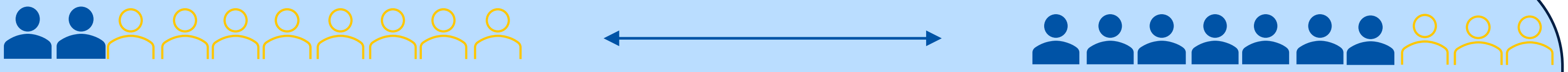
Most professionals knew lonely people among the people they cared for and carers were also often identified.

Global evidence of loneliness prevalence

Systematic review aiming to synthesize evidence of prevalence and correlates of loneliness among adults at the end of life.

668 records screened > 15 studies, mostly from North America and Europe.

Studies grouped by sample type, loneliness measure and whether patient, family or professionals answered.



Between 20% and 73% of people with a terminal diagnosis or receiving palliative or hospice care experienced moderate loneliness

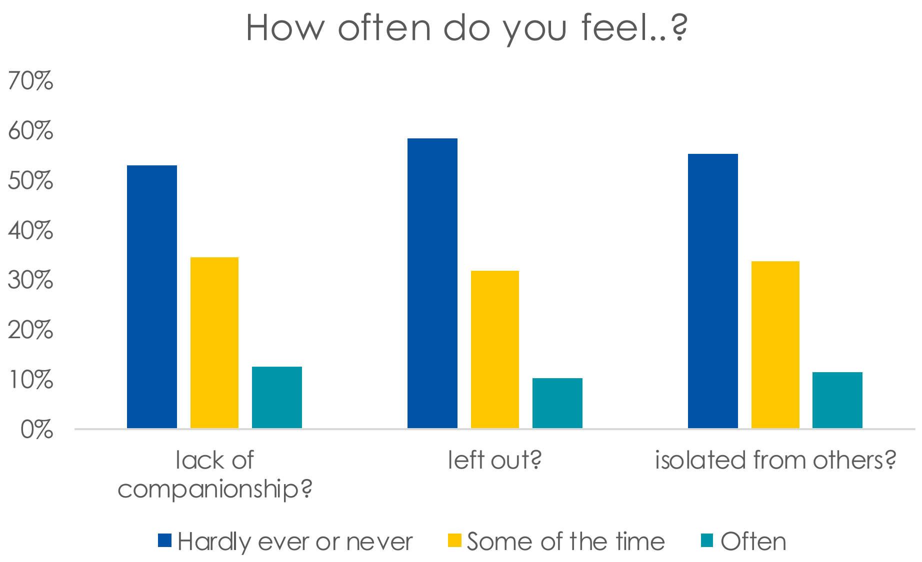
Between 8 and 33% experienced high loneliness

Emerging evidence: loneliness for non-cancer vs cancer and multimorbidity vs one diagnosis (but only two studies)

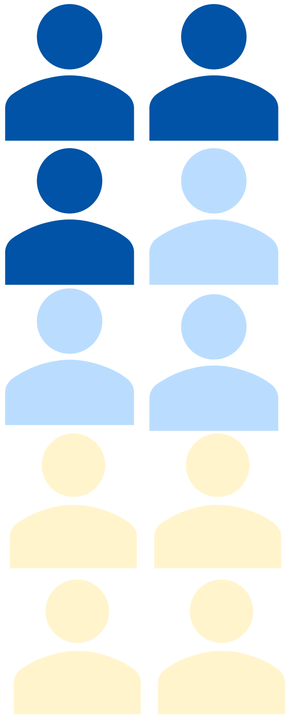
Accepted (Palliative Medicine): Maun, E., Gardiner, C., McConnell, T., Seddon, K., Woodhead, A. and Hudson, B., (2026) Loneliness among adults at the end of life: a systematic review of prevalence and correlates

How many people feel lonely in their last year of life in the UK?

Analysis of loneliness in the year before death, among 740 people who died in a nationally representative survey of people in the UK (deaths between 2018 and 2022)



Loneliness scale scores 3 to 9
(feeling loneliness = scores of 6 or more)



Loneliness: 32% answered *“sometimes” or more often*

Some loneliness: 28%

No or hardly any loneliness: 40%

Under peer review: Maun, E. Gardiner, C., McConnell, T., Seddon, K. and Hudson, B (2026) *Loneliness prevalence and risk factors in the last year of life: analysis of UK household panel data*

Understanding Society
THE UK HOUSEHOLD LONGITUDINAL STUDY

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Potential risk factors

Which population groups are more likely to be lonely in their last year of life?

Logistic regression to estimate odds of feeling loneliness for social, financial and health characteristics of people in their last year of life.

Women
(but explained by other characteristics)

Unmarried/ widowed/ divorced

People with 3+ impairments

People a probable mental health condition

Surprisingly, people who were living alone were not more likely to be lonely (but may be less likely to be identified as having died in the survey).

Under peer review: Maun, E. Gardiner, C., McConnell, T., Seddon, K. and Hudson, B(2026) *Loneliness prevalence and risk factors in the last year of life: analysis of UK household panel data*

Where next?

Some research possibilities from these studies

- Previous research often small-scale but large-scale survey downsides.

- Many contexts of end of life – how does loneliness differ and what influences experience of loneliness across care homes, private homes, hospitals and hospices? Condition-specific factors.

- Better measurement of loneliness at end of life
  - inclusion of existential loneliness
  - encompassing carers and family members
  - over time, links to prior life circumstances and as end of life approaches

- Intersections for instance with financial insecurity

Loneliness in Advanced Life-Threatening Illness: An Integrative Review

Objectives

- Develop an understanding of the causes, experiences and impacts of loneliness
- Explore modifiable factors to mitigate loneliness for those
- Identify knowledge gaps in relation to loneliness from studies

Review Article

Loneliness in Advanced Life-Threatening Illness: An Integrative Review

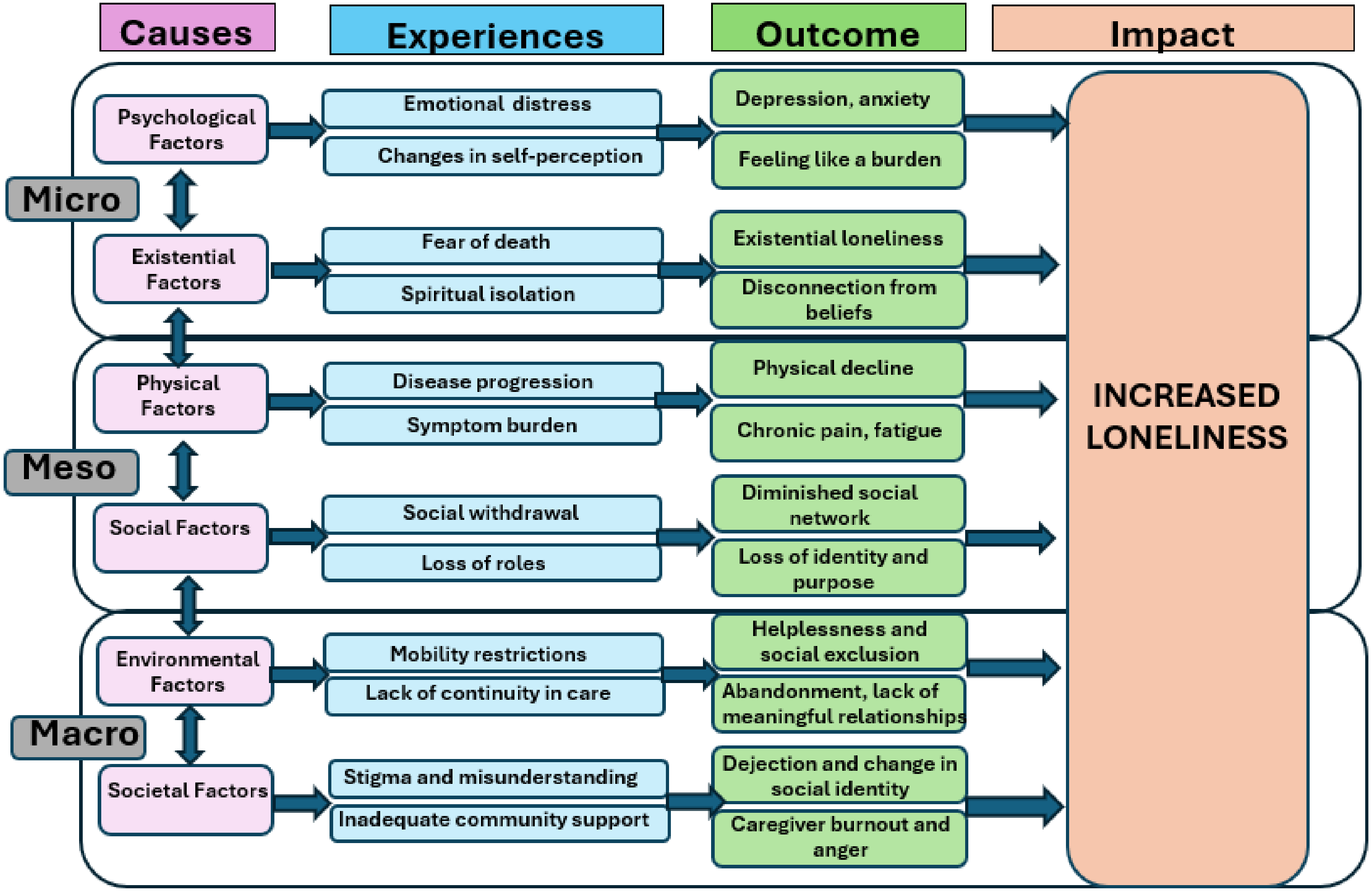
Carolyn Blair, PhD, Tracey McConnell, PhD, Natasha Bradley, PhD, Anne Finucane, PhD, Briony Hudson, PhD, Angela McCullagh, PhD, Austin Orr, MA, Sharon Paradine, BSc, Katarzyna Patynowska, MSc, and Joanne Reid, PhD

Abstract

Two patient and carer representatives from Marie Curie Research Voices were an integral part of our team

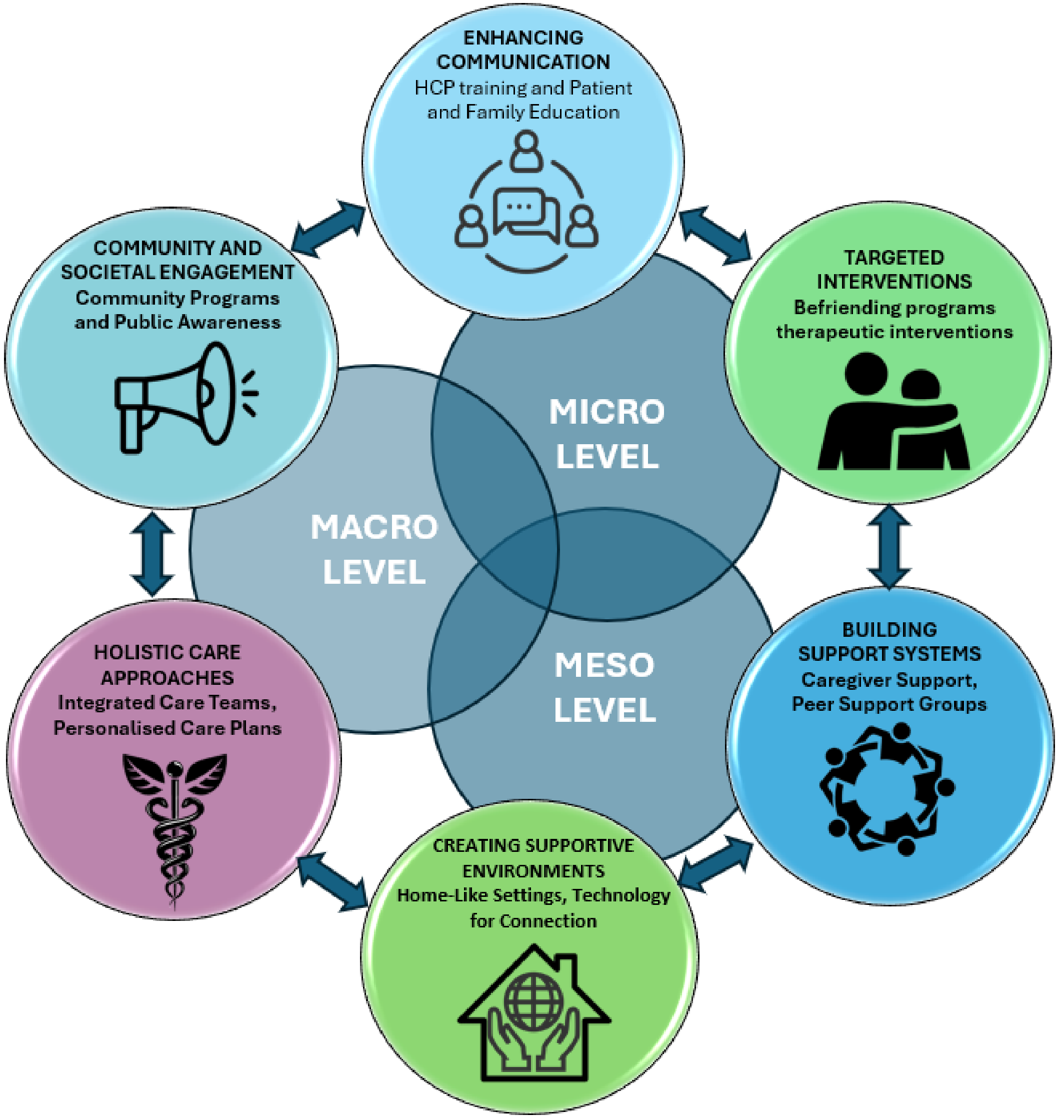
2738 studies were screened, 19 observational studies and 6 intervention studies were included

Causes, experiences and outcomes leading to loneliness



	Causes	Experiences	Outcome	Impact
Micro	Psychological Factors	Emotional distress Changes in self-perception	Depression, anxiety Feeling like a burden	INCREASED LONELINESS
	Existential Factors	Fear of death Spiritual isolation	Existential loneliness Disconnection from beliefs	
Meso	Physical Factors	Disease progression Symptom burden	Physical decline Chronic pain, fatigue	
	Social Factors	Social withdrawal Loss of roles	Diminished social network Loss of identity and purpose	
Macro	Environmental Factors	Mobility restrictions Lack of continuity in care	Helplessness and social exclusion Abandonment, lack of meaningful relationships	
	Societal Factors	Stigma and misunderstanding Inadequate community support	Dejection and change in social identity Caregiver burnout and anger	

Modifiable factors to reduce loneliness



Specific interventions which lead to enhanced social connectedness

Technology- and Sensory-Based Psychosocial Interventions

Mitchell et al. (2020) – Complementary Therapy in Dementia Care

Demirag et al. (2022) – Robotic Pet & Fish Therapy

Woo et al. (2023) – Virtual Reality Relaxation (FLOW-VRT)

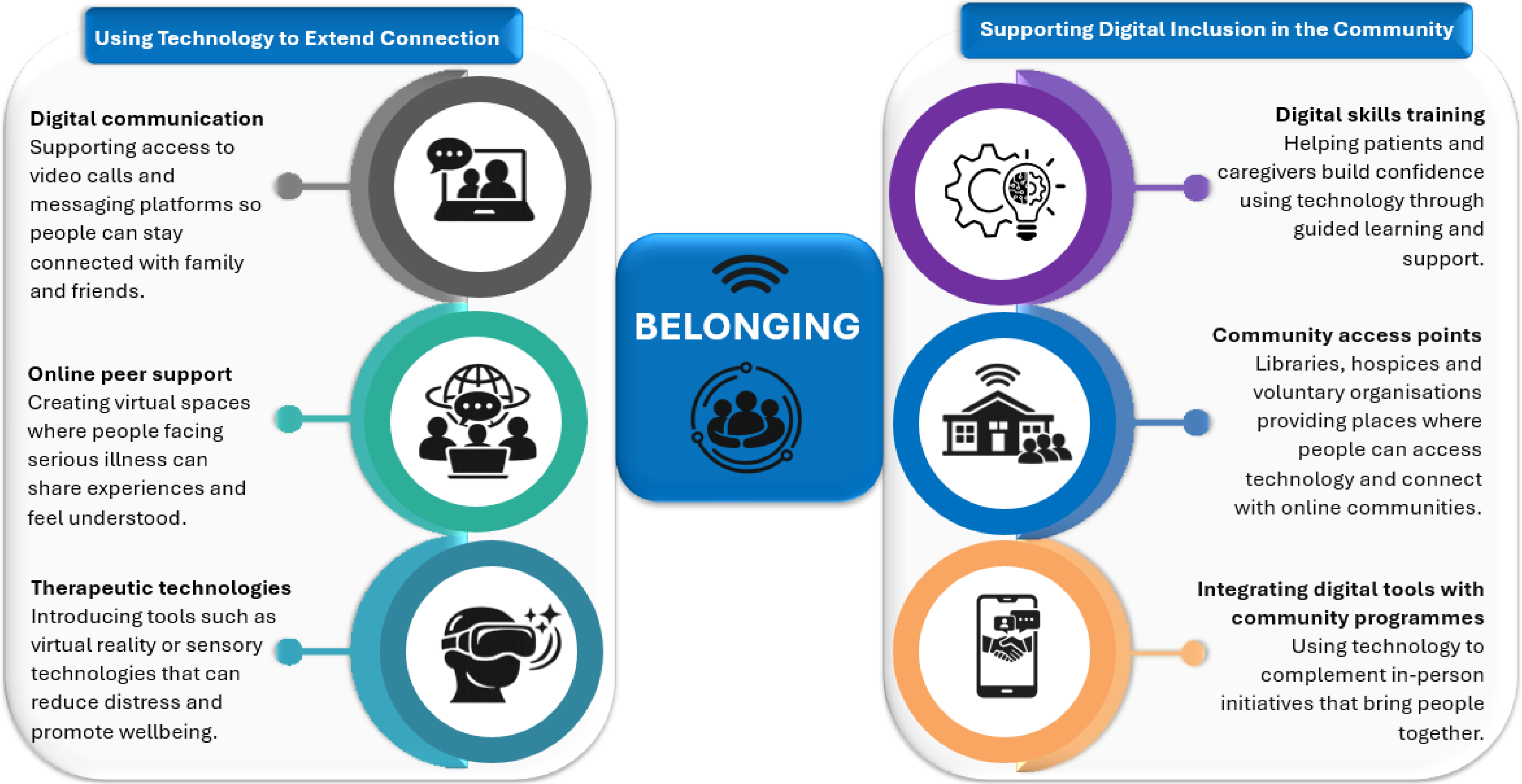
Volunteer-Led and Community-Based Social Interventions

Gardiner et al. (2016) – Befriending Services

Walshe et al. (2016) – Social Action Volunteer Support

Aoun et al. (2022) – Compassionate Communities Connectors

Using technology to reduce loneliness what can local communities do?



Using Technology to Extend Connection

Digital communication
Supporting access to video calls and messaging platforms so people can stay connected with family and friends.

Online peer support
Creating virtual spaces where people facing serious illness can share experiences and feel understood.

Therapeutic technologies
Introducing tools such as virtual reality or sensory technologies that can reduce distress and promote wellbeing.

BELONGING

Supporting Digital Inclusion in the Community

Digital skills training
Helping patients and caregivers build confidence using technology through guided learning and support.

Community access points
Libraries, hospices and voluntary organisations providing places where people can access technology and connect with online communities.

Integrating digital tools with community programmes
Using technology to complement in-person initiatives that bring people together.

Men’s Sheds: An essential part of the service

Rachel Perry, Marie Curie
John MacArtney, Associate Professor University of Warwick
March 2026

Background

- Hospices are an important hub for communities and can provide places for peer support.
- Struggle to reach men who have a life limiting illness, or who care or cared for ill partners.
- Project originated from Men's shed members
- Little known about how Men's Sheds can be successful in the hospice context or how they can benefit members.

Men’s Shed as an intervention to support wellbeing

What is a Men’s Shed?

- Therapeutic support
- Community-based male-friendly space
- Practical skills and interests
- Social activities
- Being with those in a similar position

Who is it for?

- Focus on mental health, aging, social isolation and loneliness
- Gender specific peer support

What happens in Sheds?

- Social opportunities
- Practical activities
- Laughter and friendly banter
- Tea and biscuits!
- Peer-to-peer support

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Key Messages

Essential Service

Different to other forms of support

Low cost

“I believe the Men’s group is an essential part of the [hospice] service. To be blunt I think every hospice should have a group of this kind…it’s a way of coming to terms with your loss”

“Men need to grieve and talk which is the whole basis of this group”

“It’s very difficult to describe to people how you feel, you’re lost, you feel angry, completely lost…others (services) helped in a sense, but the Men’s shed was even better because you met men who had experienced similar problems and you could talk quite openly…to unburden yourself”

bitly

Link to report

Reducing Social Isolation and Loneliness

- **A place where there can be laughter, camaraderie and fun**

“And there’s banter because most of us are retired. And one of the things, when you do work, is that you have general banter and that’s what we get here.”

- **Naturally created opportunities to make social connections and (new) friendships**

“it was great for me in the sense that it got me out at the house and it was somebody to talk to. Because my friends, in effect, were my wife’s friends and, of course, that social side of it, it went [when she died].”

“…before coming it was like Covid you know locked down, you know stuck at before coming it was like Covid you know locked down, you know stuck at home”

Loneliness: Impact of Men's Sheds

A safe space to be with others experiencing similar feelings

"Most of us live on our own…you live with your memories and you do get lonely…"

"couldn't talk to anyone else, even close family for fear of upsetting them

"it was like a place where I felt that people were listening to [me] not always giving me the answers because we're all different when we grieve and when we try to come to terms with loss and we support and we allow"

"

Thank you
Rachel Perry
John MacArtney
rachel.perry@mariecurie.org.uk

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Compassionate Communities

- A form of support which largely operates at the 'meso' level (though may intersect at a 'macro' level)
- A social model of care, recognising that death is a part of life and that the community are uniquely placed to support one another
- Rebalancing of roles- communities take the leading role, supported by healthcare professionals

The 95 percent rule [4], as identified by Prof Allan Kellehear (Northumbria University), states that a person living at home with a serious illness may only come into contact with healthcare professionals up to 5 percent of any day. As a community, what can we do to fill that other 95 percent with care and connection?

This critical question has inspired the development of 'compassionate communities'.

Empowering People to Act

Compassionate Communities

Focus is on local neighbourhoods (e.g. suburbs or villages)

Harnesses the strengths within each community to address unmet need

Wide variety of initiatives, anchored in a community development approach

Compassionate Cities

Larger scale- aiming to engage local governments and institutions to make broader, systems-level change

Death Literacy

- Practical knowledge and skills to plan, access, and provide end-of-life care
- Talking about death and dying is one component of this
- Research shows many people feel uncomfortable discussing death, highlighting opportunities to strengthen community capacity
- Those with lived or professional experience report higher death literacy – this can be mobilised across communities
- Compassionate communities provide the social framework for death literacy to be put into action

Graham-Wisener et al. BMC Public Health (2022) 22:906
https://doi.org/10.1186/s12889-022-13319-1

BMC Public Health

RESEARCH Open Access

Understanding public attitudes to death talk and advance care planning in Northern Ireland using health behaviour change theory: a qualitative study

L. Graham-Wisener[1*], A. Nelson[2], A. Byrne[2], I. Islam[2], C. Harrison[3], J. Geddis[1] and E. Berry[1]

Creating a death literate society

The importance of boosting understanding and awareness of death, dying and bereavement in Northern Ireland

Graham-Wisener et al. BMC Palliative Care (2022) 21:143
https://doi.org/10.1186/s12904-022-01032-0

BMC Palliative Care

RESEARCH Open Access

Psychometric validation of the death literacy index and benchmarking of death literacy level in a representative uk population sample

Lisa Graham-Wisener[1*], Paul Toner[1], Rosemary Leonard[2] and Jenny M. Groarke[1,3]

The Art of Life

The Art of Life is a cross-border project which aims to normalise conversations around death and dying using creative approaches.

This project is led by 'Creative Cavan' who have collaborated with the Irish Hospice Foundation, Compassionate Communities, Cavan Age Friendly, South West Age Partnership, Healthy Ireland at your library, Libraries NI and Cavan Library Service.

The project will be delivered during 2024 and 2025 and 'creatives', care professionals and the wider public will work together to maximise reach and build a lasting legacy.

The 'creatives' (artists) will be trained to lead the project and deliver a range of events across Cavan, Fermanagh and Tyrone.

Several death positive libraries and reading lists have been developed and an art piece reflecting the project has been commissioned that will be donated to a meaningful location.

> *"My heart and chest felt really warm after this - I felt as if the block of ice, that has been around my heart for 20 years, had melted. The opportunity to talk about death and dying was brilliant! I honestly feel this project should be made available to more people and groups. It is so beneficial."*

PARTICIPANT IN AN 'ART OF LIFE' PROJECT

Extra Special Kids

In 2023, parents in Donegal decided to take the national online support group 'Extra Special Kids, Ireland' offline to create a club specifically for life-limited children.

The club is an informal group where parents communicate and arrange events with each other via a WhatsApp group.

Extra Special Kids provides a space that is too often unavailable for children with complex medical needs.

Through the club, children and their families are provided with a supportive environment where they can make memories to last a lifetime. The club engages in many activities including messy play, music therapy, coffee mornings, mothers meet-ups and come Christmas time, Santa videos.

> *"We created a community of parents of children with disabilities and complex needs so that we could provide a social and fun friendship experience for our gorgeous children who don't get to have the experiences that neurotypical children have. We also created this space so as carers and friends we have our "tribe" so we can support each other."* A MOTHER OF A CHILD WHO ATTENDS THE CLUB

Evidence base

Impact on individual-level outcomes

Recent systematic reviews indicate the need for more formal evaluations, but promising evidence for impact on a range of individual-level outcomes (Dumont et al, 2022; Quintiens et al, 2022; Roleston et al, 2023)

Cost-savings

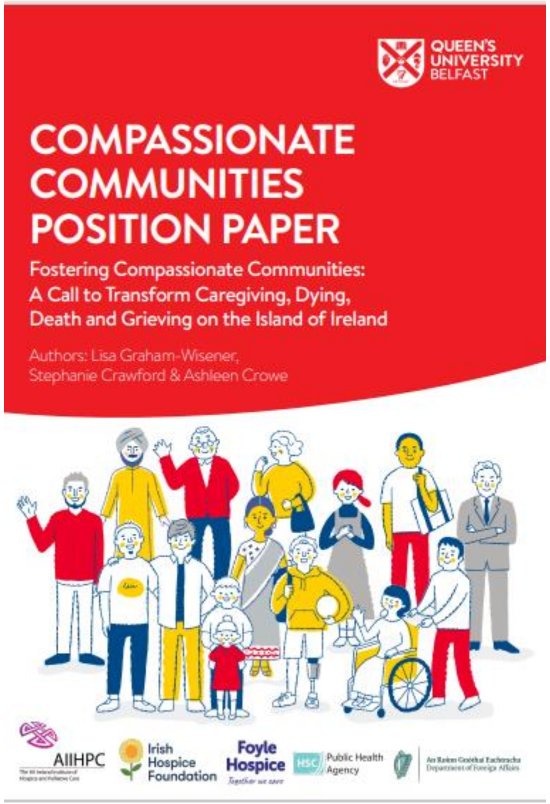
Evidence of reduction in emergency department visits and unplanned hospital admissions, fewer unscheduled visits to primary care and out-of-hours care (Abel et al, 2018; Aoun et al, 2023; Solinis et al, 2014)

Alignment to Policy

Reference within National Palliative and End of Life Care Partnership Ambitions for PEoLC (2021-2026)

Alignment to evolving policy direction more broadly

In Ireland -
The new National Adult Palliative Care Policy (2024) includes a recommendation to support the development of compassionate communities.



QUEEN'S UNIVERSITY BELFAST

COMPASSIONATE
COMMUNITIES
POSITION PAPER

Fostering Compassionate Communities:
A Call to Transform Caregiving, Dying,
Death and Grieving on the Island of Ireland

Authors: Lisa Graham-Wisener,
Stephanie Crawford & Ashleen Crowe

AIIHPC
Irish Hospice Foundation
Foyle Hospice Together we care
HSC Public Health Agency
Department of Foreign Affairs