



# SING OUR OWN SONG

**End-of-Life Care and the Irish Community in Britain:**  
findings from a national consultation



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## End-of-Life Care and the Irish Community in Britain: findings from a national consultation

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Mary is a retired nurse academic with a long-standing commitment to the Irish community in Britain. She has researched and published widely on Irish health, especially among older people and those with dementia.

Published February 2026 by Irish in Britain and Innisfree Housing Association as part of the Meitheal Muintire Irish End-of-Life Care Project.

The project's name has deep roots in Irish community culture – Meitheal denotes collective effort, neighbours and community members coming together in a shared task, traditionally farming and harvesting, while Muintire symbolises people, family, household, kin, community – those who belong to one another.

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ISBN: 978-1-906325-45-9

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To me, Irishness is...

home, family  
and the craic!  
London born  
Irishman.  
Tipperary parents  
Never had a  
British passport.  
Only the harp  
will do!  
Will be buried  
at home!

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**“To be truly human is to bear the burden of our own mortality and to strive, in grace, to help others carry theirs; sometimes lightly, sometimes courageously.”**

**Kevin Toolis, author of My Father’s Wake**



# EXECUTIVE SUMMARY

The Irish in Britain and Innisfree Housing Association Irish End-of-Life Project was initiated in response to concerns raised by Irish community organisations about the quality of palliative and end-of-life care (PEOLC) experienced by Irish people in Britain.

Recognised as a minority ethnic group with a distinct cultural, social and health profile, the Irish community in Britain also has the oldest median age of any ethnic group, at 54 years. This demographic reality, combined with high levels of dementia, cancer and chronic illness, results in sustained and growing demand for high-quality, responsive PEOLC.

Drawing on evidence from community consultations, key informant interviews, digital surveys and a panel discussion, this report identifies persistent gaps in culturally competent care at the end of life and after death.

While examples of good practice were identified, the evidence highlights a systemic lack of understanding of the cultural, religious and social needs of Irish people within PEOLC services. These shortcomings persist despite both the ageing profile of the community and the prevalence of complex long-term conditions that require end-of-life support.

Irish community organisations, with deep community roots and expertise, remain underutilised as partners in PEOLC planning and delivery. The Irish community in Britain is diverse and there is no single set of beliefs or practices around death and dying. However, shared traditions and experiences continue to shape expectations of a “good death”, often informed by practices in Ireland even among those that are long resident in Britain. These include a preference for care at home, if possible, the central role of family and community, and the importance of ritual and meaningful farewell, whether care takes place at home, in a care home or hospital.

The report highlights specific and often unmet needs among Irish LGBT+ people, survivors of institutional abuse, people with dementia, Irish Travellers, and those experiencing sudden or premature death. Extended time periods between death and the funeral in Britain, in contrast to Irish practice, can disrupt customs, rituals and the mourning process.

Trauma-informed, person-centred and culturally sensitive approaches are essential to minimise distress and enable inclusive and respectful care. The report concludes with four priority areas for coordinated action:

**Representation and policy:** Ensuring Irish ethnicity is recognised in data, planning and commissioning, and strengthening engagement with national and local decision makers.

**Raising awareness and education:** Developing understanding of rights, entitlements and advance planning across community networks, alongside culturally competent professional practice support.

**Practical provision:** Expanding resource advocacy material for providers, individuals, families and carers. Investing in capacity for bereavement support and navigation services delivered through community organisations.

**Service development:** Innovating and scaling culturally sensitive PEOLC models, particularly home-based, trauma-informed and community-led approaches.

Together, they represent a whole-community framework for improving PEOLC. With appropriate investment and collaboration, Irish in Britain and its member organisations are well placed to improve outcomes, reduce crisis-driven care, and advocate for respect for cultural difference in this critical area of health and social care.



# FROM MOTION TO ACTION

## Project timeline

The Meitheal Muintire: Irish End-of-Life Care Project emerged from a member motion proposed at Irish in Britain's 2024 AGM by Innisfree Housing Association, calling for action to better understand the experiences of Irish people navigating end-of-life care in Britain. Unanimously adopted, the motion was formalised as a partnership project between Irish in Britain and Innisfree Housing Association. Using a community-led model, the project delivered a national consultation involving providers, families, carers, NHS, hospice community, faith groups and individuals with lived experience.

Rooted in our long tradition of Irish community activism, we gathered in the places where we have historically organised. Workshops at the London Irish Centre in early 2025 were followed by sessions in Leeds Irish Centre and Liverpool Irish Centre, creating open forums for professional and personal reflection. Participants shared experiences with honesty and generosity, sometimes with tears, often with laughter, always with mutual respect for difference – and united in a shared ambition for positive change.

Songs and stories from Kevin Toolis' Wonders of the Wake, Ian Duhig's evocative poetry, and Hannah Donelan's community podcast series brought the richness of Irish ritual and diaspora memory into these conversations. While there is much to do, we take comfort that there is a deep well of custom and practice to ground the work.

Online surveys and in-person interviews extended participation through to October 2025, capping the largest ever community consultation on end-of-life care for the Irish in Britain. A panel discussion on themes and next steps at the 2025 AGM marked the first anniversary of the project, an acknowledgement of progress and commitment to build on the recommendations.

Irish in Britain AGM  
Motion passed

NOV  
24

APR  
25

Project launched at the London Irish Centre with a workshop and cultural performance

Workshop in Leeds  
Irish Centre

MAY  
25

JUN  
25

Workshop in Liverpool  
Irish Centre

One-to-one interviews  
and online survey expand  
the consultation

SUMMER  
25

NOV  
25

Panel discussion at  
Irish in Britain AGM

Project report published

FEB  
26

# PREFACE

As a nurse and academic, I have spent my life advocating for care that recognises the whole person, their history, their culture, their family and their right to dignity at the end of life.

This report speaks to a long-standing truth, that good palliative and end-of-life care cannot be delivered through clinical excellence alone. It must be shaped by cultural understanding, grounded in the confidence of the community, and built on meaningful partnerships.

The Irish community in Britain has contributed profoundly to this country, yet its distinct experiences of migration, identity, faith, trauma and belonging have too often been rendered invisible within health and care systems.

The Meitheal Muintire project from Irish in Britain and Innisfree offers a powerful and hopeful response, rooted in community experience, collective care, and respect for tradition, while engaging confidently with today's health services.

I welcome this report as both an evidence-based call to action and a statement of possibility. It shows how community-led models can help restore humanity to dying, support families with compassion, and build a future where end-of-life care is truly person centred.

*Professor Dame Elizabeth Anionwu,  
Patron of Irish in Britain*

**Irish  
in Britain**



# 01

## CONTEXT

“This is a much needed conversation. We need to talk more in the community about what we need and what we can expect. But also, as a community, we need to discuss how we represent our needs, and articulate what is culturally important to us.

“Too often, care at the end life can be unplanned and impersonal. We all deserve to have the care we need, delivered in the ways that are important to us. And time and time again our communities have told us: our Irishness matters. ”

**Rachael Loftus, Chair, Leeds Irish Health and Homes, Head of Regional Health Partnerships at the West Yorkshire Health and Care Partnership**

# CONTEXT

Over the last 60 years it has become increasingly likely that dying and death take place in hospital. In the past, dying, and the death which followed, was a social and family event that tended to take place in the home with an element of medical support. Today it has become a medical event with less reliance on the family or social component. Despite some examples of good practice, there are many reasons why hospital is not the best place for death and dying (Marie Curie 2024).

There is widespread evidence that people at the end of life do not receive the quality of care they deserve (Marie Curie 2024). While acknowledging that high quality palliative and end-of-life care (PEOLC) exists, services are overstretched, poorly coordinated and unable to meet the needs of patients and families. Increasing longevity, accompanied by complex and long-term conditions mean an increasing need for palliative and end-of-life care. However, NHS funding has not kept pace with the volume or complexity of demand. Social care is in a perilous state with Local Authorities struggling to meet demand, offering limited services, brief visits by possibly underqualified and undertrained staff and little continuity. At a time of increasing need, 20 percent of hospice beds are closed, PEOLC services are reducing and hospices are making staff redundant. Not surprisingly families feel unsupported.

Recent research demonstrates that a significant majority of the population would wish to die at home, close to those who are dear to them, yet only a quarter are able to do so. Clearly not every person is suitable for PEOLC at home and not all families or social situations make this feasible. However, families who want to provide care at home experience great barriers in accessing services and support to enable them to provide the comfort their dying loved one needs. Instead, family carers have to resort to A&E visits or hospital admission because of lack of support and access to timely medication to relieve pain and symptoms (House of Commons 2025).

While these are issues for the whole community, there is evidence of additional inequality in access to, and the quality of, services to particular groups. The Independent Expert Panel on PEOLC describes inequalities experienced in the availability and quality of services in different parts of the country particularly by underserved or marginalised communities (House of Commons 2025). These include people from black and other minority ethnic groups, older people, those with dementia, learning disabilities and mental health problems. In addition, the needs of Lesbian Gay, Bisexual and Transgender (LGBT+) people, homeless people, prisoners, Gypsy, Roma and Travellers are generally unmet (CQC 2016).



An undated Public Health England/Marie Curie Cancer Care report on palliative care for Black, Asian and Minority Ethnic groups in the UK (probably 2013-4), noted the ageing of minority ethnic communities, and rightly included the Irish. Given the older age profile of the Irish community and the significant numbers of Irish people over 65 in the 2011 census, the authors questioned how the needs of the Irish community and in particular Irish Travellers could be planned in the absence of data (PHE undated). Over a decade later, there is still a lack of research on this community in Britain.

Conceptualisations of ethnicity based on skin colour assume that, being (mostly) white, the Irish are the same as the majority British population. While sharing many similar characteristics, aggregating the Irish in the overall 'White' category neglects cultural differences, migration trajectory and discriminatory experiences that are akin to those of Caribbean, Asian and other minorities. Clearly lack of evidence does not mean lack of need.

While the older median age of the Irish community compared to the majority population indicates a need for better PEOLC services, there are other factors which planners need to take into account. Irish community organisations in Britain confirm the limited and dated research that points to high levels of cancer, heart and respiratory disease and growing levels of dementia among the Irish. These underlying conditions are the most common contributory causes of death in England (OHID 2024). They also involve multiple visits to A&E and hospital stays during the last year of life.

As with any community, the Irish in Britain are not a homogeneous group, differing by age, gender, place of birth, religion, education, occupation, housing and other social determinants. Irish Travellers have some of the poorest health in Britain with long-term physical and mental ill health, disability and accidental injury contributing to extremely short life expectancy. Irish Travellers also have the highest rates of maternal death, pregnancy loss, neonatal and childhood mortality.

Research shows that in terms of mental health, Irish people are less likely to be referred for help by the GP and are more likely to reach mental health services through acute and emergency provision, with elevated rates of hospitalisation and longer stays especially among older people. The older age profile and other factors contribute to high levels of dementia, the most frequent cause of death in Britain among the Irish community (Tilki 2015). Suicide and self-harm rates are the highest of any ethnic group in Britain, but particularly for Irish Traveller men. Many Irish people carry trauma linked to institutionalisation in industrial schools, orphanages and Mother and Baby Homes as well as family separation.



Many people left Ireland because of their sexual orientation and while some found freedom in Britain, some of the older generation are still uncomfortable about disclosing their sexuality. There are also many Irish people among the homeless and in prison, especially Travellers.

There are differences in terms of religious beliefs, affiliation, experience and observance. There is a tendency to assume that all Irish are Catholics and forget that some, especially from Northern Ireland, could be Protestant. However, while people were born into a particular faith, many may have stopped attending services, although not necessarily rejecting the associated beliefs. For various reasons others may have abandoned their faith following experiences of rejection on grounds of sexual orientation, abuse by clergy or in

institutions. However, during acute illness or towards the end of life, some may want to seek comfort from prayer, religious rituals or ministry. More recently, people from across Ireland identify with other religions or increasingly no faith at all.

It is important to note that many people born in Britain to Irish parents or grandparents consider themselves Irish despite speaking with London, Birmingham or other accents. Some may not particularly follow Irish beliefs and practices around death and dying but may still want to honour the wishes of their relatives. A proportion of the Irish population in Britain are Black or of mixed heritage, born in Ireland or in Britain (Tilki and Rauf 2024). They may want to adhere to Irish customs to a greater or lesser degree or combine those with other cultural traditions.



# 02

## WHAT IS DIFFERENT ABOUT THE IRISH?

“The Meitheal Muintire project is a critical initiative looking at the issues facing the most vulnerable in our community at end of life – many former residents of residential institutions fear all institutional provision. Having shared our experiences, the project findings and recommended actions will hopefully help us improve the outcomes for members of our community facing end-of-life challenges.”

**Niamh O'Donnell-Keenan, UK Survivor Interest Group and former member of Emigrant Services Advisory Committee**

# WHAT IS DIFFERENT ABOUT THE IRISH?

The Meitheal Muintire Irish End-of-Life Care Project came about after a resolution was passed by a unanimous vote of member organisations at the 2024 Irish in Britain Annual General Meeting.

Irish community organisations across Britain reported families and friends were upset and dissatisfied by the poor care experienced by Irish people at the end of their lives and when they died. There was little if any consideration of cultural and religious needs and no appreciation of traditions and customs which shape expectations of dying, death and funerals.

Twenty-four people from health services, community or faith backgrounds and people with lived experience of PEOLC responded to an online survey.

Most survey respondents agreed that the distinctive needs of Irish people were either not very well recognised or not recognised at all by mainstream medical or palliative care services. The picture was only slightly better in hospices or in services supporting care at home. Conversely, respondents reported that community services, religious organisations and family care at home recognised the distinctive needs of the Irish quite well or very well.

Although medical care was very important, respondents believed that being listened to, having individual needs recognised, support from family and friends and availability of services were much more important. The respondents particularly identified the need for culturally appropriate care, respect for religious needs and awareness of cultural customs and traditions.

Respondents highlighted the importance of good communication between the various services involved, with the dying person and the wishes of the family always at the centre. The comments identified the importance of bespoke care to meet the needs of the person at the end of life as well as support for the bereaved after death.

Although paucity of services, inadequate funding and lack of community support were important barriers to high quality PEOLC, the vast majority of respondents

confirmed that not recognising cultural needs and the absence of culturally competent services were a much greater obstacle.

**“It’s not lack of services, as much as lack of culturally competent services.”**

**“If an Irish person doesn’t have any family or friends or support by Irish Community Care, they might not be supported.”**

The responses suggested that the most important opportunities to improve the availability of quality PEOLC for Irish people were through existing networks within the Irish community. These could involve developing new partnerships with relevant external agencies, particularly outside big cities, and improving existing connections with churches and building on good practice. The value of continuing community dialogue on PEOLC matters was mentioned several times as was the importance of encouraging and supporting community members to have difficult conversations with family and to have them earlier. There was a clear message that community organisations need to engage in strategic policy and commissioning to ensure equality and equity of access.

Key informant interviews brought personal and professional experience and expertise from organisations such as Compassion in Dying, Irish Chaplaincy, Coventry Irish Society and Woking and Sam Beare Hospices. Their thoughts were consistent with the findings of the survey but added depth and nuance elaborating what PEOLC would mean for Irish people and their families. In particular they highlighted ways in which Irish in Britain and member community organisations could increase awareness and understanding of Irish cultural needs. They stressed the importance of influencing practice and leveraging policy to take account of Irish people needing PEOLC.

A hundred and fifty people representing providers, families, carers, clinicians and clergy participated in consultation workshops in London, Liverpool and Leeds, again confirming concerns about the neglect of Irish



PEOLC needs. They cited local experiences, suggested collaborations and identified sensitive funeral practice in parts of the country. A panel of speakers at the 2025 Irish in Britain AGM highlighted specific issues for LGBT+ people and Travellers, and the role of community organisations in supporting repatriations to Ireland after death. The specific needs of survivors of institutional abuse were raised by participants.

The survey findings, the diverse perspectives provided by the key informants, community consultations and the End-of-Life Care panel provide a rich seam of information about how culture and religion influences what Irish people and their families would hope for at the end of life. They propose ways of addressing the deficiencies to be addressed at individual, community, professional practice, local and national policy levels.

## Cultural customs

The Irish community in Britain is highly diverse and there is no single blueprint for beliefs or needs around death and dying. Assumptions must therefore be avoided. At the same time, shared customs and traditions offer important insight into what a “good death” can mean, as cultural frameworks continue to shape attitudes to dying and death even after decades away from Ireland (Toolis 2017).

**“ And that’s at the heart of the immigration story that you always perhaps leave a piece of you somewhere else, no matter how much you settle here and go on to have your children here and have a mortgage here and a life here, there’s always a part of you somewhere else.”**

The “dream of home” often sustained Irish (and other) migrants during the hardships they faced. When that dream wasn’t realised, many still aspired to be buried in Ireland but family ties in Britain, the death of parents back home, and financial constraints led many to abandon that dream. The hope of an Irish funeral was the next best option and children or grandchildren who might not necessarily want such a “send-off” themselves would still be determined to honour the deceased’s wishes.

Most Irish people will have stayed in contact with home throughout their lives in Britain by letters, phone calls, holidays and more recently video calls and messaging. Many will have returned to Ireland to be with dying relatives or to attend funerals. However, for complex reasons, some of the most vulnerable in the community lost contact with home especially when parents died and some will have stopped practising or rejected their faith. However, the interviews and community consultations highlight that it is not uncommon at the end of life for some to want to “close the loop” reconnecting with family or church.



Just as there are expectations around funerals and burials, there are social customs around dying, most Irish people would prefer to die at home if at all possible. Although some practices have changed in Ireland, death and dying happens differently in Britain, where most PEOLC takes place in hospital, nursing or residential homes or hospices. Even where PEOLC is not home based in Ireland, processes and procedures mostly follow traditional, cultural or religious mores.

Death and dying are not taboo subjects in Ireland and terms like dead, death and dying are used rather than euphemisms like passing away. Families expect to be with the dying person during their last hours as much as possible. Friends and neighbours, including children come and go, perhaps saying the Rosary, with lighted candles, holy water or religious objects.

Some, but not all, Catholics may wish to see a priest, make confession or receive the Sacrament of the Sick (Last Rites). Others, who may not have practised or who rejected their religion in life may still wish to have religious support at the end of their lives, sometimes surprising friends and family. A number may refuse to allow prayers or visits from clergy, often to the distress of their family.

After death in Ireland, the body of the deceased generally remains at home with a funeral happening within a couple of days.

**“ And back in County Mayo, particularly for the older generation, it would be that the person is brought back to the house and they’re typically laid in front of the window, and you’ve got the Sacred Heart picture and the candles and the rosary.”**

Family, friends, neighbours and colleagues call to the house and pay their respects to the family and the deceased lying in an open coffin.

**“ ... just how normal it was for the whole village to come in. Little school kids coming in in their little school jumpers on the way back from home with their parents to pay their respects. And I found it really, really comforting. And it wasn’t morose at all.”**

Family members sit with the deceased at all times, particularly through the night, mourning, praying and reminiscing. But there is also laughter, funny recollections and music is not uncommon. Neighbours in rural areas especially take over the provision of teas, sandwiches and alcohol may be offered to anyone who calls.

**“ ...we would be laughing and joking. So, there’s none of this sort of talking in hushed tones ... later in the day, you know, having a little shot of whiskey, people talking about old times and reminiscing.”**



Death notices, which used to be in every daily paper, are now online (RIP.ie) or on daily radio, informing the community of the death and whether the deceased is “reposing at home” or in a particular funeral home. Funeral directors increasingly offer a place of rest where the deceased “reposes” until taken to church for a requiem Mass or other religious or secular service, before burial or less commonly cremation.

**“ I think there’s more of a sense of almost like peer pressure here (in Britain) that the deceased would stay at the Funeral Home. ”**

Large funerals are the norm, with male relatives “shouldering” the coffin and family members walking behind the hearse to the end of the street if not all the way to the church or cemetery. The ensuing traffic jam is tolerated more in rural places than towns. Friends and neighbours unable to pay their respects at the house or funeral home invariably attend the religious service if not the committal. The wake, which used to be in the home before the funeral, is now more likely in a hotel or pub after the service.

Religious or prayer services to honour the dead and support the bereaved will vary according to the particular faith, the extent of observance and the wishes of the person and family. Most older people and many younger Irish Catholics and/or their families will want a Requiem Mass, but services in other faiths also celebrate the life

of the deceased and in similar ways offer hope of eternal reward, freedom from pain and suffering. Funerals and increasingly cremations are gatherings that aim to help the bereaved begin the grieving process, connecting with, supported and consoled by each other.

**“ I think the way that death is dealt with (in Ireland) is very different and I think it’s actually very, very healthy, but that’s a very culturally Irish way to deal with it. ”**

The consultations, survey and interviews highlighted the need for culturally sensitive bereavement support beyond the funeral. While people facing the end of life and their loved ones may experience anticipatory grief, death still comes as a shock, no more so than when death is sudden or tragic.

Losing a parent or parents back in Ireland has an added dimension of losing the sense of “home” and community. The children of Irish parents born and raised in Britain may begin to grapple with their Irish/dual identity for the first time which complicates the grieving process.

In a powerful reminder of how uninformed policy can demean cultural identity, even in death, the family of the late Margaret Keane in Coventry had to instigate a legal case to win the right to have an inscription in Irish on her gravestone.

## Irish Travellers

Census data shows that Irish Travellers have very poor health and low life expectancy. Irish Travellers and Gypsy communities have the highest rates of suicide in comparison with any other ethnic group. They also have excessive pregnancy loss, maternal, neonatal and childhood deaths and mortality from accidents and trauma. The interviews and community consultations cite a lack of awareness of needs or the trauma experienced by Irish Travellers. Many older Travellers were incarcerated in industrial schools, Mother and Baby Homes or removed from parents or family to service childless rural families.

Irish Travellers share many of the same beliefs as the wider Irish community but have additional cultural and religious traditions. Extended kinship networks from across Britain and Ireland typically come together in support of the dying person and attend the funeral. This is deemed disruptive to hospitals and the few care homes where Travellers reside, but everybody saying goodbye is the hallmark of a good death for Travellers. Faith is very important to the Irish Traveller community and the involvement of a priest, sacraments and saying the rosary is critical.

Funerals offer a way of reinforcing family ties and community belonging, so Traveller funerals are huge, with families arriving from long distances to pay their respect to the deceased and offer condolences to the bereaved. Irish Traveller funerals are lavish events with ornate coffins, hundreds of cars, vans and horses and elaborate floral tributes and long rituals at the graveside. A small number of funeral directors in Britain are proud to respect the different values and customs of Irish Travellers and Gypsies.

Some Irish Travellers will want to return the deceased to Ireland, but the cost, logistics and need for passports can make this impossible. Families may need reassurance that it is okay to bury their loved one in Britain where they will be closer to the bereaved. Being buried in Britain will mean families travelling from Ireland to respect the

deceased and support the bereaved. The longer time taken to arrange funerals in Britain may make this easier although it can be difficult to begin grieving while waiting for the final goodbyes.

The fact that Irish Travellers experience multiple bereavements over the course of their lives has long-term consequences for their physical and mental health. Belonging to large extended families and kinship networks and living in daily contact with each other on “sites”, they are constantly confronted by death. The high number of Traveller suicides are known to be related to complex and prolonged grief reactions. The few who do seek help from GPs feel fobbed off with prescribed drugs and are rarely referred for counselling (Rogers and Greenfields 2017).

## Irish people who are LGBT+

As in other communities Irish LGBT+ people can have difficulties at the end of life, associated with difficult or traumatic experiences during life. They may have felt no alternative but to leave Ireland, concealing their sexual orientation from loved ones. Many may have lost partners and friends to HIV/Aids in the past and the majority will have experienced homophobic hate. The blame, shame and “sinfulness” generated by religious beliefs may be painful at the end of life but also an opportunity for life review and self-forgiveness. Some may have been open about their sexuality in Britain while not disclosing to family at home, thus requiring considerable sensitivity at the end of life or after death. Attitudes have changed somewhat, however, experiencing discrimination when you identify a same-sex partner as next of kin or being shunned by care staff with fundamental beliefs may still occur, although such discrimination is illegal.

## Survivors of institutions in Ireland

There are particular issues which need sensitivity when providing or delivering PEOLC. Irish people may have “secrets” from their earlier lives which were never disclosed or discussed only with trusted friends. A significant number of Irish people now living in Britain, fled Ireland at a young age having been incarcerated

**“This welcome research reflects some of the long-standing concerns raised by Irish Traveller communities about access to end-of-life care that is culturally understanding, respectful and free from discrimination. Too often, mistrust of services and a lack of awareness of Traveller family and community structures create barriers at a critical time. Meaningful improvement depends on listening to communities and ensuring that culturally safe, compassionate approaches are embedded across health and social care.”**

**Pauline Melvin-Anderson OBE, Chairperson, The Traveller Movement**



in orphanages, industrial schools or Mother and Baby Homes and suffered physical, emotional or sexual abuse. These survivors have carried stigma and trauma all their lives and are likely to be re-traumatised by suppressed memories if admitted to an institution such as a care home or hospice for PEOLC. The need for PEOLC in a safe, familiar place, with trauma-informed care is particularly critical as is consideration of their wishes around religious support. Some Irish people who were not in institutions carry trauma from abuses in the family, by clergy or teachers. Repressed “taboos” such as pregnancy outside marriage, miscarriage, or abortion may revisit them at the end of life and need sensitivity and understanding.

## Irish people with dementia

There is growing concern that PEOLC will not meet the increasing needs of people with dementia in the next decade and beyond (Marie Curie 2024). Because of the large numbers of older Irish people and significant numbers with dementia in Britain, it is important to recognise their specific needs at the end of life.

Although assumed to take place in hospice buildings, most PEOLC is provided in the community or in nursing and care homes. Dementia is the leading cause of death in Britain today, but it is not easy to know when somebody is at the end of their life. Most people with dementia have at least one other condition which can require PEOLC.

There is evidence that the cultural needs of Irish people with dementia are not understood or met (Tilki 2015) and the interviews and community consultations of this project confirm this is true in relation to PEOLC. The complexity of advance planning when somebody has dementia will be addressed later but the cultural beliefs of Irish people and their expectations of death and dying still apply even if they are not able to communicate them.

## Dying at younger ages

Although death and dying are more commonly associated with older people, it does also affect people earlier in life. Cancer is probably the most common cause of terminal illness, but younger people and children can have a range of life-limiting illnesses and accidents. Many will require PEOLC, either in their own homes or in hospice facilities and the cultural and religious needs of Irish people and particularly their families must be addressed.

Sadly, we must also take into account unexpected deaths following accidents, sudden heart attack or stroke, for example, and on occasions violence. In these situations, there is no preparation or anticipatory grief. Families are faced with having to arrange a funeral often confronted by complications such as postmortems or coroners' inquiries. Irish community organisations play an important role in advising on who to contact, how to arrange a funeral and

getting help to pay for it. However, life is on hold and grieving impossible because even without postmortem delays, funerals in England can take three to four weeks to arrange.

It is important to remember the painful unexpected loss that can occur due to miscarriage, stillbirth or neonatal or child death, which as noted is especially high among Irish Travellers. These deaths are often poorly managed in maternity services, and the cultural or religious needs of the parents or wider family receive little or no consideration. Grieving parents are left with guilt and anger, questioning themselves and health professionals while having to wait until postmortems are undertaken or even longer for coroners' inquiries. People in prison who can't attend funerals of loved ones also experience prolonged grief.

Deaths from suicide invoke complicated feelings of guilt, shame and anger, which may reflect religious upbringing. Although change is happening, many may remember a time when people taking their own lives were "sinful", refused Masses and buried in unconsecrated ground (as were unbaptised babies). This is an issue for all families but particularly for Travellers, where it is rare to find a family untouched by suicide. Traveller suicides often follow another bereavement, not infrequently another suicide, so grief is complex and sadly hidden (Rogers and Greenfields 2017).

“The end of life as we know it is when we transition from the visible to the invisible world. For us Celts between life and death there is no between. As we say in our own native language when someone passes: ‘Tá an duine imithe air slí na firinne.’ ‘She or he has gone on the way of truth’ - embarking on the infinite possibilities of Love.

“This concept is pre-Christian. We do not pray for the dead. We pray to the dead.”

**Bernárd Lynch, HIV/AIDS LGBT+ and human rights activist**



# 03

## RECOMMENDATIONS FOR ACTION

*“I think what might be helpful is a resource pack of some of the expressions around death and dying within the Irish community, as well as some of the religious aspects and the cultural nuances that might be particular in the grieving process.*

*“Also, there could be something similar within the community that included for example a list of undertakers that could help with the repatriation and chaplains who might be able to give prayers in Irish.”*

**Ruaidhri Mac Giolla Chomhaill, Pastoral Outreach Worker, Irish Chaplaincy**

# RECOMMENDATIONS FOR ACTION

There is clear consistency between the findings from the survey, key informant interviews and consultations. There is general agreement about what a good end of life and death might mean for Irish people and especially there is a need for families to have difficult conversations early.

A number of intersectional themes emerged highlighting issues that have an impact on individuals, families and the wider Irish community. There is a need to influence policy on PEOLC at a national and local level if the cultural and religious needs of the community are to be respected. Irish in Britain and its member organisations are ideally placed to take action and/or lead efforts to address them, working collaboratively with other groups as appropriate. There are four major areas of action for Irish in Britain and local organisations at a national and local level:

- *Representation and policy*
- *Awareness raising and education*
- *Practical provision*
- *Service development*

## Representation and policy

The importance of getting the message to an audience beyond the Irish community to improve understanding of cultural need is evident. Irish in Britain and its member organisations need to be able to make representations to ensure the inequalities experienced by Irish people are acknowledged and their cultural needs addressed. Current policy, guidelines, legislation and research provide opportunities to demonstrate the right to fair access and quality care. These levers can carry weight in national or local level negotiations, but can also be used to advocate on behalf of an individual. Although produced by different authorities, the recommendations and guidance overlap and are relevant in different ways to all providers of care.

Irish in Britain at a national level, and member organisations at a local level, should be seen as credible, evidence-based and accessible sources of information for policy makers and commissioners. Irish in Britain must continue to raise the issue of reductive

conceptualisations of ethnicity which render the Irish invisible in Office of National Statistics (ONS) and subsequently local statistics. Relevant bodies such as ONS, NHS, Local Government Association and major charities need to be reminded that absence of data does not mean lack of need. Analyses of Irish populations, age, health profiles and socio-economic status in government regions or Integrated Commissioning Boards (ICB) catchments should be available particularly to community organisations to underpin local representations. It is important to make authorities aware that the Irish are diverse and may be born in Britain (or elsewhere) and still identify as Irish. There are also small numbers of Black Irish people and a growing number of mixed-heritage Irish who may well be exposed to additional health risks. The health profile and low life expectancy of Traveller communities needs to be highlighted, as well distinct beliefs and customs around death and dying.

Irish in Britain briefings or information resources for community organisations should empower local teams to use policy, strategic plans and professional guidance as leverage in community representations or advocacy for individuals. The recent NHS, Fit for the Future: 10 Year Plan for England (2025) provides an ideal opportunity to ensure attention to the needs of the Irish community in general and in relation to PEOLC. The proposed shifts from hospital to community, treatment to prevention and analogue to digital are timely and afford opportunities to shape primary and community care.

Improving GP and primary care services, providing highly qualified and trained staff in the community to support family carers and avoid unnecessary hospitalisation is a key aim of the 10 Year Plan. Adequate resourcing of primary and community care and a cultural shift towards supporting unpaid carers should reduce PEOLC crises. Appropriate numbers of suitably qualified PEOLC trained and culturally competent staff are needed to prevent or minimise complications of conditions or treatment which are likely to occur. GP practices are in an ideal position to nominate a lead professional who coordinates services to meet the person's needs, involving Irish organisations where needed.

Costly and distressing hospital admissions may be avoided by guiding and supporting family carers and using Virtual Wards or Hospital at Home services if the condition and family situation allow. The Irish community in Britain has a history of self-reliance and volunteering and many would welcome the opportunity to be of practical and emotional support to friends and neighbours.

The loan of hospital beds, equipment and home monitoring is not unusual, but technical and digital developments also offer possibilities. The most important is the establishment of secure, digital records shared across all the agencies involved with accessible online monitoring and advice from professionals to guide and support carers. Covid lockdown saw many of the most marginalised Irish people improving their confidence with digital communication. Although not everybody is connected or able, there is nonetheless considerable scope for digital support for carers or peer support through chat groups.

Since most PEOLC takes place in community, residential or nursing homes, the input of the social care sector is critical. Local authorities struggle to provide the volume or quality of social care that is needed, especially for PEOLC. The Better End of Life Report: Mind the Gaps (2022) highlighted the lack of integrated, seamless high-quality care to deal with the crises that inevitably occur towards the end of life. Families feel unsupported, visits by mostly unqualified staff are short and there is no continuity. People with advanced illness and their carers need rapid, reliable, accessible and effective care, which is available out of hours and at weekends. Families should also be aware that their loved one might be eligible for free NHS Continuing Health Care (CHC) if their needs are so complex they cannot be met adequately by existing services. The assessments by multidisciplinary professionals are complex and bureaucratic but a number of Irish organisations have been successful in persuading Integrated Commissioning Boards to fund individual CHCs.

There is much work to be done raising awareness of Irish community needs and holding Local Authorities and care providers to account. This includes ensuring that they are complying with their public sector equality duty under the Equality Act 2010 and, as part of that compliance, that they have sufficient data to enable them to make

appropriate decisions. It is particularly critical not to miss the opportunity to influence the Independent Commission on Adult Social Care (the Casey Commission).

Local community organisations alone or in collaboration with specialised bodies have a role to play in influencing Integrated Commissioning Boards, who are responsible for commissioning services including PEOLC and NHS CHC on behalf of the community. There is evidence that not all ICBs prioritise PEOLC, although there is great potential to improve outcomes and reduce reliance on hospital admissions. (Chambers et al 2023) NHS England (NHSE 2022) provides statutory guidance for ICBs. The need for ICBs to commission PEOLC is clear, and the guidance highlights the importance of personalised care, support and planning. Guidance also includes involving “those important to the dying person” and therefore should take account of the importance of family to Irish people. The integration across health, social care, local government and the Voluntary, Community, Social and Enterprise (VCSE) sector is also highlighted.

This integration of VCSE in commissioning affords a role for the Irish voluntary sector since the focus on “place” requires partnerships that promote the involvement of “inclusion health groups, seldom heard voices and groups routinely missed in needs assessment”. Inclusion health groups are especially relevant for the Irish community because they include people who experience overlapping risks to health such as poverty, violence or trauma for example Travellers, homeless people and prisoners. Despite “hard-to-reach” labels, many of these vulnerable people are already within the reach and remit of Irish organisations.

Local Irish organisations are an ideal link between ICBs and the community (erroneously) considered hard to reach, partnering as is practical with other underserved groups. ICBs are required to actively and meaningfully engage with local communities and involve them in the co-production of PEOLC services. Partnerships should be developed with existing NHS or primary care providers as well as the proposed new NHS Neighbourhood Health Services. Community organisations should feel confident to remind providers of their responsibilities under relevant legislation, national policies and practice guidelines.



Organisations making representations on behalf of the Irish community should find it useful to quote the findings of the Expert Panel Evaluation of Palliative Care (House of Commons 2025) as well as NHSE (2022) Ambitions for Palliative and End of Life Partnership: National Framework for Local Action 2021-2026 (2021). This framework summarises six ambitions to make “the last stage of life as good as possible for the person concerned and their families”. The ambitions are more than requests for change but incorporate a “framework” for local action to achieve them.

Irish organisations should challenge providers on how truly individualised care can be delivered when cultural needs are not recognised or addressed. Also, how fair access to care is achieved without taking into account inequities, the needs of the person and family and their social circumstances. Staff require empathy, skills and expertise if they are to deliver culturally competent PEOLC, but unless cultural competence training includes an Irish dimension, this is unlikely. Some of the answers and actions lie in the community and its organisations being equipped to help with education, advice and advocacy. Rather than online tick-box training, community organisations should consider exchange placements where PEOLC providers spend time with an Irish organisation in exchange for experience in a hospice or with an PEOLC professional.

NHSE (2024) confirms that despite dementia being the leading cause of death in Britain, the accessibility and quality of PEOLC for people with dementia is poor with too many people needing hospital admission. Clearly PEOLC for somebody with dementia is complex but the guidance is helpful in ensuring the human rights of the person are respected. As laid out above, the age profile of the Irish community in Britain and the elevated numbers of Irish people with dementia, show that the need for culturally and dementia sensitive PEOLC is critical.

The Care Quality Commission (CQC) is the independent regulator of adult health and social care in England and one aspect of that is PEOLC care. The CQC (2016) overview report highlighted groups of people who faced barriers to access that prevented them experiencing good quality PEOLC. This includes older people, Gypsies and Travellers, those with non-cancer conditions, minority ethnic communities, LGBT+, people with learning disabilities, mental health conditions or who are homeless or in secure or detained settings. Providers must understand that a significant proportion of Irish people are in one or more of these excluded categories.

The CQC recommendations require local health and care leaders to develop and deliver quality, equitable PEOLC in their strategic planning. Commissioning bodies must address inequalities, assessing local PEOLC needs, using available data tools to agree action and monitor

outcomes. It is important therefore that Irish ethnic monitoring is undertaken but not aggregated into the overall ‘White’ category if planning and evaluation are to be accurate. The CQC also requires staff to be equipped with knowledge skills to provide culturally competent care.

Representatives might find it useful to draw the attention of providers of health and social care to the array of guidelines for PEOLC by the National Institute for Health and Care Excellence (NICE) summarised by Marie Curie (2023). Health and social care practitioners need to have physical, psychological, pastoral skills and be culturally competent. Guidelines include care being person-centred, sensitive, with empathic communication, involvement in decisions about own care, meeting physical, psychological, social and spiritual needs and including family and those important to the person in decisions. They highlight the importance of family carers, their rights to Carer Needs Assessment and adequate support. NICE is also an advocate for Advance Care planning, involving the person and family and ensuring it is recorded.

## Improving awareness and understanding at family and community level

Although Irish people tend to have a healthy attitude to death and dying, not all are able or willing to make plans for that eventuality. There is considerable scope for a community awareness campaign and an educational programme to encourage early preparation for the end-of-life or the unthinkable sudden death or loss of mental capacity. Such conversations are never easy and some people may not want to think about them. Others assume that the family will do right by them, but not everybody has family or trusts family to do what is best. Families may be reluctant to broach the subject and not infrequently individual members have differing views about place of care, funerals and property. Not everybody will have family or trusted friends to have such sensitive discussions with and many need help to record their wishes. Some Irish organisations already provide advice, support and advocacy on behalf of people needing PEOLC, but for geographical, funding and skills reasons this is patchy and inconsistent, so a whole community approach is needed.

Respondents expressed the value of the project in raising awareness of the nuances of PEOLC for the Irish community. This suggests a national campaign could encourage the Irish community to have early conversations about death and dying and begin advance planning for the end of their lives. Irish in Britain has a track record and considerable expertise in such campaigns such as the Cuimhne Dementia Programme since 2013 and more recently the Green Hearts and Cancer Comhrá Campaign.

Irish in Britain should coordinate an advocacy programme to support advance planning for the end of life, supporting community organisations, individuals, families, and carers. Legal instruments such as wills and powers of attorney are vitally important, as is the focus on enabling early, informed conversations about personal wishes, values and expectations, including preferred place of care, treatment choices, funeral arrangements and final resting place. For many, these practical discussions provide reassurance and clarity, even when legal matters feel difficult to approach.

This programme can have national reach through Irish in Britain's network and media platform, with workshops and webinars to strengthen the confidence and capability of local community organisations. Drawing on both local and external expertise, it can build understanding of advance care planning tools, including Advance Care Directives, Advance Care Decisions and ReSPECT documentation, enabling organisations to act as trusted advocates and navigators for individuals and families within PEOLC systems.

Perhaps the primary role is for community organisations to encourage individuals and families to have early conversations about end-of-life and death matters. They can play an important role in helping people make decisions and plan for the end of their lives, because they are trusted in a way in which non-Irish services are not. It is important for their own sake that the person's wishes are known in advance of death or loss of capacity, but it also alleviates the burden on family later. Wishes must be recorded as it is not safe to assume the family know, especially if there is sudden death or loss of capacity.

Privacy and trust are major issues, but Irish people who have never had their voices heard may need convincing that their decisions and wishes will be considered.

Many people and their families understand the value and importance of making (and updating) a will or power/s of attorney, but others need informing. Less is known about Advance Directives and Advance Decisions which identify the care the person would like and treatments they refuse

to have when they are unable to express them. These include Do Not Attempt Resuscitation (DNAR) orders or ReSPECT documents which are particularly important in emergencies. There is much to be gained by involving bodies like Compassion in Dying or Hospice UK: Dying Matters who help people take control of the treatment and care they would wish for at the end of life.

The findings highlight the importance of readily available clear and culturally relevant information about palliative and end-of-life care, underscored by a generational hesitancy that can make it difficult for people to seek support. Many Irish people associate PEOLC primarily with hospice care and cancer, despite most hospice support being delivered in the community and across a wide range of life-limiting conditions, particularly dementia. Community organisations are therefore well placed to broaden understanding of PEOLC as holistic, home-based and family-centred care that supports both individuals and those close to them.

The data affirms the need to develop community knowledge and understanding of statutory supports and benefits, and to mitigate the culture of self-reliance and the systemic barriers that often discourage people from seeking help. Individuals and families supporting someone at the end of life need accessible guidance on their rights and entitlements, including Community Care Assessments, Carer's Needs Assessments and financial support.

Training and support can build community advocacy skills, such as understanding of eligibility for NHS Continuing Healthcare, which is determined by the complexity and intensity of need rather than diagnosis. Fast-tracked processes for Continuing Healthcare, Blue Badges and related assessments are available in end-of-life contexts but remain underutilised. Community organisations can play a vital role in helping individuals navigate these systems and in advocating for compliance with statutory duties under the Equality Act 2010 and the Mental Capacity Act 2005.



## Practical provision

As the infrastructure organisation, Irish in Britain provides strategic coordination and support, providing member organisations with research evidence and policy intelligence to strengthen local representation and collaboration. It should keep member organisations up to date with policy and legislative changes, current research, **consultations, development possibilities and funding opportunities.**

Representatives from Irish community organisations should contribute to local policy making and be upskilled to sit on strategic, planning, or commissioning bodies of ICBs, NHS or independent providers. Importantly Irish in Britain should facilitate the sharing of ideas and good practice exemplars, learning from and with other Irish and relevant organisations. Irish in Britain is well placed to facilitate PEOLC training to improve knowledge of end-of-life issues, collaborating with other groups with expertise. Irish in Britain and its members should also connect with wider PEOLC services in recruiting and training Irish volunteers for groups such as Compassionate Neighbourhoods and the National End of Life Care Coalition.

Currently Irish organisations offer services depending on local need, their expertise, and capacity to deliver. Many provide advice about benefits and rights, advocating for individuals or signposting them to external services and sources of support. As the community ages and healthy life expectancy decreases, the need for greater emphasis on PEOLC will increase. Organisations currently provide practical information about what to do after somebody dies. At a time of profound grief and shock, families have difficulty finding funeral directors who will provide for the Irish custom of quick burial, “reposing” and viewing at home, or arranging for large numbers to say goodbye in a funeral parlour. Some organisations have connections with local funeral directors who understand and meet Irish cultural customs and traditions. They may also have links with Catholic churches to help families who don't live locally or who respect their relatives wish for a Catholic (or other faith) funeral.

Irish organisations are well versed in helping families to repatriate the deceased for funerals in Ireland, sometimes tracing long lost relatives or local communities to attend

funeral services. They also support people who need to return to Ireland for funerals, arranging fast passports and possibly loans in emergencies. It would be useful to have a list or directory of funeral directors who understand and can help meet Irish expectations. Irish Community Care in Liverpool is an example of good practice in liaising with sympathetic funeral directors who will facilitate wakes at home and/or repatriation.

The need for culturally sensitive bereavement support is important. Generic bereavement services may be helpful for some but rarely understand the nuances of grief within Irish culture which reflects the experience of migration, the influence of religion and the complexity of dual identity. Irish people who have experienced abuse in family, relationships or at school have an ambivalent relationship with Ireland so cultural understanding and personal history is critical. Grief support must especially take account of the trauma of people with experiences of being incarcerated in orphanages, reformatories, industrial schools or Magdalene Laundries. Specialist Irish organisations currently offer culturally sensitive, trauma-informed bereavement services as part of their counselling or therapy provision, but there is much scope to expand this provision.

## Service development

Irish in Britain and member organisations individually or in partnership have different but overlapping roles in expanding or innovating services. Irish in Britain should continue to lead on raising awareness of the need for high quality, culturally sensitive PEOLC for the Irish community in Britain at a national level. The campaign has already begun to develop a community alliance, **building partnerships between member organisations** and strengthening ties with external expert bodies and in time corporate businesses. Work on representation should continue at a national level while equipping member organisations to lobby local ICBs, Local Authorities and PEOLC providers. The NHS 10 Year Plan for England and the forthcoming Commission on Adult Social Care offer potential to shape future NHS and social care provision. Raising awareness at provider level might be best served by a national conference, involving key decision makers, sharing concerns, showcasing good practice and building collaborations.



“A peaceful death can and should be a reality for all patients. People should not be dying in hospitals if they wish to die in a hospice or at home. Appropriately funded palliative and end-of-life care services would deliver equitable access to a well-managed, peaceful death for all who need and want it. Hospices currently care for up to 80 percent of their patients at home. Funding this community-focused model appropriately will also support improved access to hospitals and primary care services nationwide.”

**Mark Byrne, CEO, Woking & Sam Beare Hospices**

Improving awareness and understanding at a community level has begun and should be expanded using online and social media platforms. The potential to provide accessible information digitally is great and might include online resources, educational webinars, discussion forums and workshops. Funding to develop and run an information line or chat groups should be pursued.

Member organisations should consider expanding existing or developing new services to meet the increasing numbers of Irish people who will need PEOLC. They should seek to build on their existing strengths, developing specialist expertise in collaboration with external bodies where it is possible, rather than every organisation doing a little.

Some members already provide bereavement support but may wish to collaborate with other existing Irish organisations to expand or develop new services. While there is a need for formal counselling or therapy provision, it is also important to recognise that labelling a service “counselling”, “therapy” or even “bereavement” might be discouraging for some of the most vulnerable. Member organisations in the past have got round this successfully by providing activities such as flower arranging, cake decorating, walking groups or playing cards that included a therapeutic dimension. There is also a need to consider the value of online or telephone support for bereaved people who for various practical reasons are unable to undertake face-to-face sessions.

Organisations with suitable structures, staff or volunteers should consider developing or expanding existing befriending services. Some may feel equipped to provide a “sitting-in” service to offer respite overnight or allow family carers to have a break from caring. End-of-life befrienders or sitters are rather like the village woman, the “bean chabrach” who sat with the dying and prepared them after death in rural Ireland. They are similar to Death or End-of-Life Doulas who are becoming increasingly common in modern society.

End-of-Life Doulas are ordinary people with “confidence, knowledge and skills to be with death and dying”. They

provide practical, emotional and spiritual support, sit with the dying person to listen, talk, provide comfort and reassurance. They share knowledge of helpful local resources and coach family and friends on what to expect before and after death. They guide people through the decisions and choices to be made at the end of life, acting as an advocate if personal wishes are not being upheld. They can be a point of contact for the dying person and other support services, empowering families who may wish to care for their dying at home, hospital or nursing home. There are a number of training opportunities for those who want to fulfil this role.

Irish in Britain might take a lead in negotiating and resourcing Death Doula/End-of-Life Doula training from a number of sources in Britain but perhaps more appropriately from Ireland. Irish organisations might also consider seeking collaborative funding for innovative roles which include end-of life advocacy, service navigation, or coordinating befrienders.

Similarly, there is scope to establish “death cafés” – safe, confidential and welcoming places where people can come together perhaps monthly to share thoughts, feelings and questions about death, dying and mortality. There is no specific structure and no particular philosophy is pushed. They can be facilitated or peer-led, online or face-to-face with coffee and cake. The important thing is they are an opportunity to talk about death and dying, from the practical to the metaphysical.

The project findings are very clear about the need for a culturally focussed model of support for PEOLC. There is considerable expertise and potential to expand within the community and in its organisations and there is much to learn from Ireland and other minority ethnic groups and Jewish Care models in Britain. The consultations also found immense support for an Irish community project, piloting a small PEOLC unit with a nurse-led pathway into which people could be referred. If successful, it could be adapted and scaled for other areas. This would require creative thinking, clear planning and secure funding, but the Irish community, who have contributed so much to Ireland and Britain, deserves nothing less.

## Conclusion

The Meitheal Muintire End-of-Life Care Project presents robust evidence of the poor quality of palliative and end-of-life care experienced by many Irish people in Britain. Its findings reflect national concerns about the over-medicalisation of dying, identified by the National End of Life Care Coalition, the House of Commons Expert Panel and the Better End of Life Programme.

While medicalised models of dying have become entrenched within modern health systems, the Irish experience, including in urban settings, has long interpreted death as a social process, supported by family, community and appropriately coordinated clinical

care. Current policy frameworks consistently call for person-centred approaches, stronger family involvement, and care delivered as close to home as possible – ideally with voluntary and community sector support.

The Irish community in Britain represents a significant and established population with deep roots in collective care and mutual support. Irish in Britain and its member organisations have the reach and operational expertise required to act as strategic partners to commissioners and providers. With appropriate recognition and investment, they are well placed to co-design, deliver and sustain culturally competent palliative and end-of-life support – improving outcomes, reducing crisis admissions and restoring dignity at the end of life.

**“I paid my way here I’ve earned my grave.”**

**The Trojan Donkey: A Leeds Irish Health and Homes Poetry Anthology, eds Teresa O’Driscoll and Ian Duhig**



# 04

## REFERENCES

*“Meithal Muintire, the Irish End-of-Life Care Project event held last year was deeply impactful for our service and for the survivors we support. It gave much-needed visibility to the lived experiences of Irish survivors of institutional care and opened up vital conversations about the additional vulnerabilities they face at end of life.*”

*“Delivered with compassion, cultural sensitivity and honesty, the day created a space for raw, respectful discussions that are so often avoided, yet desperately needed within our community. It was both informative and engaging, bringing people together in a way that felt meaningful and human.*”

*“The opportunity to connect with others who share a commitment to dignified, culturally sensitive care has strengthened our understanding and led to ongoing relationships and partnerships. Most importantly, it helped ensure that the voices of survivors remain central as we continue to advocate for care that truly meets their needs.”*

**Katie Doyle, Survivors Integrated Service Manager, London Irish Centre**

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## GLOSSARY There are many definitions of End-of-Life Care (EOLC).

End-of-life care involves treatment, care and support for people who are thought to be in the last year of life (Marie Curie 2024)

[Click here](#)

Palliative Care includes caring for people who are nearing the end of life. It offers physical, emotional and practical support to people with a terminal illness. It can be offered at any point after a terminal diagnosis

[Click here](#)

NB for the purposes of this report, we do not differentiate. Instead, we use the term Palliative and End-of-Life Care (PEOLC)

# 05

## ACKNOWLEDGMENTS

*“Irish Community Care welcomed the opportunities presented in the invitation to join in Meitheal Muintire; to draw our communities together, with partners from across the North West, in a safe space to share powerful memories, tears and laughter, talking about what a good death might mean for us.*

*“We looked at gaps in service delivery spaces and places where our voices could bring positive change for everyone in end-of-life services.*

*“Everyone present told us they felt changed by the opportunity to be involved, and we look forward to sharing these insights with wider audiences, and continuing these important conversations, ensuring our Irishness is as alive in our dying as in our living.”*

**Win Lawlor, Strategic Policy and Partnerships Lead, Irish Community Care**

# ACKNOWLEDGMENTS

“ We have been overwhelmed by the breadth and depth of the support so many people have already given to this project – it has been a wholehearted response. The thoughtful, personal and emotional contributions offered to us through the workshops and individual testimonies have made us feel privileged to have been entrusted with such important life moments. We thank everyone who contributed to this national conversation, including the individuals and organisations whose generosity and commitment helped shape the project. ”

**Brian Dalton, CEO, Irish in Britain**

**John Delahunty, Chief Executive, Innisfree Housing Association**

## Special thanks to...

Angela Murphy

Bernárd Lynch

Caitríona Ni  
Chennabháin

Caroline Leen

Compassion in Dying

Coventry Irish Society

Dr Mary Tilki

Dr Sharon Mallon

Ellie Rogers

Fréa

Hannah Donelan

Ian Duhig

Irish Chaplaincy

Irish Community Care

Irish Community Care  
Manchester

Irish Cultural Centre

Kevin Toolis

Leeds GATE

Leeds Irish Centre

Leeds Irish Health  
and Homes

Leeds Older People's  
Forum

Liverpool Irish Centre

Liverpool Irish Festival

London Irish Centre

Luton Irish Forum

Mark Byrne

North London Hospice

Shauna Mulligan

Simon Wilson

Sonia Mayor

St Gemma's Hospice,  
Leeds

Survivors Integrated  
Service

“ Very often, in the first contact people have with us about returning home to Ireland they mention wanting to come back to ‘die at home’. That wish to reconnect with their culture and community as they near the end of their life is powerful – we hear it all the time, and we always say back to them ‘We hope we can give you time to LIVE in Ireland first!’ ”

**Karen McHugh, CEO, Safe Home Ireland**



“ The work and focus of the Irish End-of-Life Care Project is very welcome and very timely. At Birmingham Irish Association we see every day how difficult it can be for individuals, their families carers and friends to navigate the end-of-life care journey. As a community we need better recognition of our story and heritage – as a service we are well placed to educate and inform on what we should expect in the care of our loved ones. ”

**Maurice Malone, Chief Executive, Birmingham Irish Association**



*My own experiences of supporting loved ones at the end of their lives reflect much of what is set out in this report – especially the central role of family, and the deep preference most people have to die at home, surrounded by those they love.*

*For Irish people living in Britain, end-of-life care is shaped by cultural, emotional and historical factors that are not always understood or recognised.*

*Questions of home, belonging, ritual and connection carry particular weight. When systems fail to respond to this, the impact is not only practical but deeply emotional, and it leaves a lasting legacy for families and communities.*

*These issues were felt most acutely during the Covid pandemic. Separation from family, disrupted rituals around dying and death, and limits on connection intensified existing inequalities. The emotional consequences have been profound and long lasting.*

*This report matters because it calls for end-of-life care that is more humane, more culturally informed and more responsive to what truly matters. Dignity, family and the right to die well must be made real for Irish people in Britain – as they should be for everyone.*

**Dr Sarah Hughes, Chief Executive, Mind**

ISBN 978-1-9063254-5-9



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