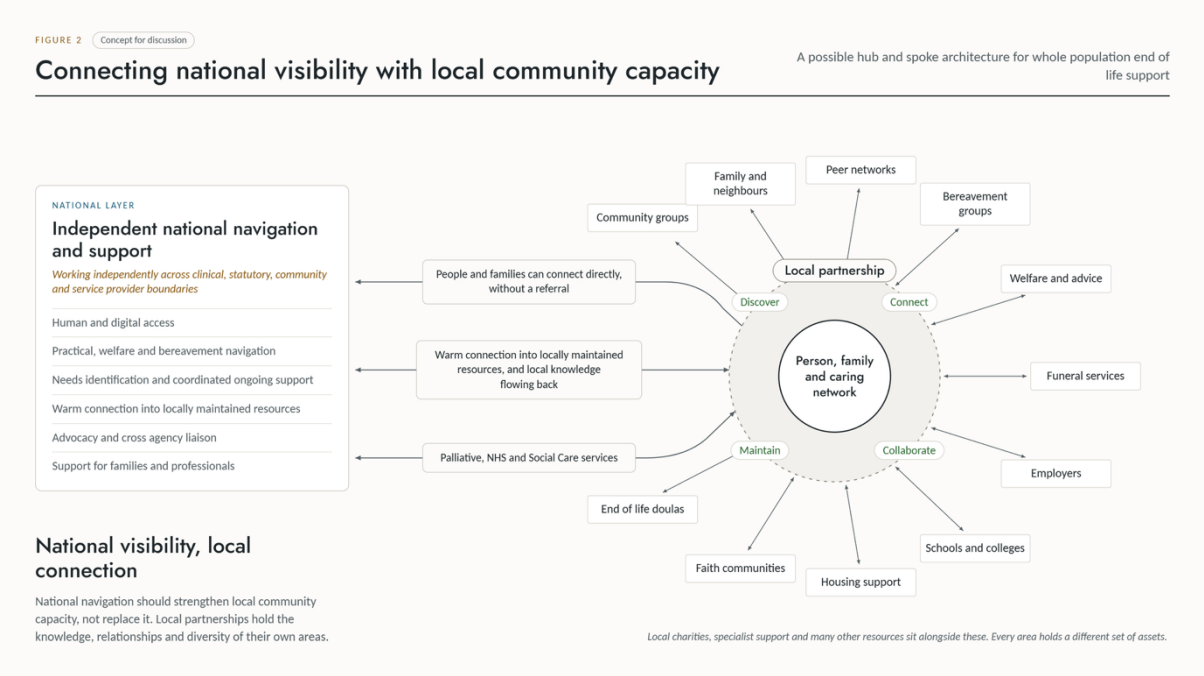
National End of Life Care Coalition

The First National End-of-life Care Coalition Report



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Foreword

By 2050, one in six people will be over the age of 65.[1] Today as never before, ageing, dying, caregiving, and grief and bereavement are fundamental public health lifestyles – and challenges. This report makes one critical observation, and it is this: national policies for this major public health challenge at the end-of-life cannot be adequately addressed – in equitable, economic, or service development terms – by relying solely on clinical palliative care policy development.

Most of the real work of palliative and end of life care more broadly is shouldered by families, communities, civic sector organisations, social care services, and a range of community-based services. Medical support for the end-of-life is essential, but it is not the most important – an often counter-intuitive observation. This is because dying is no mere physical act or journey, but rather a largely social, spiritual, and psychological one. Furthermore, dying is only one part of the population story of end-of-life care – long-term caregivers, and those living with loss and grief multiply our challenges for care, its reach, and its costs over and over again.

Most of our end-of-life care as a nation is invisible. This report aims to make the invisible and the taken-for-granted visible once again. By doing so, we draw attention to the essential need for these populations and taken-for-granted services and supports to be included in future national end-of-life policy development.

We must draw a line under our past stereotype of believing that recognizing and funding palliative care alone will address our future challenges of ageing, dying, caring, and grief. Supporting this single field and approach is not enough, not near enough, to address the real challenge of a whole-population approach to the end-of-life.

End-of-life care is at a national crossroad. In this report, you will read about the broad, typical but often under-recognized players engaged in end-of-life care. By recognising the real work being done in our country, you will help us begin to restore the inclusive balance needed to develop a fair and equitable national policy for all.

Professor Allan Kellehear OBE

[1] UN data in ageing: https://www.un.org/en/global-issues/ageing

Executive Summary

The problem with existing palliative care strategy

The current dominant model of end-of-life care focuses on the clinical practices of palliative care and formal social care. What happens outside of professional services remains largely hidden from this health and social care sectors and is not included in strategic thinking and planning at national and local levels. Yet the challenges facing people undergoing the experiences of death, dying, loss and caregiving are extremely varied and not limited by definitions of palliative care service provision. Care and support are given in an enormous number of different ways, within the many diverse contexts and cultures in which people live. The lack of partnership between these forms of support and health and social care services, including specialist palliative care, means that the huge potential of what could be achieved through taking a partnership approach between services and the broad range of supports is lost, resulting in a reactive increase in health and social care usage when people fall through the large gaps in the clinical model of palliative care. It is unrealistic and unaffordable to try and close these gaps with more professional care alone. Nor is it desirable, as what can be done by communities is best done by communities.

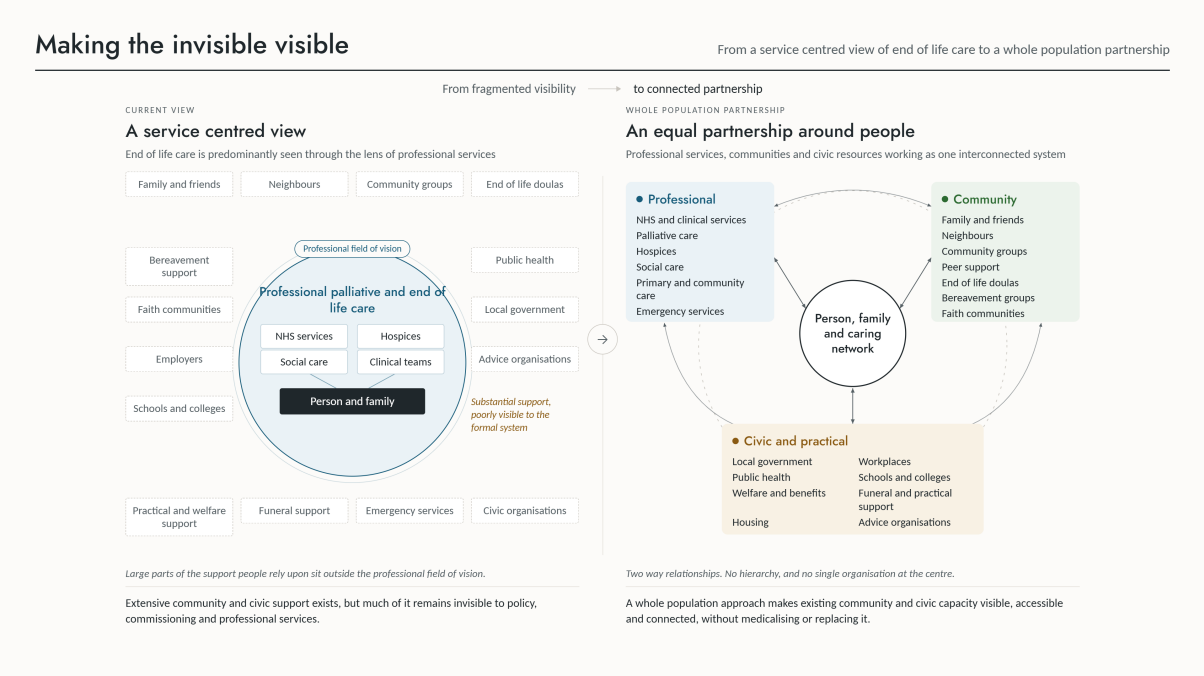


Figure 1. Making the invisible visible: from a professional view in which community and civic support sit outside strategy (left) to a whole population view of three equal fields connected by two-way partnership (right).

Report Summary

Through this report, the National End-of-life Care Coalition is calling for a rethink of national end-of-life care policy making, one which takes a whole population approach through partnership working with all the supports available. The report provides examples of these

supports and uncovers what is often hidden from health and social care providers and policymakers. The examples given are the tip of the iceberg, because at a local level there are hundreds of ways of providing care, beyond the physical and clinical. Impacts happen irrespective of cause of death or diagnosis, whether this be due to sudden death, natural disasters, murder, suicide, accidents as well as death from ageing and chronic diseases. Supports are found in different settings, including the civic spaces of workplaces, educational institutions, places of worship, public spaces and others, as well as in people's homes, and in health and social care institutions.

Recommendations

1. An overhaul of the representation in palliative and end-of-life care policy commissions and associated bodies. These should not be chaired or dominated by specialist palliative care.
2. Future policy narratives to include social care, public health (health promotion), and community perspectives, with deliverable actions, and associated funding recommendations.
3. A cessation of the conflation of palliative care with all end-of-life care. We need greater recognition of the role of aged care, intensive care, emergency care, disaster and terror management among other relevant services. We want a variety of clinical specialisms as well as social, public health, and community care to be represented on all future policy making boards.
4. Increasing death literacy through public education is fundamental to increasing the capacity of the 90% not directly involved in caring for family and friends at end-of-life, to care for the 10% who are.
5. Local partnerships of civic initiatives, communities and professional services are needed in every area, to uncover the invisible and often ignored resources which should be made available, encouraged and supported to everyone experiencing death, dying, loss and caregiving without any limiting or defining characteristics.

A new national commission for end-of-life care inclusive of the above recommendations is required now.

CHAPTER 1

Introduction

In most palliative care policies and strategy documents over the last 20 years, there is little narrative about experiences of dying, caregiving, and grief/bereavement. Most of these documents are taken up about what needs to be done by whom, meeting needs through using the different palliative care services, both specialists and generalists. This includes physicians, nurses, social workers, pastoral care workers, general practitioners, volunteers and others. Yet a person with a life limiting illness spends just 5% of their time in contact with these services. 95% of the time is spent in the company of community of family, friends and community members (Wenk 2006). The existence of the 95% is not included in policy making and commissioning, or seen as worthy of partnership with clinical palliative care services.

This invisible workforce does the major provision of care and support at the end-of-life and bereavement that remains largely hidden to palliative care services, policy makers and commissioners. Some of this support is done through formal organisations, such as end-of-life doulas, funeral services, death literacy education in the community, and others informal, such as support given by family, friends, neighbours, workplaces, educational institutions and more organised civic initiatives including compassionate communities and cities, and grief festivals. Much also naturally happens in community, in the many community groups and places where people gather.

The National End-of-Life Care Coalition has been formed to redress this imbalance, to make visible what is invisible. We take a whole population approach to providing support irrespective of age, demographic, cause of death, or diagnosis. This inclusive approach is founded on the principles of equity, with equal partnerships between communities and all health and social care organisations. Our membership represents a wide (and largely) invisible workforce. Our work is everywhere palliative care is, but far more extensive and wide ranging. We represent the large variety of organisations involved in end-of-life care and promote the idea that care at the end-of-life is not just delivered by a specialist clinical service to the dying person but involves networks throughout a person's community and the institutions surrounding them.

This report is written on behalf of the National End-of-Life Care Coalition to provide a different narrative from existing policy documents and strategies.

The report is a call to action for partnership, in three main areas.

1. We call on policy makers to see the much bigger picture of end-of-life, to develop end-of-life policies which take a whole population approach that supports everyone experiencing death, dying, loss and caregiving. In particular, we call for a review of future funding decisions to ensure that partnership working lies at the heart of end-of-life care, supporting civic initiatives and organisations at a local level.

2. We ask commissioners to bring together the wide range of supports covered in this report at a local level, including existing palliative care services and organisations, to develop local plans that ensure that support is given to all, in a way that enhances and takes into account social relationships and cultural context.

3. We call on clinical services to work in equal partnership with the wide range of supports available, and to participate in local initiatives which make partnership working the bedrock of strategy. This report is saying clearly that the work of clinical service is enhanced by this approach rather than threatened by it. This way of working is as relevant to hospital deaths as it is in aged care institutions, homelessness, hospices, prisons, schools, and other places where people live and die.

Our report is founded on four important principles which are a constant part of the experiences of death, dying, loss and caregiving, which remain present in all stages.

1. People live, care for, die and grieve in relationship to each other.

Rather than focusing on a patient, or even a person with an illness, when talking about end-of-life care, the report is referring to all those experiencing death, dying, loss and caregiving. We live in relationship to the people and environment around us. Lying at the heart of this is the fundamental importance of the role of social relationships. Good social relationships are the foundation of health and wellbeing (Holt-Lunstad 2022). Loneliness and isolation have disastrous health consequences. For example, people with heart failure who report severe loneliness and isolation have a 350% increased risk of dying compared to those who are not lonely (Manemann, Chamberlain et al. 2018). The impacts of good social relationships, and of loneliness and isolation have deep biological roots which are clearly elucidated (Holt-Lunstad, Smith et al. 2010) (Slavich, Mengelkoch et al. 2023). These relationships happen wherever there are people and are not limited to homes, communities or neighbourhoods. The 13 sectors of the Compassionate City Charter include workplaces, educational institutions, places of worship and others (Kellehear 2015). When this report talks about caring networks, we are referring to all of these sectors.

2. Social and cultural context is fundamental

The social and cultural context in which people live and die shapes their lives. How friendship, love and support is given is unique and the context in which this is given plays a fundamental role in determining outcomes of experiences of death, dying, loss and caregiving. The dominant biomedical model of end-of-life care is not universally applicable to all cultures and settings.

3. Equity

Equity of access to palliative care services has been problematic for decades. This happens by diagnosis, cause of death, ethnic and cultural diversity, intersectional issues such as homelessness, prison populations, LGBTQ+ people, learning disability, gender, and others (Abel, Kellehear et al. 2021) (Marie Curie 2025). It happens in every setting that death happens, whether this be sudden deaths, deaths in aged care institutions, care homes,

intensive care units, or community settings of any description. The social consequences of death happen irrespective of any defining characteristics of the death. These include loneliness and isolation, anxiety and depression, lost school days, lost work days, social rejection, drug and alcohol misuse and more. These have associated physical morbidities and mortalities that go with them. This report is applicable to any kind of death, whether this is from chronic disease, sudden death, assisted dying, murder, suicide, accidents, natural disasters, war, and death at any age.

4. Death Literacy through public education

Death literacy plays a foundational role in the experiences of death, dying, loss and caregiving. It is defined and can be measured as having 4 major components (Noonan, Horsfall et al. 2016)

> **Practical Knowledge** refers to how well a person perceives they can talk with their friends and family about dying, death and loss and contribute to hands-on care when someone is dying.
>
> **Experiential Knowledge (learning from experience)** refers to the wisdom and skills learnt from direct end-of-life experiences with caring and/or death education. This relies on previous experiences with loss, grief and death.
>
> **Factual Knowledge** refers to people's knowledge about the death system, particularly information needed to plan well for dying, caregiving and death. These include questions about access to palliative care, completing end-of-life documents and funeral plans, and decision making related to dying at home, and body disposal.
>
> **Community Knowledge** refers to knowledge of services and other end-of-life and grief supports that exist within the community.

Death literacy can be applied to a single person or to a whole community. It is a measure of how ready communities are to support people when most needed.

All four of the above points remain relevant throughout all stages of the trajectories of death, dying, loss and caregiving and must be acknowledged and enhanced. It is the responsibility of policy makers and commissioners to take this whole society approach, so that the invisible is visible and supported, rather than sporadic and ignored. We call on professional palliative care services to see how they can support this bedrock of end-of-life, not through taking over but through working with the wide range of communities and supports in a way that enhances this work in the cultural context in which people live and die.

The fundamental role of connection and belonging

One of the key features of community based support is finding other people who carry the same feelings. This is eloquently expressed by Jack Baxter, cofounder of The New Normal charity.

> *"In these support groups that go on, especially ones that I attend, you don't have to speak. You don't have to come and have this elaborate story and confess your undying*

> *love for your person that you lost. You can just be there in a room with people who just get those feelings. You can just listen."*

That sense of connection and belonging, knowing that there are others in your community who carry the same feelings, is a powerful link to others that can bring friendships that last a lifetime. This is not the domain of professional services. As Bessel van der Kolk says in his book The Body Keeps the Score, "no doctor can write a prescription for friendship and love. These are complex and hard earned capacities." (van der Kolk and Sky 2014)

The different ways in which people can be helped are typified by two examples from the report. The first comes from the Routes to Rights programme run by Dr Colette Hawkins (Hawkins 2026). This programme brings together a wide variety of people to help them face the different challenges of death, dying, loss and caregiving. Participants are from multiple backgrounds, representing multiple services and people, including carer representatives, prison services, acute and mental health services, hospice, charities, social services, social care providers, advice sector and legal professionals. The range of problems discussed reveal the numerous challenges which lie outside of the clinical sphere, including housing, work, communities, legal and financial issues amongst many others. These problems must be addressed by a much broader range of people than those limited by clinical services. One of Colette's significant discoveries through her Routes to Rights work was that in every community, there are people who have lived experience and expertise who are willing to support others. This could be an enormous benefit if these people could be utilised in a way that helps others in the same situation they were in.

The second example is the work of Life and Loss UK (formerly Funeral Experts), which started as a service aimed to help people find local comparative funeral directors, using an online platform. Jason Ghous, founder and CEO, working with founder of the SWAN Model of Care, added a bereavement support and navigation service. He found, as Colette had done, that people asked about a wide variety of issues that were pressing at the time of arranging a funeral. People wanted financial advice, administration support, housing support in addition to the emotional support needed. These are not sporadic issues that occasionally need addressing for bereaved people, but are everyday experiences of bereavement whatever the cause of death. The essence of this report, and the recommendations contained in it, is that strategy must include everyone experiencing death, dying, loss and caregiving. It also must encompass all the problems that people face, not those limited to clinical and social services. Finally, it must make use of the invisible, the wealth of knowledge that communities already possess.

Structure of report

This report takes a reformist approach to describing support at end-of-life. It is divided into two sections. The first covers the trajectories of death, dying, loss and caregiving, and does not include professional palliative care services. Each chapter will be illustrated with examples provided by our members and those represented by them, of how these wide ranging supports form a vital part in supporting people experiencing death and loss. Some of the examples start with time of diagnosis of chronic illness or life limiting disease and go through into funerals

and bereavement. End-of-life doulas, for example, will accompany a person or family from illness into bereavement. Some are focused on a particular aspect of the trajectory, such as caregiving or bereavement. Life and Loss UK provide a phone line of help and support and advise people who are seeking to arrange a funeral on what is available locally, helping to navigate difficult choices of which funeral director to choose. Each example will be illustrated with a story of how this work is put into practice and has a direct impact on helping people.

The examples given are chosen to highlight the wide variety of supports available, providing support for areas not covered by professional end-of-life services. They also aim to demonstrate that many kinds of support are best done by non-professional organisations and communities, developing relationships in ways that are not limited by service provision or hindered by barriers such as referral criteria.

The second part of the report focuses on civic initiatives in which areas come together to work on the wide variety of supports that exist, looking to see how these can be enhanced and how new supports can be started as needed by local communities. There are many areas within the UK that are already participating in this kind of programme, some of them using a compassionate cities framework. The report will give examples of how palliative care services are already beginning to explore ways of working in partnership with other sources of support that are not traditionally part of health care organisations, whether these are hospitals or hospices.

The report does not contain an exhaustive list of the thousands of different ways people can be supported. Rather, we make visible what is often invisible by highlighting examples of how this works. Each area across the UK, through working in partnership with palliative care services and communities, can bring to light what is happening and how this can be of benefit to the people seeking support.

CHAPTER 2

Life Limiting Conditions

Death comes at any time. It can happen in a matter of seconds. It can also be preceded by a long illness which might last years or just be a natural consequence of frailty and ageing. In this chapter, we will be considering what can be done to support people experiencing death, dying, loss and caregiving when there is an extended period of time between diagnosis of an illness or increasing frailty and the moment of death.

The lived experience of having a life limiting condition does not fit easily into medical diagnostic categories. Predicting prognosis is a tricky skill. Accuracy can increase as people get closer to death but when people's prognosis is months or years, reliability is poor. Artificial constructs, such as find your 1%, in which health professionals try and identify those people who may die within a year, are not reliable. These kinds of initiatives are in part aimed at trying to make best use of healthcare resources through planning about wishes and care arrangements. Inclusion and exclusion criteria are artificial boundaries that reflect healthcare service provision rather than lived experience. They are also focused on the person with an illness or condition which may result in death, rather than the extended network of support. Predicting when a death will happen is more of a health service perspective rather than one of lived experience.

When someone has a life limiting condition, which may or may not include illnesses, whether they realise it or not, the impacts ripple out in the broad caring network. The types of support people seek at this time differ from one community to another, from culture to culture. Many challenges do not need health or social care solutions. People benefit from many kinds of support, all of which are included under the banner of death literacy. Support happens in the everyday life of communities, from families and friends to community groups, sports clubs, choirs and the other wide variety of community activities.

Increasing death literacy is so fundamental to the experiences of death, dying, loss and caregiving that a separate chapter is dedicated to it, as there are numerous community based initiatives that specifically focus on it.

Examples of different supports when faced with life limiting illness

Supports at the time of increasing frailty and poor health are aimed at both the person with the illness and those who surround them. Navigating complex cultural, emotional and social environments can be complicated. Being able to do this at the time of the emotional distress of ill health can be challenging for all concerned, especially when this happens for the first time in people's lives. Finding ways of doing this can be made a lot easier by making use of the experience of people who know how to work with these complex challenges.

The examples in this chapter are drawn from the national organisation End-of-life Doula UK, a programme focusing on equity and legal rights at end-of-life called Routes to Rights, a local charity in Birmingham called Evolve and Flourish, and a small organisation called Speak For

Me which focuses on issues around care planning at end-of-life. Compassion in Dying aims to provide support and information in diverse settings about end-of-life wishes and challenges. They each demonstrate a different aspect of support for issues at end-of-life, from local to national, and demonstrate the variety of options open to people seeking support.

End-of-life doulas provide a good example of how a motivated and trained community member with an interest in supporting people experiencing death, dying, loss and caregiving, can provide help in navigating the many challenges faced by caring networks in their own homes. Their care spans across the whole range of end-of-life experiences, helping people to manage the wide variety of problems and solutions that arise for both the person with the illness and the caring network. End-of-life doulas do not have one model of care which is applicable in all situations. There is no gold standard of care. Rather, care is given in context of culture and tradition. Doulas working in different settings help to illustrate this point. As familiarity with end-of-life doulas grows, people from a variety of cultural backgrounds are now trained, bringing the combination of their cultural knowledge and doula training to their own communities. For example, doulas offer voluntary community-based support focused on the needs of Muslims approaching the end-of-life, working alongside other organisations to support Muslim patients who are experiencing difficulties. This work helps to increase death literacy and create more opportunities for open conversations about death and dying within Muslim communities. Through exploring and setting up community coffee mornings, practical workshops and “how-to”, sessions, conversations become more accessible and encourage greater engagement.

The Routes to Rights project aims to help people face the wide variety of challenges at this time, across health and care needs, including legal support and problems of daily life. Through learning events which bring together a broad range of participants from a variety of backgrounds, representing multiple services and people, including patients and carers, prison services, acute and mental health services, hospice, charities, social services, social care providers, advice sector and legal professionals, people learn from, and about, each other. Facilitated discussion of lived experience is used to demonstrate how the end-of-life care extends into almost every facet of life, and everyone has a role to play. Learning events build understanding of the breadth of issues, the importance of legal rights, entitlements and protections, and connections across diverse supports are made. The project has identified that there are people in every community who, through having experienced caring for someone who has died, carry enormous expertise with them. This type of community asset is underutilised and should be part of the multiple ways in which people are supported at this troubling time.

Suzanne MacArthur at Evolve and Flourish runs courses, training and cafes particularly focusing on issues of equity such as in prisons, homelessness, young people, building community support in challenging times in the end-of-life setting. Amongst other activities, she has run projects in prisons and with South Asian women in Birmingham and gives a good example of how priorities are different in diverse cultural settings. When she asked her South Asian women about what mattered most to them in the end-of-life setting, they replied

forgiveness. She double checked to make sure they did not forget pain and they did not change their priorities.

Community led advance care planning is the focus of Claire Fuller through her organisation Speak For Me. She does this through individual support, running courses, cafes and a podcast.

Compassion in Dying is a charity which aims to level the playing field, ensuring people have the knowledge, language and confidence to participate meaningfully in decisions about their own, or their loved ones', treatment and care. One of their strengths is not unifying a model of advance care planning, offering a specific focus on diversity. They have produced communication supports for Portuguese communities in South Lambeth, a Somali end-of-life guide called Tie Your Camel First, and a South Asian planning document called Tea, Talk and Samosas. Uniquely, they provide support for people seeking assisted dying. This is particularly important because the issues facing supportive networks in the circumstances of either a planned death or someone taking their own life without planning still exist and still cause significant sorrow with the consequences that go with it. This kind of support is needed regardless of the potential future legal adoption of assisted dying within the UK.

Increasing death literacy through public education is important in supporting the 10% each year who are directly experiencing issues of death, dying, loss and caregiving. It is the responsibility of all of us, the 90%, to support those who are because it will not be long before it is us (Verdery, Smith-Greenaway et al. 2020). This support, as mentioned, takes place everywhere in all settings, home, work, school, church, temple, mosque, playgrounds, football clubs, amongst people from all walks of life. The list goes on. Civic initiatives, discussed in chapter 8, therefore play an important part. It is not just that support needs to be present, it has to be ready for the time it is needed. This means that organised programmes of civic activity are ongoing and part and parcel of end-of-life care, if everyone is truly going to access help and support when it is most needed.

CHAPTER 3

Dying and Caregiving

There is no clear dividing line between being diagnosed with a life limiting illness and entering the dying phase where there is physical deterioration. Rather, it is a spectrum of experience that is marked by physical decline and increasing need for support. There is also no clear time frame for this. It may range from years before death, with prolonged illness and frailty, to sudden marked deterioration that may happen in a matter of hours or days. The key component of this phase is the need for increasing support from the caring network.

All of the issues mentioned in Chapter 2 remain relevant but intensify as someone becomes frailer. In addition, there may be increasing needs for physical caring. The ability to do this is both a marker of death literacy and demands on the caring network and is therefore not simply a case of knowing how to do manual handling. Building resilient caring networks, already covered in the section on end-of-life doulas, has even greater importance.

A variety of different organisations help to increase the knowledge and skills of communities to make it easier to support both each other and the person with the illness.

Examples of supports when faced with dying and caregiving

Compassionate Brereton, an example quoted in Chapter 8 on Civic Initiatives, provides a good example of community volunteers who will sit with someone nearing the end of their life. This was done in the larger context of community building, addressing the needs of people at different stages of their illness.

End-of-life Aid Skills for Everyone (EASE) is a programme for increasing death literacy in the community run by the Scottish Partnership for Palliative Care. EASE is therefore also included in the chapter of death literacy. After completing EASE, participants are better equipped to provide informal support to friends, family and community members dealing with death, dying and bereavement. They will have more skills to deal with these issues when they have to face them themselves and know where to find further information and support in relation to these issues. The examples from EASE is in the chapter of death literacy.

The Anne Robson Trust works to improve the experience of dying by helping healthcare organisations and communities provide emotional, social and practical support alongside clinical care. They work in partnership with healthcare organisations to help them establish and sustain Butterfly Volunteer Services. These trained volunteers offer companionship, emotional support and a reassuring presence to people who are dying and those important to them. They provide time, human connection and continuity at a period when many people feel isolated, frightened or overwhelmed.

Care Choices, previously known as Compassionate Companion Service, provide volunteers who are trained to provide compassionate, community-based, non-medical support for people

and their loved-ones experiencing life-limiting conditions, including severe frailty and dementia.

Companion Voices is a charity bringing comfort and compassionate presence to people nearing the end-of-life and their loved ones through song. Small groups (usually three to four Companions) offer gentle singing at the bedsides of people who are dying.

These examples and those shared later in the report demonstrate the breadth and diversity of supports there are hundreds of other examples in neighbourhoods, communities including online across the county.

CHAPTER 4

Funerals

Funerals affect everyone. There are no defining characteristics of whether someone is going to need a funeral of some description or not. It is not limited by diagnosis, cause of death, age or any other features of the cause of death or the cultural context.

Making choices about funerals is emotionally demanding when people are feeling very vulnerable, immediately after they have been bereaved. The type of concerns that people raise at this time are not just about the type of funeral. Life and Loss UK, which started as a web based company, helps people who are seeking a funeral director to compare what is available in their area. Choosing a funeral director is upsetting in itself, on top of being newly bereaved. Being able to make a decision about which one is best within a price range is difficult to navigate. Jason Ghous, founder and director, also started an advice line to help support people, drawing on the work of the SWAN model for bereavement and is part of the contract with Liverpool City Council and Liverpool University Hospitals. This work emphasises that the problems faced by people experiencing loss are much wider than simply emotional issues. Through analysing case management data for his service, Jason found that more than half of all calls required more than a single phone call. Although the primary reasons for the call were about funeral and benefits advice, people commonly asked about administration questions and housing. They also needed emotional support and had further questions about the process of what to do once someone had died. Complex cases required liaison with other agencies. The advice line became an important source of support for people, with multiple calls happening for a year or more.

Taking a whole population approach, funerals are an entry point of support to the diverse needs people have and it's important to recognise that no single service will solve them all. The contents of the previous chapters still apply. Loneliness and isolation are even more pronounced after loss and this is further complicated by changing life circumstances. The building of community resource and connection that will have hopefully begun prior to death becomes increasingly important during bereavement. The role of doulas and other kinds of support that might have started a number of months before someone died does not stop after death.

Examples of supports for funerals

Examples are drawn from local to national organisations. Some, such as Life and Loss UK, will provide support for people who are navigating how to find a funeral provider and also support people who have questions on a variety of matters at this time. An example of equity-orientated funeral support is the National Burial Council, which supports Muslim populations.

Diversity in funeral provision is an important factor for finding appropriate care after someone has died. 6.7% of the English population are Muslim, according to the Office for National Statistics in their census of 2021. That is 3.8 million people. The National Burial Council is a

UK wide body that helps people find Muslim funeral directors. Other specialist funeral advice services exist for diverse populations, such as Funeral Partners, who provide special advice for Hindu funerals. Individual funeral directors may cater for a specific demographic and will have developed longstanding relationships with specific communities, such as Romany and traveller communities.

There is a wide variety of ways of holding a funeral service. According to the census of 2021, 38% of people said they were not religious and a further 6% did not answer the question about faith. Independent death celebrants have a significant role to play in holding funeral services where religion plays no part.

Tina Naldrett is an independent funeral celebrant and gives a good example of how a bespoke funeral service helps people to provide their unique way of celebrating someone's life.

Unique provision of care and support highlights the many gaps in professional services. Knowledge of the presence of these supports can make an enormous difference. Innovation often happens through community and an example is Manaaki Mats, who have developed a way of keeping people, including babies, cool after they have died. This creates the opportunity for bodies to be moved back to home. This does not mean that every one of these types of innovations should be funded by NHS England or local government. Access to information and partnership working are the critical issues.

CHAPTER 5

Loss and Grief

Whilst the experiences of loss and grief are universal, their expression is deeply rooted in culture, rituals and tradition. Not only does this vary from person to person, it also varies from one community to the next. There are no standard solutions. Research from the University of Western Australia has shown that people who are bereaved have found the support of family and friends to be the most meaningful and effective (Aoun, Breen et al. 2018). During times of isolation and loneliness, often worsened by the experience of loss, connection and belonging are fundamental and necessary for everyone. Professional grief support is available at most to 5% of people bereaved and access to this is patchy, but 100% of people need love and friendship, both in life and in grief. Rather than starting with a psychological approach to grief support, community resources should be available to everyone, responsive to culture and diversity.

Examples of supports during bereavement

There is an enormous variety of sources of community based grief support, many of which are often invisible, underrated and not appreciated by professional services. People seeking support from professional services can easily find themselves isolated when the support offered does not fit with their demographic, culture or tradition. For example, for many young people, being referred to someone outside of their demographic or age group can exacerbate their feelings of isolation and loneliness that are often a part of the normal response to loss. Omission is a harmful act, not a neutral one, because of this negative impact. Many grief groups are set up to cover these specific demographics. Examples include WAY (Widowed and Young) which is the only national adult charity for people under the age of 50 who have been bereaved.

Amber Jeffrey started The Grief Gang podcast as a way of working through her own grief as a young mixed race woman unable to find support. Aiming to help perhaps one other person, she found thousands of people who felt like her, alone and unsupported. Likewise, Benjamin May and Jack Baxter, two young men who had lost their fathers, simply wanted to talk about their loss. Growing from this straightforward desire, their charity has now become international.

Jane Harris and Jimmy Edmonds lost their young adult son whilst he was travelling in Vietnam. Their grief connected them with others with similar experiences. They have gone on to make films, write books and run weekend retreats which focus on peer support for people who have lost children of any age.

Grief Festivals

Grief festivals are also finding ways of connecting people with grief who otherwise struggle to work through the difficult times of loss.

Community expressions of grief are not a pathology. They are not something that is wrong that must be fixed. They are a normal part of everyday life that finds expression in the different ways in which people come together to remember those who were precious to them. One of the best known forms of this is the Mexican Day of the Dead, a two-day national holiday on 1 and 2 November of each year, where families welcome back the souls of the deceased with joyful celebrations. Over recent years a number of grief festivals have sprung up in the UK. The Good Grief Fest was founded by Professor Lucy Selman in 2020. Since its inception, the Festival has hosted over 300 events, had 400 speakers and has been visited by 40,000 attendees. It started as an online event and now has in person meetings as well. Grief festivals have been held in Weston-Super-Mare and Hastings with further festivals planned across England.

The Scottish Partnership for Palliative Care has, for over a decade, taken a public health approach to bereavement. In partnership with others SPPC has developed a series of bereavement charter marks for workplaces, schools and most recently a prison which promote and support the creation of more bereavement-friendly environments. Every year in the first week of November, SPPC curates To *Absent Friends* a festival of storytelling and remembrance. The festival aims to reduce the isolation often experienced in bereavement, to provide solace though acknowledgement of the shared experience of loss and to build community connections. Events in the festival are organised by and for communities across Scotland

CHAPTER 6

Equity

The issue of inequity in end-of-life care is enormous and like other aspects of the broad community approaches of support, it is often invisible to professional palliative care services (Hospice UK,2021) (Abel J et al, 2021). Even the framing of the question of equity has a lack of equity built into it. Palliative care services seek to improve their inequity by building equity of access to their service. There is an inbuilt assumption that the service provided is one that everyone would want. However, this is often not the case. As we have seen with Suzanne MacArthur in her project with South Asian women in Birmingham, what was most important to them in the context of life limiting illness was not pain control, which is the assumption for palliative care services, but forgiveness.

The question for palliative care services is therefore how can they help and support diverse communities in the way that those communities want and would find meaningful? This approach is clearly expressed in the report Sing our own Song, End-of-Life Care and the Irish Community in Britain: findings from a national consultation, published by the Irish in Britain and Innisfree Housing Association as part of the Meitheal Muintire Irish End-of-Life Care Project.

> *"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 Palliative and End-of-life Care 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." (Tilki M, 2026)*

These same problems can be found wherever there is diversity, whether this be ethnicity, gender, homelessness, addiction, learning disability or any other intersectional issues. Maria Hughes, Team Manager and Project Lead at Birmingham LGBT, reflects on her experience of working with queer people experiencing end-of-life.

> *"Very generally speaking, across the community, there is an aversion to accessing health and wellbeing services that are in the mainstream, especially health services. People have either had very poor experiences of inappropriate care or they felt like they can't be out and authentically themselves with the healthcare providers they're working with. They are just directly discriminated against. There's a double barrier there. If you go to a health provider, first of all, how are they going to react to who you telling them who you are, and all about you, because people's sexuality and gender*

> *identity is part of them, it's not an add-on? And is this going to mean that person treats you any differently? Secondly, is the care they're offering actually even appropriate? It's one of the reasons why my organisation provides LGBT sexual health services. It's about the approach that's taken and about making people feel safe and comfortable. Unfortunately, as people age, they tend to need more healthcare. And unfortunately, as the LGBTQ community ages, the older they are, the more likely they are to have had adverse experiences. Some will avoid having the checks they need, avoid going to see the clinicians they need to see. Or if they do, they might have to hide part of themselves to feel safe and accepted. The same applies to palliative or end-of-life care."*

Examples of Equity

There are many excellent examples of work done on equity at end-of-life, both within the UK and internationally. In this chapter, we provide two such examples, from No Barriers Here and Birmingham LGBT. The reason for this is that they exemplify the approach of working with communities, coproducing the support that these communities want.

The starting point for understanding how diverse communities support equity is to discover the community strengths. This approach emphasises what is right about a community rather than what is wrong. A way of doing this is to ask the question 'how are people supported when experiencing death, dying, loss and caregiving'? This elicits a very different response from 'how do palliative care services meet your needs?' Often there is a rich description of the culture of care at end-of-life in diverse communities. For example, asking an Imam at a mosque this question reveals how people are supported by the mosque community throughout the end-of-life journey, from illness into bereavement. At this point, it is then possible to ask how could palliative care services help, rather than describing what palliative care services do.

This approach is perfectly described by Gemma Allen from No Barriers Here on work with a Roma community.

> *"No Barriers Here used a co-produced approach, supported by a Roma community development worker with established relationships within the community. They acted as a trusted bridge between the community and project team, reflective of community development principles associated with Cormac Russell's work, particularly the importance of working alongside communities and recognising existing community strengths."*

No Barriers Here is an innovative, arts-based approach to care planning that was co-produced with people with learning disabilities in 2019. Since then, it has grown through collaboration with underserved communities, creating inclusive and creative ways for people to explore their wishes, values and priorities for the future.

Everyone deserves the opportunity to think about, talk about, and plan for what matters most at the end-of-life. Yet for many people, this opportunity is limited by inequality, exclusion and barriers within health and care systems. Using accessible, arts-based methods, No Barriers Here enables people to express themselves in ways that go beyond words. The approach creates safer, welcoming spaces where everyone can participate in exploring care planning. In

doing so, No Barriers Here also contributes to death literacy – helping individuals, communities and professionals build the knowledge, skills and confidence to understand death, dying, grief and planning ahead.

Birmingham LGBT is a charity in Birmingham that supports the LGBT community in a wide variety of different ways. As part of the Compassionate City Group, Maria Hughes, project lead at the charity, organised a series of workshops on end-of-life care and planning ahead. This was specifically a response to discrimination experienced by the community in health care and palliative care. The workshops resulted in both increasing death literacy and producing specific documentation that aimed to help wishes being respected.

CHAPTER 7

Public Education and Death Literacy

The ability for people to support those experiencing death, dying, loss and caregiving is directly related to death literacy. As we have seen, this is defined as practical, experiential, factual and community knowledge. This is not simply knowing about or demystifying death. Most importantly, it takes into account people's previous experience, cultural traditions and customs which all help in the end-of-life setting, not just for the person with the illness but those who surround them. Caring, looking after carers and the caring network is as equally important as supporting the person with the illness. Increasing death literacy is therefore a significant and vital part of end-of-life care. It is directly related to the ability of networks to support those experiencing death, dying, loss and caregiving. This is not just about what happens in people's homes, it includes what happens in workplaces, educational institutions, places of worship, prisons, homelessness, public spaces and others. The support that carers receive in these environments makes a huge difference. This will be discussed further in the next chapter on civic initiatives.

In the context of this report, public education refers to the different ways of increasing death literacy. This is much more than simply providing education sessions about death and dying, which is often a way of professionals telling people what to do.

There are many existing initiatives run by a wide variety of individuals and organisations. End-of-life doula training, such as that provided by Living Well Dying Well Training, is one form of this. As already mentioned, the EASE course run by The Scottish Partnership for Palliative Care, is another effective way of addressing death literacy.

The Omega Course is another form of death literacy training run in the Midlands. Community members attend a series of workshops to discover more about the experiences of death, dying, loss and caregiving to help overcome the common taboo of not thinking or talking about it.

DEAD GOOD is an arts-led social enterprise. Their work contributes to compassionate communities approaches by increasing public confidence, knowledge and participation around death, dying, grief, funerals, legacy and remembrance

Creating Conversations is a Community Interest Company that aims to change how people talk about death, dying and grief and create compassionate communities where these important conversations can happen. They do this in a variety of ways, through running workshops, grief cafes, grief walks and events about death literacy.

CHAPTER 8

Civic Initiatives

People who live with life-threatening or life limiting illness, their caregivers, and the bereaved are segmented social groups, forced to experience lifestyles that are commonly socially hidden and disenfranchised from the wider society. Outside of the health services that deal specifically with their immediate problems, these populations suffer from a range of other troubles that are separate but linked to their health conditions or social circumstances – loneliness, isolation, job loss, stigma, depression, anxiety and fear, or even suicide. These populations also suffer from a range of other debilitating health problems often caused by their social and psychological troubles - insomnia, cardiac arrhythmias, chronic fatigue and headaches, hypertension, and gastric-intestinal disorders.

Compassionate Cities are communities that publicly recognize these populations, and these needs and troubles, and seek to enlist all the major sectors of a community to help support them and reduce the negative social, psychological and medical impact of serious illness, caregiving, and bereavement. A compassionate city is a community that recognizes that care for one another at times of health crisis and personal loss is not simply a task solely for health and social services but is everyone's responsibility.

From The Compassionate City Charter (Kellehear A, 2015)

There are many kinds of civic initiatives which help support people at end-of-life and help support those caring for people who are at the end of their lives. Compassionate cities is a formalised approach of how this is done from villages to cities of any size. Other ways of achieving the same aims exist. The key feature is that the impact of caring, life limiting illness and loss is open and accommodated, and supportive environments are created and enhanced.

Lying at the heart of civic initiatives is mobilisation of community strengths to help community members through the demands of death, dying, loss and caregiving.

Where does the civic initiative take place?

The experiences of death, dying, loss and caregiving happen everywhere. This means that it is possible to plan for supports to take place wherever it happens. Broadly speaking, support can be summarised in two ways. The first is practical, involving shopping, cooking, cleaning, walking pets, covering for somebody at work whilst they attend hospital appointments, picking up children from school amongst others. The second is emotional, paying attention to someone's emotional wellbeing. This might be talking about how they are, what is going on in their life, and it might be doing the normal things of friendship, such as making tea, going for a drink after work or the other many ways in which people share kind hearted time. The Compassionate City Charter takes an organised approach to the civic initiative and lists 13 sectors as a starting point to launch a combined effort across a geographic area. These are educational institutions, workplaces, places of worship, communities, hospices and nursing homes, peacetime memorial parades and public events, museums and galleries, civic

participation through a mayoral prize, homeless and prison populations, local government and a commitment to add sectors annually.

How do civic initiatives start?

The motivation and impetus for civic initiatives can come from multiple directions. They can be community-led, as in the example of Brereton and ground up communities of practice developed in Suffolk and Norfolk. They can focus on a particular area of end-of-life, such as grief festivals. They are sometimes initiated by palliative care teams and services who have an interest in public health palliative care. Examples include Compassionate Sheffield and Compassionate Inverclyde. They may start with public health teams taking an interest, as happened with Compassionate Birmingham (Hodges E et al, 2026).

Who is involved?

Civic initiatives may be led from state institutions but must involve ground up support, developed by the communities involved. Companionship and friendship form the basis of this support, and this means mobilising communities to rally round people experiencing death, dying, loss and caregiving. It is the communities themselves that should decide on what kinds of supports are needed rather than being told what to do from an outside agency. Community development is the methodology of how this happens, and is sensitive to power relationships, equity and culture.

If an organised approach, such as compassionate cities is the main methodology, then the different elements of civic leadership need to come together, so that a cross sector work programme can be arranged. This can include the mayor's office, the chamber of commerce, media representation, educational leaders and the other sectors mentioned in the charter. Participation from palliative care services is extremely helpful as they may be able to offer communities support in developing death literacy, such as how to move people who are frail, how to participate in community led what matters and advance care planning conversations and familiarity with grief and loss. In accordance with the five action points of the Ottawa Charter for Health Promotion, they can begin the process of service reorientation in line with community development.

Examples of civic end-of-life initiatives

Brereton is a ground up citizen led approach, developed from an existing community project stimulated by the Big Lottery. End-of-life became particularly noticeable during the Covid-19 pandemic where people were particularly isolated and needing support.

Compassionate Birmingham grew out of support from the Strategic Health Authority, who became interested in the practice methods of public health palliative care, supported by Public Health Palliative Care UK. They initially funded four organisations to develop a compassionate city approach, including Murray Hall Trust, a community development organisation in Sandwell. Social care and public health services in Birmingham helped, with the hospices participating.

The Good Grief Festival was started by Professor Lucy Selman, a social scientist, and colleagues at the University of Bristol, who had an academic interest in bereavement. The Good Grief Festival, initially an online meeting, now has festivals in the seaside towns of Weston-Super-Mare, Hastings and Blackpool.

CHAPTER 9

Health and Social Care Partnerships

The report up to this point has focused on community and charitable initiatives that seek to support people experiencing death, dying, loss and caregiving in multiple settings. The examples given have been practical and aimed at increasing death literacy through public education, making it easier for communities to support people. One of the largest problems with enhancing community capacity is that health and social care professionals may not value this support or see it as fundamental. As a consequence, much of what goes on is invisible. Services tend to only see their role and not that of others outside the professional sphere.

Efforts over the last two decades to highlight this problem are now bearing fruit, with practical examples of how these partnerships can be developed. The inclusion of Communities Are Prepared to Help as the sixth ambition of the Palliative and End-of-Life Ambitions Framework (England 2021)was a step in the right direction. However, many of these initiatives are quite small in scale and are often dominated by top down hierarchies of service provision, rather than stimulating ground up community capacity building.

Before turning to UK examples of partnerships, it is worth mentioning two deeply embedded models in the international setting. The first is the Neighbourhood Network in Palliative Care initiative run from the Institute of Palliative Medicine in Kerala, India. Started by Suresh Kumar in 1993, the programme is owned and run by multiple groups in civil society, including political parties, religious groups and local government, and is a complete example of community participation. There are now over 1000 palliative care units with more than 400 units run by community groups. The community, rather than the health service, employs local palliative care professionals and trains community volunteers. Kerala does not have rich healthcare resources, so community participation is crucial for end-of-life care. Saif Mohammed, Faculty Member of the Institute of Palliative Medicine in Kerala and previous state manager says

“The doctors and nurses are answerable to the community not to a health service board. When it comes to community, it's a very small unit. It happens in a village so there are very few people, so the doctor and nurse have no other place to go but to do their job properly.” The doctor and nurse do their visits in people’s home, with family and trusted community members in attendance. This means that the visiting team get a proper view of the context of the illness and will work with the supportive network to ensure that the care that is given is in the context of their lives in the home.”

The second example concerns the work of Naheed Dosani. Dr Dosani is a palliative care physician and the founder and lead of Canada's first and now largest mobile palliative care programme for people experiencing homelessness. He is the Medical Director of Toronto's largest hospice, Kensington Hospice. He started working in the homeless setting in palliative care and developed the PEACH programme, Palliative Education and Care for the Homeless. Working in this way requires developing relationships with homeless people at the outset,

because they often have huge distrust of services and may have a long history of trauma. He says about his work

> *"When serving people who live in the community, particularly doing outreach working in respite shelters and drop-ins, the approach to care often really has to be different. For example, we focus on the issues that concern people who experience precarious housing rather than necessarily medical issues. If they have medical issues they're often the result indirectly of other issues upstream, like not having housing, food or money or not having the social supports to get to medical appointments. When I'm doing PEACH outreach visits, I'm supporting people and transitioning them, for example, to our hospice program, which is a program called Radical Love, which is an equity oriented hospitality of care program There's a lot of attention paid to the social determinants of health."*

The Radical Love programme of Kensington Hospice educates medical and nursing staff in equity orientated care, changing the traditional consultation to one that pays attention to social history and context as a primary driver of palliative care. Clinical staff rotate through the PEACH programme, attending homeless people in the community, to learn the skills needed to do this. This way of working is an example of the reorientation of healthcare in accordance with the five action points of the Ottawa Charter for Health Promotion, which strengthens community action as a primary driver of health and wellbeing.

Both of these examples demonstrate the integrated partnership working between professional services, community and civic life. This is summarised in the four cogs diagram of palliative care, the New Essentials. (Abel, Kellehear et al. 2018)

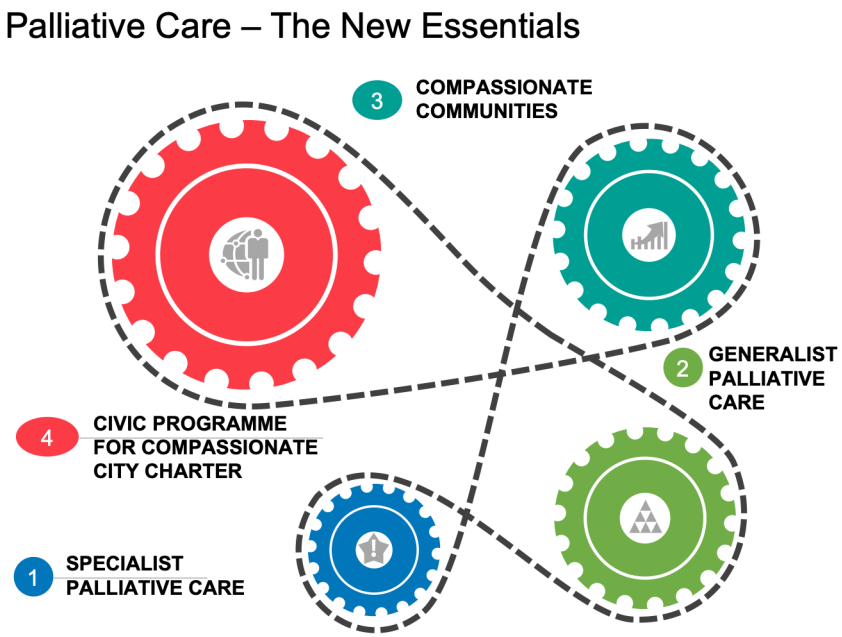


Figure 3. Palliative care – the new essentials: the four cogs of specialist services, generalist services, compassionate communities and civic action.

A whole system, whole population approach requires partnerships across all sectors to ensure that no one is left out of the opportunity for help and support when experiencing death, dying, loss and caregiving. Professional services alone are unable to do this, not just because it is unaffordable but because, as we have seen, there are many examples of help and support that can only be done effectively by community and civic participation.

Part of the process of working with community partnerships is to see the wide variety of resources that are available in community. A way of doing this is to develop an asset map, also called a treasure map, of the different types of resources which can be called upon. A good example of this comes from Good Grief Weston mentioned previously.



Figure 4. Asset map drawn at a Good Grief Weston community meeting, Weston-super-Mare. Permission from Professor Lucy Selman.

This map was drawn at a community meeting in which all the different services and community groups came together to work out what was already going on in Weston-Super-Mare. Although it is quite detailed, it is possible to see that the four cogs of the New Essentials diagram are represented in a variety of ways, including community groups. Some of these may be related directly to bereavement support, such as drop in cafes and some happens as part and parcel of support that takes place naturally when people come together. The social environment itself is a form of support.

Less well established examples of community partnerships with palliative care services exist in the United Kingdom.

CHAPTER 10

The Wider but Equally Crucial 'Invisibles' in National End-of-life Care

Death, dying, loss and care occur in all kinds of circumstances in all kinds of ways. The consequences of these events affect everyone without distinction and without any defining characteristics. The approach in this report is to consider how people undergoing these experiences can be supported whatever the environment. Civic programmes such as the Compassionate City Charter outline 13 sectors of participation, from institutions such as workplaces to places of worship, to educational institutions, the media, public spaces and others.

There are other areas which have not yet been discussed but nevertheless form an important part of consideration of end-of-life care beyond the clinical provision of services. Some of these, such as residential and nursing homes, care for people who may have long illnesses such as dementia or are simply a facet of increasing frailty. Others may care for people with sudden deaths, such as intensive care units, hospital wards and paediatric units. Yet others may require the attention of emergency services, such as police, ambulance and fire crew. This includes road traffic accidents, natural disasters and major industrial events. Assisted dying and people who choose to end their own lives have also to be included. The consequences for these events can be large and life long. Help and support pre and post death can give significant benefit. The challenge for the variety of institutions and services is determining how the extra forms of support can be brought to bear when they do not have the familiarity of end-of-life care practices. The key for doing this is through training, linking to community resources and stepping outside of the institutional, service delivery gaze.

How to link to community resources

The diagram drawn to represent the wide variety of resources available in the community organised by Lucy Selman's Good Grief Weston festival is an example of a treasure or asset map. These can be collated into a resource directory. A good example of this can be found in the Health Connections Mendip Resource Directory as part of Health Connections Mendip, the community development arm of the variety of supports available to health services in the Mendip area of Somerset. Separate resources are listed for end-of-life care, such as bereavement care, befriending and pet loss. Bereavement care has 37 resources, some of which are professional services, some are different sized bereavement charities from national to local, and some are informal grief support groups run in cafes and local meeting spaces. Most areas across the UK now have some kind of a community resource directory. Some are more sophisticated than others and many do not have end-of-life related community support on them. In addition, some areas have multiple directories that may not be up to date. Accessing information on a local support group that no longer exists is a discouragement to using the resource directory again. Part of end-of-life planning in local areas needs to include having an

efficient resource directory that has the right information on it. Clinical teams can then easily link to these resources so that when people come into contact with their services, part of ongoing care is to develop links into communities. For example, an intensive care unit frequently supports families that have been suddenly bereaved. Access to organisations such as The Compassionate Friends helps to continue supporting bereaved parents and families in the community for people who have suffered sudden loss. Brake is another charity that supports people affected by road deaths.

Ease of access to resource is crucial. If busy clinicians are going to link to the wealth of community knowledge, then the information needs to be readily available. Likewise, emergency services can make use of this broad community resource, including police, ambulance services and the fire brigade. Whenever these services are involved in a death, then making use of community resource to support the bereaved should be routine.

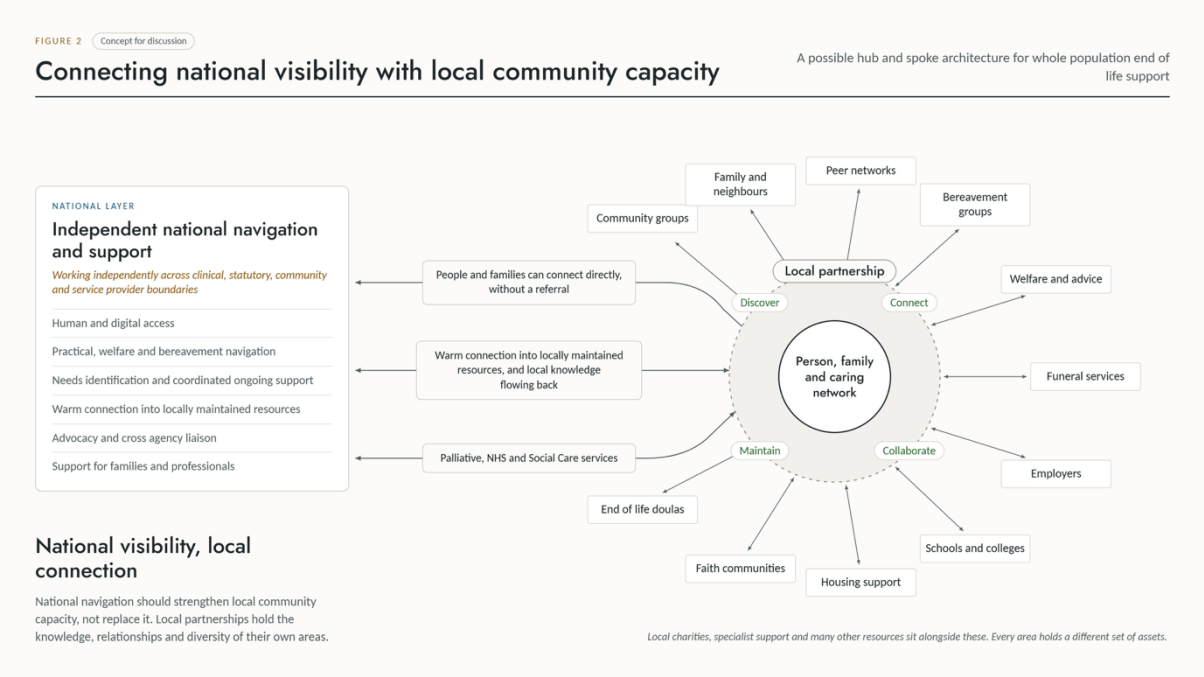


Figure 2. Connecting independent national navigation and support with local community capacity: the person at the centre, with direct access nationally and warm connection into local partnerships.

Local partnership working

Gathering together community resources and ensuring that local services can access these resources has to happen at a local level. Discovery of community treasures must be done by the communities themselves, working in partnership with local services. Civic initiatives such as the Compassionate City Charter bring together partners from communities and different services. These partnerships can expand their activities into different sectors as part of continuing growth in end-of-life care. Inviting police and ambulance services, for example, will help dissemination of relevant information into these services so that the wide range of community supports is used.

People seeking assisted dying, those who take their own life and the families involved are often excluded from end-of-life service provision. However, as part of a whole population approach,

it is important to provide support in these circumstances as well as any others. In the UK, more than 650 people take their own lives in the end-of-life setting or travel abroad for it. The impact on families is significant, and communities have an important part to play in giving support. In total, over 7,000 people in the UK take their own life. Given that nine people are directly affected by every death, 70,000 people per year suffer loss and grief from these events (Wenk et al 2012). The impacts are felt in schools, workplaces and other civic sectors as well as communities. Irrespective of the legality of assisted dying, supporting people at this time is included in the broader approach of end-of-life care.

Health and social care sectors outside of palliative care services should participate in the broader civic initiatives. For example, hospital palliative care teams should be part of the civic partnerships. Once they become aware of the broad range of supports, they can then help other departments in the hospital to use these supports as a matter of routine. Offices which issue death certificates in hospitals can also make use of them. Residential and nursing homes can link to communities for their residents and also support those bereaved by becoming part of these partnerships.

Commissioning bodies such as Integrated Care Boards can help to stimulate civic initiatives by incentivising palliative care teams to participate. Likewise, the Care Quality Commission can develop standards that require palliative care teams, including hospices, to take part.

CHAPTER 11

Summary and Recommendations

This report has been written specifically for the attention of politicians, health and social care commissioners and palliative care service providers, including hospices. The existing palliative care framework, strategy, commissioning and clinical practice excludes more people than it includes. One percent of the population die each year. For each death, nine people (on average) are directly affected, equating to 10% of the population. Everyone needs help and support at this time, not just the person with the illness but those who surround them as well. The current model of palliative care restricts access to services by diagnosis and separates dying from grief and loss. It also pays scant attention to supportive networks and does not see that increasing death literacy through public education is a concern or relevant to palliative care service provision.

The reality is that the bulk of care is done by communities, by family, friends, neighbours, by workplace colleagues, school friends, by community members and by the numerous professions, volunteers and groups that are part and parcel of end-of-life care. The report gives a sample of the types of help available in these different settings, both community and in civic life. These examples are a minute proportion of what is already existing.

The National End-of-Life Care Coalition calls on politicians, commissioners and palliative care professionals to rethink end-of-life care and see that partnerships with communities and the wide range of organisations that provide help at life's most challenging time are critical and necessary. It is not just that taking a whole population approach to end-of-life care using palliative care services alone is unaffordable (Cummins L, 2025), it is not even preferable. Love, friendship, practical help and the wisdom of community and civic life are the bedrock of end-of-life care. These things should not be sporadic or present by chance but need to be part and parcel of planning and partnership working at end-of-life. Professional relationships, however good they are, last as long as professional contact is in place, bound by referral criteria. Relationships developed and deepened through community links may be life long and enduring. These are deeply meaningful interactions between people which are imbued with both love and a sense of belonging. Even the best professional care cannot replace long lasting friendships and support. When these supports are absent, the burden of care falls on inappropriate use of health and social care services. This is an enormous drain on precious resources when other, better options are available.

Death does not happen by diagnosis, age, cause of death, or any other characteristic. It is not a single event that is only relevant to the dying person. It is guaranteed for everyone, and the experiences of death, dying, loss and caregiving will happen multiple times in people's lives until everyone's own final one. In those moments, everyone needs the love and practical support of the people around them. They need the deep wisdom that is present in communities of how to help. When these things are absent, the results can be catastrophic.

Palliative and end-of-life care policy and practice must take a whole population approach so that everyone experiencing death, dying, loss and caregiving has supports available to them that are culturally appropriate, meaningful and long lasting. For this to happen, partnerships between the multiple organisations and communities involved at end-of-life are needed. Professional dominance in policy and planning must give way to genuine equal partnership together to support people at a time of greatest need.

Recommendations

1. An overhaul of the representation in palliative and end-of-life care policy commissions and associated bodies. These should not be chaired or dominated by specialist palliative care.
2. Future policy narratives to include social care, public health (health promotion), and community perspectives, with deliverable actions, and associated funding recommendations.
3. A cessation of the conflation of palliative care with all end-of-life care. We need greater recognition of the role of aged care, intensive care, emergency care, disaster and terror management among other relevant services. We want a variety of clinical specialisms as well as social, public health, and community care to be represented on all future policy making boards.
4. Increasing death literacy through public education is fundamental to increasing the capacity of the 90% not directly involved in caring for family and friends at end-of-life, to care for the 10% who are.
5. Local partnerships of civic initiatives, communities and professional services are needed in every area, to uncover the invisible and often ignored resources which should be made available, encouraged and supported to everyone experiencing death, dying, loss and caregiving without any limiting or defining characteristics.

A new national commission for end-of-life care inclusive of the above recommendations is required now

APPENDIX 1

Examples from the chapters

Chapter 2 – Life Limiting Conditions

CASE STUDY

End-of-life Doulas

https://eol-doula.uk

Navigating the many and varied challenges facing a supportive network is a central issue where help can make an enormous difference. End-of-life doulas help people throughout the journey of caring. End-of-Life Doula UK is the membership association charity for end-of-life doulas and doulas in training. An end-of-life doula is a compassionate, trained companion who supports individuals approaching the end-of-life either through terminal illness or older age, and those important to them when someone has a life limiting illness. Their role is to equip ordinary citizens with the knowledge and understanding needed to accompany others in these experiences in a safe, ethical and person-centred way, within their own communities. Doulas do not necessarily have a background in health or social care but have the knowledge, enthusiasm and confidence to help the people around them navigate difficult times at end-of-life.

Support generally includes planning, emotional support, practical assistance, educating people about the dying process, respite for carers, legacy work, advocacy, and support before, during, and after death including with funeral planning and organisation. The support continues for a family in the initial weeks and months after their person has died.

CASE STUDY

End-of-Life Doulas – example

A woman in her late seventies was living with advanced illness and wished to remain at home for the end of her life. She lived with her husband and had two adult children. Her daughter had become the main carer and was experiencing significant carer burnout, while her son who lived further away struggled to accept that his mother was dying. This led to disagreements within the family about care needs and responsibilities. Her daughter had contacted End-of-life Doula UK (EoLDUK) seeking support and had an initial telephone conversation with an EoLDUK volunteer who listened to their situation, offered guidance, and explained what an end-of-life doula could provide.

The family was matched with an end-of-life doula by EoLDUK who provided support to the woman and those important to her. The doula facilitated open conversations within the family, provided support to both adult children (remote support to the son), and helped them better understand one another's perspectives and focus on what mattered most to their mother.

The doula worked alongside health and social care professionals, supported advance care planning, coordinated communication between those involved in the woman's care, and advocated for her wish to remain at home. The doula also helped the family understand what to expect as the illness progressed and talked them through the dying process. This increased their confidence, reduced anxiety and crisis-driven decision making, and helped them feel more prepared.

The woman died at home, surrounded by people important to her. Whilst her death was still profoundly sad for her family, they felt prepared and were able to recognise the physical changes of the dying process which reduced anxiety. When she died, the doula asked the family whether they'd like to wash and dress her, and the doula guided them through this. They remarked that after spending this time they felt more ready for the funeral directors to take her out of the family home. The doula continued to support the family with after-death administration, funeral planning, and initial grief support.

CASE STUDY

Routes to Rights

Routes to Rights is a national project helping people understand how legal rights contribute to holistic, compassionate care around end-of-life. It highlights issues around equity, choice, rights, professional responsibilities and the importance of a connected system-wide response. A foundation of research has led to public and professional resources and education to drive change in this space.

By engaging diverse individuals and organisations across the UK, the research identified two key areas where legal rights, entitlements and protections play an important part in end-of-life care: health and care decisions and day-to-day life (eg money, jobs, housing, social care). It revealed the breadth of need and the challenges of feeling heard and finding the right support. Lots of support is available, but often invisible or hard to access.

Education is based on lived experience and facilitated discussion. Pilot events brought together people from diverse backgrounds and services to explore the breadth of issues people face, the barriers, and the facilitators to the help they need. Routes to Rights will be a core pillar in the End-of-life Learning Hub CIC.

CASE STUDY

Suzanne MacArthur and Evolve and Flourish
https://www.evolveandflourish.co.uk

Initially trained as an occupational therapist, Suzanne became increasingly interested in the role of community support at end-of-life. She became a community development worker at end-of-life and has participated in numerous projects in diverse areas. She runs Evolve and Flourish, with the aims of normalising conversations about death, dying and loss, and building stronger community support networks for those who are becoming more socially isolated due to ageing, being a caregiver, dealing with loss and grief or due to living with a life limiting illness. It does this by:

- Helping communities and their assets take back responsibility for supporting those around them who are approaching end-of-life, living with frailty, who are caregivers, or coping with loss.
- Reducing public reliance upon statutory and professional services for help and support that can be provided by the community.
- Improving public awareness about the systems and processes that support those who are dying or coping with grief.
- Allaying anxieties that the public have about the process of dying.
- Dispelling the myths that society has about death and dying.
- Developing public confidence in knowing where to access help and support.
- Encouraging people to be active participants in their own end-of-life planning.

CASE STUDY

Evolve and Flourish – example

Suzanne worked with prisoners in Birmingham to help them develop their support networks inside the prison. They wanted help to design their own education materials and deliver the education themselves so that prisoners facing bereavement into the future could access support.

During the discussions in the planning stage of the project personal stories were openly shared by the inmates of how imprisonment had affected their ability to deal with loss and grief. “The fights you have to go through are not fair” one inmate stated, describing the challenges he had faced to attend a loved one’s funeral and offer support to his family. Another inmate described not being able to attend his stepfather’s funeral (a man who had raised him since the age of 10 years) and that no bereavement support was offered at the time. He added “I am so glad we are doing something about it”. He added that “on the outside you can arrange to view the body and pay your last respects, you can’t do that in here”, adding to the sense of grief.

The Recovery and Service User Involvement Manager who supported the project gave feedback about the project:

“It has enhanced their existing skill set while aiding their confidence to tackle such a difficult subject. Previously it has been a one stop shop for bereavement in terms of Chaplaincy support. However, enabling peers to provide support, offers an additional network both on a one-to-one basis and from a regular help point perspective. I think the involvement of the men for each other’s support helps build a greater sense of community and supportive fellowship which certainly has a positive impact during their sentence.”

CASE STUDY

Speak for Me

https://speakforme.co.uk

The main focus is on planning ahead, ensuring that what matters most to people is the driving force behind the care they receive and the life they

Having identified a gap in the knowledge and understanding of Advance Care Planning through my professional and personal life, and seeing the impact this has, my passion is to improve professional knowledge, raise public awareness and normalise these conversations and plans.

This includes:

- Co-founding the national ACP Awareness day & Conference
- Working on a 1:1 basis supporting clients with Advance Care Planning
- Lasting Power of Attorney Consultancy & awareness
- Hosting the podcast Conversations About Advance Care Planning
- Creating content & awareness through a blog
- Hosting the legacy blog for Clair Fisher

Chapter 3 – Dying and Caregiving

CASE STUDY

The Anne Robson Trust

https://annerobsontrust.org.uk

The Anne Robson Trust works to improve the experience of dying by helping healthcare organisations and communities provide emotional, social and practical support alongside clinical care. They work in partnership with healthcare organisations to help them establish and sustain Butterfly Volunteer Services. These trained volunteers offer companionship, emotional support and a reassuring presence to people who are dying and those important to them. They provide time, human connection and continuity at a period when many people feel isolated, frightened or overwhelmed.

CASE STUDY

Anne Robson Trust – example

From an acute hospital - and a patient's daughter:

My father passed away on Wednesday evening. When I arrived to visit dad, Carol (a Butterfly Volunteer) was sitting with dad and was so friendly. I noticed dad's breathing became shallow, so I called in the nurse, and she told me call in my family. I asked Carol to stay with me until my family arrived. She was absolutely fantastic - kind, doting and supportive at probably one of the most critical times in my life. I can't begin to tell you what a relief it was to have a Butterfly Volunteer with me. Without Carol I would have felt much more nervous, and lonely. I wouldn't have been able to be as comfortable in the situation as I felt. I am so grateful to her. I never knew about this service and am very grateful for it. With the lack of doctors and staff in the NHS, and more people getting sick and dying, there is a real need for volunteer visitors. It's a vital service – as much for the family members as the patient

Chapter 4 – Funerals

CASE STUDY

Life and Loss UK

Life and Loss UK provides practical, emotional and welfare support to people affected by bereavement, end-of-life issues and caring responsibilities. People experience multiple challenges at once, including grief, financial uncertainty, caring responsibilities and complex administrative tasks. This includes unpaid carers who may be balancing the demands of caring, financial pressures, employment concerns and anticipatory grief whilst supporting someone approaching the end-of-life. Life and Loss UK support includes emotional wellbeing and bereavement support calls, support for unpaid carers, welfare benefits advice and income maximisation, council tax advice, housing advice, employment support, bereavement administration and support with navigating probate and estate administration processes. They provide advocacy and liaison support on behalf of clients, helping them communicate with health and social care providers, statutory agencies, local authorities, utility providers, housing providers, employers, DWP and other organisations

Example from Life and Loss UK

An older patient was referred to Life and Loss UK following the death of her husband whilst both were receiving treatment in hospital. The patient was registered blind, recovering from surgery and had no close family support. She was overwhelmed by her bereavement and anxious about how she would manage funeral arrangements, financial matters and the practical administration following her husband's death.

Following referral, Life and Loss UK provided immediate practical and emotional support. We visited the patient in hospital, explained the steps that needed to be taken following the death, provided guidance regarding funeral arrangements and supported her with death notifications and bereavement administration.

A full benefits review was completed to maximise income and ensure she was receiving all available entitlements, and support was provided with welfare benefits, council tax matters and accessing the practical support available following her bereavement.

Regular contact continued following discharge, providing reassurance, practical guidance, advocacy and liaison with relevant organisations where required. She reported feeling significantly less isolated and more confident managing the practical and emotional challenges she faced following the loss of her husband.

CASE STUDY

National Burial Council

https://nbc.org.uk

Objectives

- To be the national representative umbrella body for the diverse Muslim funeral directors and community groups offering bereavement and funeral services in the UK.
- To provide strong and effective representation as a consultee and a lobbyist within all tiers of central and local government for our members.
- To lead the transformation and professional development of Muslim funeral directors and bereavement services guided by the tenets of Islam to improve and further develop services to the members and the community.
- To promote National Burial Council both within the association, within the community and with all stakeholders.

CASE STUDY

Funeral Celebrants

https://funeralcelebrants.org.uk

A Funeral Celebrant is a person who can help plan, write and lead a Funeral service. People from all walks of life choose to become a celebrant but all are motivated by a strong desire to help families give the person who has died a good send-off, one that honours, gives thanks for, and, even, celebrates a life. Some Celebrants are introduced to families by a Funeral Director, others are approached directly. Either way, all will work closely with the family and the funeral director to ensure everything goes to plan.

Association of Independent Celebrants

The AOIC (Association of Independent Celebrants) is the leading trade association for independent celebrants. The organisation was founded in 2007 to provide a network of professional, highly trained and reliable celebrants. It gives its members the chance to join together and support one other, receive recognition from other professions and provides a "group voice" to lobby in political campaigns. Above all, the AOIC encourages its members to operate under their own right and with their own individuality while providing each member with mentoring, career development, a code of conduct and a unique insurance package which we have recently negotiated.

CASE STUDY

Tina Naldrett, Independent Funeral Celebrant

My work as a celebrant allows me to officiate funerals and memorials and celebrations of life in all sorts of places, traditionally, but also in gardens of family homes, on trams, boats and in village halls. After death care is changing and I want people to know what is available to them.

Last year I officiated a ceremony for a family whose mum had died in their garden. We planted a tree, sang songs, watched a video, told her life story. We did some crafting which was her favourite thing to do, to celebrate her life.

CASE STUDY

Manaaki Mats

https://www.manaakimats.org

Manaaki Mats is a social enterprise that improves experiences of death,

dying and bereavement by helping healthcare organisations develop sustainable

systems of compassionate after-death care. They provide safe, simple, specialist cooling resources, education, implementation support and ongoing advisory services to hospitals, hospices, bereavement charities, funeral providers and healthcare organisations.

Originally developed for perinatal bereavement care within New Zealand, Manaaki

Mats are now used across maternity, neonatal and paediatric services and are

expanding into adult palliative care, hospices, care homes and community settings.

The approach enables families to spend meaningful time together and to care for their

own in the days between death and the funeral.

CASE STUDY

Manaaki Mats – example

A baby died unexpectedly shortly before birth at 37 weeks. Using Manaaki Mats, the

bereavement midwives supported the family to keep their baby with them throughout

their hospital stay and then return home together. The parents spent precious time

holding, dressing and being with their baby, introducing siblings and grandparents,

taking photographs, creating handprints and footprints, and honouring their cultural

and spiritual traditions. The parents later shared that this time gave them memories they will treasure forever and allowed them to care for their baby without feeling hurried or disconnected.

Chapter 5 – Loss and Grief

CASE STUDY

Amber Jeffrey and The Grief Gang podcast

https://www.thegriefgang.com

Amber was 19 when her mother died unexpectedly. She was devastated by her sudden death. She found the experience of grief extremely painful and she describes becoming the nastiest version of herself because of it. She searched for grief support for a period of three years without any success. She tried the NHS, could not afford private grief counselling and tried online support, which proved to be disastrous. Nothing helped and she ended up feeling depressed and suicidal. She thought it must be her fault, not being amenable to therapy or having enough money to pay for a private therapist. Part of the problem was that she was unable to find anyone who looked like her, young and mixed race, who could relate to her life experience. She reached the point at which she decided she would run a podcast about her experience. This was back in 2019 when podcasts were beginning to become popular. She had no idea whether anyone would be interested to hear what she had to say but pressed ahead anyway. She called it The Grief Gang because it is the gang that no one wants to join.

As it turned out, Amber found that there were thousands of people like her, who had no place to express their grief with relatable people.

She describes the Grief Gang

"The Grief Gang isn't a place where we promise fixes- there isn't one. But what we do promise is community. True, genuine and honest community that's got your back. What we, I do, here in GG isn't rocket science or has a secret formula. We bring it back to basics and allow humans to be humans- in all their messiness and wonderfulness. We honour the sacred time and spaces it takes to sit with our grief - in both its sadness and weirdly sometimes, joy."

Seven years and over 280 episodes later, the appetite for The Grief Gang continues to grow. With a listening community of over 65,000 people, her guest list is extensive and diverse. Any kind of grief appears, whatever the background, from childhood death to dying of old age, to remembrance and celebration of important days.

CASE STUDY

The New Normal – Benjamin May and Jack Webster

https://www.thenewnormalcharity.org/meetings

Ben and Jack became close friends over the grief of their fathers. They found that simply talking about the death of their fathers, complex men of both love and confusion, helped each other, knowing that a friend who had similar feelings. They decided there must be others who felt the same way and struggled to find a place to express these feelings, knowing that even simply being in the room with others, would be a great source of support in times of turmoil. They started The New Normal charity with this simple purpose in mind.

Ben described the process as follows

“You get some people who come once and they come once and we might not see them again. We get a load of people who come two, three or four times and then we don't necessarily see them again. But then we also get a lot of people who'll come for a sustained period of time, anywhere between three and nine months. We see them in poignant moments, birthdays, Christmases, anniversaries. And that's when we actually start to see the kind of recurrence of people coming back into that space and using that space.”

The New Normal continues to grow as a charity. There are a number of regional groups, both within the UK and internationally, with meetings run in Hong Kong and the United States. Between 25 and 30 groups are run each month. There are also groups that cater for diversity, for example Boy’s Talk, Black and Brown Grief, Parental Loss, Queer Good Grief and others.

CASE STUDY

The New Normal – example

The New Normal has met thousands of people from around the world since the first ever meeting in 2018, and in that time has supported people who are experiencing complex emotions, most notably those feeling isolation and loneliness. The impact of the spaces provided is evident from the feedback from our attendees.

“My mental health spiralled and on the first anniversary of my husband’s death, I attempted to take my life. A few weeks later, I found TNN.

I was watching a session at The Good Grief Festival and on hearing the founders of TNN talk; I convinced myself to try a Good Grief meeting online. I talked, cried uncontrollably, and shared my story. The other attendees reassured me that I didn’t need to censor my grief. I finally felt some relief and seen by people who really understood.

I continued to attend and slowly started to acknowledge that although I had no hope, there may be the possibility of hope.

Without a doubt, The New Normal saved my life. I still struggle every day, but I have an empathetic community to go through it alongside.”

CASE STUDY

Good Grief Festival

https://www.goodgrieffest.com

Good Grief Festival began online during the pandemic, when more than 5,000 people attended a free weekend of talks, workshops and conversations about grief. Nearly all attendees had been bereaved, a third within the past year.

For some, it reached where nothing else had. One attendee described it as “the first time in 13 years that I felt I finally found a place” to explore their loss and meet others who understood. Another wrote that they had learnt a great deal about their own grief but doubted they would have found the courage to attend anything in person; joining from home made it possible. Attitudes shifted measurably: after the festival, attendees were significantly less afraid of saying the wrong thing to a bereaved person and significantly more confident that they would know what help to offer.

Bereavement services work to referral criteria and case closure. Grief does not. Two in five bereaved people who want formal support never receive it. A free festival open to anyone at any point after a loss, asks for no referral and sets no time limit.

CASE STUDY

To Absent Friends festival

https://www.toabsentfriends.org.uk

To Absent Friends is an annual festival of storytelling and remembrance that takes place in the first week of November each year. It is curated by the Scottish Partnership for Palliative Care People who have died remain a part of our lives – their stories are our stories, yet many Scottish traditions relating to the expression of loss and remembrance have faded over time.

The To Absent Friends Festival exists to encourage participation. Groups, communities and organisations are welcome to plan events, and these become the To Absent Friends event programme. Events can be public or private, large or small, celebratory or reflective… communities are invited to take part in whatever way works for them.

To Absent Friends gives people across Scotland an excuse to remember, to tell stories, to celebrate and to reminisce about people we love who have died. It is an opportunity to revive lost traditions and create new ones.

CASE STUDY

The Good Grief Project

https://thegoodgriefproject.co.uk

The project is based on ideas that flow from the concept of 'continuing bonds', of not wanting to cut off from the deceased, but of building a new kind of relationship with your child.

We cannot bring our child back but neither do we want to shy away from the pain of our loss – to do so is to deny the feelings and the very life forces that sustain our humanity.

Wide ranging in its activities, the Good Grief Project has produced seven films, including A Love That Never Dies, Beyond The Mask and Say Their Name. They have published a book When Words Are Not Enough and run weekend grief retreats run exclusively for the bereaved by the bereaved. This brings together people who have lost sons or daughters, sisters or brothers, to help you manage and express your grief in ways that are both active and true to individuals.

CASE STUDY

Working with Roma Communities to explore Advance Care Planning (ACP)

Roma communities are among the most marginalised in the UK, experiencing structural racism, poverty, health inequalities and barriers to accessing healthcare. For a community experiencing significant discrimination, deprivation, insecure housing and multiple unmet health needs, thinking about death and dying can feel unimportant when everyday life is focused on survival.

No Barriers Here used a co-produced approach, supported by a Roma community development worker with established relationships within the community. They acted as a trusted bridge between the community and project team, reflective of community development principles associated with Cormac Russell's work, particularly the importance of working alongside communities and recognising existing community strengths.

Three workshops were delivered by staff from The Mary Stevens Hospice and No Barriers Here team in a local church, identified as a safer place by the community. Translated information and interpreters were provided and participants were encouraged to express their experiences and views through arts-based methods.

Participants described experiences shaped by poverty, discrimination and barriers to services. The workshops demonstrated that engagement with ACP requires more than providing accessible information and care planning cannot be separated from the wider circumstances in which people live. When immediate needs remain unmet, planning for the end-of-life may understandably feel less urgent.

A key learning was that trust cannot be assumed, it must be built through sustained community engagement and relationships. This requires services to:

- Build relationships before expecting engagement
- Work alongside communities rather than designing services for them
- Recognise the impact of social and structural inequalities
- Use creative, culturally responsive and accessible approaches to communication
- Invest in community development roles and relationships

The case highlights the need for palliative care services to listen differently and engage differently: recognising people's immediate realities while creating safer opportunities to be heard and valued, with trust in the systems asking questions about future care. For communities who have historically been underserved, genuine and sustained community engagement is critical to developing equitable palliative care.

CASE STUDY

Birmingham LGBT

https://blgbt.org

Birmingham LGBT ran a series of workshops under the banner “Living Your Best Life”, which concluded with “Planning Your Fab Funeral – Planning the End of Your Life”. This workshop encouraged participants to set up their own end-of-life folder, with sections on lasting power of attorney, advance directives, insurance and payments, my funeral, my will, important documents and contracts (passwords, etc.).

Whilst many heterosexuals and/or cisgender people have family who are involved in their end-of-life decisions, LGBTQ+ people, especially of this generation, may be estranged from family, even their own children. They often build “family of choice”, and the workshops emphasised the importance of involving their chosen family members in their plans, especially where there was the risk of “blood” family being hostile to the LGBTQ+ person’s plans. There are trans people whose family have buried them under their birth, “dead”, name and excluded their family of choice, for instance. So, having the tools to be able to live

their later life and end-of-life in an affirmative way and having made plans for their

death, funeral and will is very important for the LGBTQ+ community (1)

Chapter 7 – Public Education and Death Literacy

CASE STUDY

Living Well, Dying Well Training

https://lwdwtraining.uk

- a not-for-profit training organisation, supporting people affected by death, dying and loss and those currently at the end-of-life by providing death education and through the training of end-of-life doulas. Our role is to equip ordinary citizens with the knowledge and understanding needed to accompany others in these experiences in a safe, ethical and person-centred way, within their own communities.
- The Foundation training is grounded in a citizenship approach and explores death, dying and loss as shared human experiences rather than purely clinical or medical. This level of training supports learners to develop awareness of their role as citizens within their communities, encouraging openness, compassion and confidence in engaging in conversations about death and dying. It helps normalise these conversations, reduce isolation, and build confidence in being present with others in times of uncertainty, whether as family members, friends, neighbours or community members.
- At Diploma level, our training focuses on the role of the end-of-life doula. We support
- learners to develop the competencies required to provide non-medical, non directive accompaniment to people who are dying. This includes cultivating compassionate presence, active listening and emotional and spiritual support. Across both levels of training, our approach is grounded in relational, person-centred practice. We also support learners to recognise when additional support is needed and how to signpost appropriately to health, social care and community services, ensuring practice remains safe, collaborative and complementary to existing provision.

CASE STUDY

The Omega Course

https://www.omegacourse.co.uk

We teach people in our community about death and dying so they are more confident in living life to the full. We then teach them how to talk to sick, dying or bereaved family, friends and neighbours, despite the awkwardness of the moments. This is so they are able to become supportive community members.

Being more accustomed to their own mortality and knowing what sensible preparations help maintain choice, and leave things tidy for their family, they develop confidence to support others at the end-of-life and in bereavement

We aim at our healthy population but also welcome people at any stage of life.

CASE STUDY

The Omega Course – example

Jenny and her husband, both in their 80s, came to the course together as dying was an issue of some concern to them as they aged. Apprehensive at first they settled into the gentle supportive learning environment and enjoyed talking about a fearful topic in a new way. They appreciated the discussions and social sharing as well as the learning and communication training. He had a go at a role play scenario despite not being certain of what he would say. He learnt a lot from it.

They gave good feedback to the facilitators and said how much they had learnt and that they had chosen three things they needed to concentrate on. e.g. a lasting power of attorney, tidying up their passwords, bank accounts and bills, and sorting their loft so their kids did not need to do it at a sad time. They felt released from dread and able to almost enjoy their talking and planning about death as an achievement.

Some days after finishing the course they noticed unusual activity at a house on the opposite side of their busy road. A police car, then an ambulance arrived and stayed for a few hours. Later the wife arrived home in the back of another police car. This worried them as it looked like something had happened. They discussed what their facilitator on the course had taught them: 'When unsure, it's better to say something rather than say nothing, no matter what the response.'

They took courage, picked up a cake baked that morning, and went over and rang the doorbell. The wife opened the door and seemed surprised but said their visit was welcome. They introduced themselves as neighbours from opposite and asked if she was OK as they had seen the ambulance and police. She tearfully explained her husband had hung himself in the garage overnight. They said how sorry they were and reminded her they lived close by and would be happy to be on hand if needed. She said her family were aware and she was ok in the house alone, but not up to inviting them in that day, but asked if they could go over the following afternoon to have a cup of tea and some of the cake. They did have tea and cake getting to know her and her story better. They remain in contact.

Contact was made with a woman in distress and the couple put into effect, surprisingly early, their learning from The Omega Course. They remarked later:

"We looked at each other and said "What did she say to do? – we better go and do it as something has definitely happened over there.".

CASE STUDY

DEAD GOOD

https://www.deadgood.org

DEAD GOOD is an arts-led social enterprise. Their work contributes to compassionate communities approaches by increasing public confidence, knowledge and participation around death, dying, grief, funerals, legacy and remembrance.

They provide creative workshops, public events, training, consultancy, celebrancy, resources and community projects that increase death literacy and encourage participation in end-of-life care.

Rather than providing clinical or therapeutic interventions, they create supportive, accessible spaces where people can explore difficult subjects through creativity, conversation and shared learning. Our approach helps people move from avoidance to agency, from isolation to connection, and from uncertainty to greater confidence around death, dying and loss.

CASE STUDY

DEAD GOOD – example

A participant attended one of our eco-funeral planning workshops a few months before the expected death of a close family member. Prior to attending, they reported feeling overwhelmed by funeral decisions and uncertain about the options available.

Following the workshop, they ordered a wool shroud from a local artisan business and chose a green burial plot at a local natural burial ground. After their family member died, they commissioned us to help them design and hold a DIY funeral ceremony in a community allotment. They described the experience as empowering and appreciated having a space where their values and death could be discussed openly without judgement. This example reflects a common outcome of our work: increasing confidence, knowledge, participation, creativity and connection around the end-of-life.

CASE STUDY

Creating Conversations

https://creatingconversations.uk

Creating Conversations create spaces in our local community for open conversations about death, dying and grief. Their mission is to change how we talk about death, dying and grief and to help create compassionate communities where these important conversations can happen. They work across the London Boroughs of Waltham Forest and Redbridge, and in Glasgow, supported by a team of ten volunteers all with lived experience and who have previously attended our spaces.

The work focuses on two key areas: grief support and death literacy.

- Grief Support:

They run a range of community-based grief support activities in Waltham Forest and Redbridge. These include:

- Grief Cafes – monthly in Leytonstone, Walthamstow and Wanstead, providing peer-led spaces where people can talk openly and connect with others who understand.
- Grief Walks – in Walthamstow Wetlands combining the benefits of nature, movement and conversation.
- Grief Awareness Talks – including our introductory talk, ‘Understanding Grief’, alongside more focused sessions developed in response to themes emerging from our grief cafes. Topics have included: managing anger and guilt, neurodiversity and grief, and LGBTQ+ grief.
- Death Literacy - Talking about death and dying and end-of-life care planning:

They run community events that encourage open conversations about death, dying and planning for the end-of-life. For example we recently ran an event ‘Talking about the End-of-life: A Conversation Worth Having’ at a local library. Speakers included members of the local palliative care team and a funeral director.

This work aims to increase death literacy, reduce fear and stigma, and help people feel more informed and able to put plans in place.

CASE STUDY

Creating Conversations – example

Leroy, age 50s

“My mother died from dementia after I had cared for her for ten years. It was a challenging time for me. My GP suggested attending the Grief Cafe so I went to my first session, not quite knowing what to expect.

Two months later my father passed away, which meant I had to navigate two significant losses at once. My GP encouraged me to continue attending the Grief Café and I have been doing so.

Since attending the Grief Cafes I've learned to set my ego aside. I was never one for showing emotions, but now, if I feel like crying, I simply let it happen. I used to struggle with feelings of shame about crying, but I've come to accept it as a natural response. What will be, will be.

Before attending the Cafes, I had never spoken about my feelings to anyone. Now, attending and being with people in the same situation as myself I’m finding it easier to open up and express how I really feel”.

Case study

End-of-life Aid Skills for Everyone (EASE)

https://www.goodlifedeathgrief.org.uk/plan-illness-ease/

End-of-life Aid Skills for Everyone (EASE) is a free course for members of the public in Scotland who want to be better equipped to help friends or family who are caring, dying, or grieving. It was developed by the Scottish Partnership for Palliative Care.

EASE welcomes adults of all ages, experiences and walks of life. The course aims to provide a safe and friendly environment where participants can grow more confident supporting others going through these difficult times, and to think about how they cope with these issues themselves. Through activities, short films and group discussion participants explore a range of issues that can arise when someone is approaching the end-of-life, and some practical ways a friend or family member can offer support. The course takes approximately 8 hours to complete over a period of four weeks.

EASE is a community-based, volunteer-led model. Anyone who has completed an EASE course can go on to become an EASE Facilitator and bring the course to their own community. We now have volunteer facilitators all across the country, from the Borders to the Highlands, and from the Isle of Mull to Aberdeen

CASE STUDY

EASE Impacts

Numbers

EASE has grown steadily since the course was piloted in 2019.

Total number of courses delivered: 119

Number of facilitators trained: 108

Total people who have completed a course: 1048

Impact

All participants are asked to complete pre- and post-course feedback questionnaires. The data from the questionnaires demonstrate that the course is very effective at increasing knowledge, skills, comfort and confidence across the topics covered.

Examples of feedback from course participants:

“I feel more confident about discussing death, dying and bereavement now and feel I could talk to people about this more easily.”

“I will take away a new strength in being able to help, plan and offer support.”

“A wonderful course. Challenging, thought provoking and extremely worthwhile.”

“It has been a deeply reassuring exercise, even just to know that I am not alone and not doing the wrong thing. How to get help and how to cope. A really valuable life lesson.”

“Wish I'd done this before my Dad died. It's been hugely supportive. I've met a wonderful community. Very special group that really trusted and shared very sensitively and openly. Learned/relearned so much.”

Chapter 8 – Civic Initiatives

CASE STUDY

Resident Led – Brereton, A Compassionate Village

“Compassionate communities are built by residents, not services – neighbours supporting each other through life, death, and everything in between”

Brereton, a town in the midlands of 7000 people and 3000 households, was awarded a Big Lottery grant in 2016 to help build their community. The 2020 Covid-19 pandemic brought new challenges. Sue Merriman, the lead for the Brereton Millions community fund, described spotting an elderly resident who should have been shielding on her way to the shop. “Her son had COVID and was locked in his room whilst she was sitting at home watching the news telling her she needed to stay indoors. It turned out she hadn’t

eaten for four days, and she was absolutely petrified. We sent her back home and went to the local grocery store, the Co-op, for her. That’s when we got talking about how there must be lots of residents like this. The Co-op said they could provide surplus bread, and with our Brereton Million volunteers, we started knocking on all the doors. We knocked on every door in the village, all 3,000 of them.” Despite knowing much of the community members, they were surprised to find people who were house bound and living alone who really needed help and support. It was not long before end-of-life issues came to the forefront, with people struggling to look after partners who were dying, or not having anyone to look after them. “

She described what happened next

“I, and a few volunteers, started to step in and sit with people who were seriously ill

and dying to allow their partners to sleep. We could provide the support and reassurance the family needed. Most of the time it would just be sitting them up, giving them a drink, putting their blankets on, then they want their blankets off, brushing teeth and hair, and

listening to them when they want to talk. And most of the time, it was just reassuring them that you were there. They just needed to know they weren’t on their own. There was no training, and there were plenty of times where I was petrified. There was no choice, and we just had to get up the next day and keep going. Even now, after the pandemic, there is still a lot of support needed around death, dying and loss. There is the funeral to organise, and some people don’t have support to do that and there is a lot of paperwork to deal with. We’ve supported all of that too. Luckily, one of our residents has experience in this and has been able to help. We still check in on residents who had a loved one die during COVID and since. We’re still doing jobs for them.

CASE STUDY

Compassionate Birmingham

Organisations working in Birmingham were some of the first in the country to actively engage in compassionate communities nearly twenty years ago. These organisations advocated for a compassionate communities' approach being key as part of a wider palliative and end-of-life care strategy. However, it was difficult to gain traction. Other local hospices also started to advocate for and build public health approaches. The focus remained on clinical pathways and the many challenges associated with reducing deaths in hospital, early identification of people who would benefit from palliative care and advance care planning.

There was little interest in compassionate communities becoming a key strategy or policy driver across the city. However, the impact of COVID created the necessary political and organisational will to move forward on this initiative. Key people from healthcare, hospice and adult social care started to reshape compassionate communities as a whole population approach that did not reside within just hospice or palliative care services.

Because of the earlier work and the activities of a range of organisations including Brum YODO (you only die once), a CIC that aims to create a society that talks openly and honestly about death and dying, there were already many examples of compassionate communities' activities that demonstrated progress against the components of the Compassionate City Charter.

A network of individuals and organisations worked together gaining support from the Informal Cabinet of Birmingham and the City's Health and Wellbeing Board along with many other senior key stakeholders. The city was awarded compassionate city status in February 2022.

Since then, Public Health Birmingham has supported the ongoing development of compassionate city, compassionate communities and how these approaches connect to other city initiatives such as Age Friendly Cities.

The characteristics of Birmingham make it challenging to work in because it cannot be approached as one area, but instead, it must be approached as many smaller communities. This hyper-local approach must then be connected at an organisational and service level where organisations are often working in several communities or city wide, and at local government level to influence policy and change.

One of the many community tools implemented by Birmingham City Council are Neighbourhood Network Schemes. These are funded by Adult Social Care and Public Health departments within local government. They aim to provide support for people to live happy, healthy and independent lives in their own homes and communities and are ideal catalysts for compassionate communities. The local

approach works alongside city wide initiatives such as the annual festival A Matter of Life and Death (AMOLAD), organised by Brum YODO and a strategy for a city wide approach to bereavement (Roberts and Hodges, 2026).

Further information regarding Birmingham's experience is availablehttps://www.taylorfrancis.com/reader/download/407ec0d9-541e-4e3c-91dc-ac2125601a77/chapter/pdf?context=ubx

APPENDIX 2

The Art of Dying in a Democratic Society

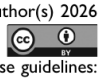
Professor Allan Kellehear, 2026

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Original research article

Critical Social Policy

The art of dying in a democratic society

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Abstract

Palliative care policies struggle with the challenges of social diversity in modern democracies. These policies privilege aspirations toward a 'good death' – a death characterized by awareness, preparation, and a desire for healthcare management of prolonged suffering. However, 'good death' as a cultural ideal is both a medically misleading and socially unrepresentative concept. As a policy ideal, good death denies: (1) different styles of dying, and (2) its opposite and contiguous social reality – the diverse lifestyle perceptions and experiences of the 'good life'. This review argues that the challenge and task for inclusive democracies are to create health and social care policies that reflect the characteristic pluralism of their populations, even at the end-of-life itself.

Keywords

democracy, diversity, inclusion, palliative care, social differences

Introduction: What is the problem?

The biggest obstacle to inclusive end-of-life care policymaking today is the persistence of a narrow understanding of diversity and participation in UK society. This begins with the conflation of a broad understanding of end-of-life care with the far more narrowly focussed field of palliative care. This conflation is then exacerbated by palliative care efforts to privilege a specific image of dying as a long process that requires their brand of attentions. The argument between need (dying) and the service best able to address

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it (palliative care) is largely made on public health (population) grounds. However, in a diverse democracy, how accurate or reliable is that claim?

Without doubt, palliative care professionals are a significant sector who care for others at the end-of-life but so too are general practitioners, geriatricians, and intensive care professionals. Among these professionals are others such as clergy, bereavement care workers, family and childcare specialists, social workers, and funeral and care home workers. Under-recognized among this 'workforce' are also end-of-life doulas, families, neighbourhoods, workplaces, and schools, as well as local government services and faith groups – many of whom are rendered 'invisible' by the clamour of policy noises made by professional healthcare.

Caring for people at the end of their lives takes a village, indeed even a society, but it is the hospice and palliative care movement in the last half century that has seemed synonymous with that help and support. This would not be a policy issue of itself if hospice and palliative care interests were inclusive in their understanding of their own role and essential partnerships and alliances but alas the evidence for that magnanimity is modest.

The recent opposition toward assisted dying in the UK by palliative care lobbyists (Colburn, 2024; Downar and Preston, 2025) betrays a singular vision of the dying experience and its care. It is from this opposition that we hear the startling news that there is a right way to die. The social caricature of ideal dying is presented as: open awareness of dying, preparing for death, requiring suffering to be moderated and tempered, with final hours surrounded by family and friends. This image – commonly entitled a 'good death'– does not represent the factual diversity of dying either epidemiologically or sociologically, because it does not represent the diversity of values and the different choices people make in life, and by extension, whilst living with dying.

Dying behaviour is not determined by underlying medical conditions, or by a single style of ethical-rational decision-making, but rather multiple rationalities drawn from an array of cultural and social value systems. Dying is no mere medical act (Glaser and Strauss, 1968; Kellehear, 2014; Seale, 1998). Rather, dying as the final phase of living, is best described as an existential and social art reflecting the life of its creator. The art of dying reflects the personal and social storylines of an individual's life and culture. The mixture of values, experience, meaning making, and skill that produce a self-directed, final work – such as a life –is not changed abruptly and out-of-character by the emergence of a new scenario, even one posing as death. There has never been a single way to die, and therefore there can never be single way to care for it. In policy terms then, multiple care models are strictly *de rigueur*.

Privileging a singular version of dying, and consequently a single model of proposed care, creates a mismatch between different experiences of dying and the needs and aspirations that emerge from that diversity. It is the aim of this essay to demonstrate this mismatch. I do not dismiss or minimize the valuable contribution of palliative care services as a major provider of care for dying people in the UK. However, when any care politics or policy exaggerates its claim of representation, in this case for those facing death, then both the claim and the alleged constituents require scrutiny and evaluation. That is my intention here. I will argue that policies derived from this mismatch are unfair and antithetical to the principles of an inclusive democracy.

Famous last words

In this essay, I make distinctions between palliative care and end-of-life care. All care at the end of life is a single or mixed offer of health, social, and pastoral services, information, advice, supports, and guidance. Palliative care is the multidisciplinary care of dying people and their families (some definitions also include 'carers') (Radbruch et al., 2020). In the UK, both hospice and palliative care tend to be used interchangeably although hospice more commonly refers to an inpatient facility. Palliative care, originally a Canadian term (Loscalzo, 2008), refers much more to the type of services offered rather than a particular setting such as hospice, hospital, or home. Both the traditional setting, and the type of service, have their origins in Christian traditions of clerical care for the poor, wayfarers, and pilgrims, a service dating back a thousand years of Christian history (Idler and Kellehear, 2017; Kendall, 1970). Today, palliative care is usually a formal health service that includes palliative medicine, specialist palliative care nurses, social workers, counsellors, allied health, chaplains/pastoral care workers, and sometimes volunteers.

End-of-life care is also a term used variably. This term is sometimes employed to refer to the last year of life but also to the broader care (NIHR, 2022) that includes but goes beyond palliative care and may include aged, bereavement, and cancer or dementia care for examples. At present in the UK, there is no unified end-of-life care policy. What passes for end-of-life care policy is palliative care policy. The current national Palliative Care policy document (National Palliative and End of Life Care Partnership, 2021) and the current Commission for Palliative and End-of-Life Care (Finlay et al., 2025) are typical examples of that combined nomenclature and policy identity. This brings us back to palliative care as the leading policy field that not only speaks for palliative care but also more broadly to issues related to end-of-life care. Key to the vision of palliative care in the UK is an image of dying and its care characterized as 'good death'.

Good death is somewhat variably defined but commonly has core features that include ensuring that a dying person is aware that they are dying, is prepared interpersonally and financially, has their symptoms managed well, and can die in their place of choice, surrounded by family and friends. These images are replete in the palliative care policy literature (Borgstrom, 2024; McEwan, Hardill & Merlane, 2026). As a phrase, good death is not a recent invention of modern hospice and palliative care. Instead, good death is a phrase with a substantial back story in anthropology, history, and in folkloric and classical studies.

Derived from two Greek words *Kalos* (good) and *Thanatos* (death) (Humphries, 1981) *Kalos Thanatos* referred to a death that is 'good' if well prepared for. Such a death ensured its recipient a death with dignity. In many Greek texts *kalos thanatos* appears as *to kalos thanein,* the more common (adverb) form that suggests an action (Kellehear, 1990,29). In both forms, the outcome (*kalos thanatos*) and the action (*to kalos thanein*) suggest dying nobly because one is prepared and in control. This is also how historians and anthropologists employ the term, and this partially explains its ready adoption by the hospice movement.

However, there is another Greek source for a phrase that is similarly translated as good death. These are the terms *eu* and *thanatos*. *Eu* is commonly translated as 'good' but is

more accurately translated as meaning 'well'. Hence *eu thanatos* is best translated as 'dying well' in the sense of dying painlessly or easily (Partridge1959:189; Oxford English Dictionary 1933: E325). This meaning of the good death as dying well forms the basis of the contemporary phrase 'euthanasia'.

In the UK, advocacy for voluntary euthanasia (physicians directly hastening the death of their dying patients at the patient's request) and assisted dying (physician-prescribed but self-administered fatal pharmacy) dates from the nineteenth century. Both options remain illegal at the time of this writing. Although suicide in the UK was decriminalized in 1961, the act of assisting others in their (now legal) act of suicide remains illegal. There have been repeated legal and political attempts in the UK to decriminalise assisted dying in recent years, in the courts and in changes to parliamentary legislation (McSorley, 2024; also Guardian 2024). The parliamentarian Kim Leadbeater's 2024–26 attempt to legalize assisted dying is the most recent UK example in a litany of historical disappointments.

Although both meanings of the good death from *kalos* and *eu* sources revolve around ideas of virtue, what is viewed by palliative care or euthanasia/assisted dying advocates as virtuous is very different. Hospice and palliative care policy narratives emphasize health services control to facilitate personal preparation and choice of settings, and it is this arrangement that is viewed as 'good' or virtuous. On the other hand, the euthanasia and assisted dying policy narratives tend to emphasis the forfeiture of unnecessary suffering and the insistence of self-control (autonomy) that is viewed as 'good'. The palliative 'good' assumes good will come from placing oneself under prolonged health care. The euthanasia 'good' assumes good will come from avoiding lingering dying and any prolonged care at all.

The palliative narrative wishes to see death come 'naturally' while the euthanasia/assisted dying narratives emphasize the timing of death to be actively chosen by the dying person. This last insistence has several consequences. Insistence on personal control erodes medical authority by requiring doctors to relinquish their control at the end of life. Furthermore, actively insisting on controlling the timing of death links this form of dying to suicide – a rupture in the Christian foundations and values of the hospice and palliative care movement.

Finally, the requirement for medical complicity and co-operation breaks the professional paternalism of the patient-doctor relationship (the doctor knows best) by creating or applying a business relations approach (the customer is always right) to medical services. The result is a critical erosion of medical power at best, and at worst, rejection and stigma as the price for social dissent and difference.

The policy polarisation between competing ideas of the 'good' death exposes the most under-recognized problem with palliative and end of life care policy ruminations today, and it is this: There are many ways to die (or not) and the current models of palliative and end of life care restrict themselves to simply one – aware, prepared, and compliant. Deviance from this social prescription of the good death is unwelcome. Social difference inside the experiences and identity politics among dying people – as we have seen in the case of the assisted dying movement in the UK – is not to be tolerated. UK palliative care is a one-care for one-society policy. A one-size-fits-all approach. However, dying is not one size.

Who are the dying?

About 600,000 people die annually in the UK (NIHR, 2022). The public health patterns for this exodus are well known. People mainly die of illness, with most of this death occurring to people over the age of 65 (British Geriatric Society, 2025). Within this pattern is an equally well-known list of major causes – circulatory diseases, respiratory and neurological disorders, cancers, and dementia. Beyond these mortal ridges lie suicides, accidents, poisonings, homicides, and misadventures of every stripe. However, these are public health images conveying a faceless set of patterns linking numbers to biological cause and tell us little else (Gazillo et al. 2026). Most people don't think of dying as a population matter, and crucially from a policymaking perspective, these statistics don't shape their end-of-life care needs, behaviours, or decision-making. Because in all truth, the subject of 'dying' for most people is experienced as a personal and social matter. This subjective perspective is front and centre to understanding the politics of identity among dying people (Kellehear, 2024).

Not everyone who experiences what doctors view as a life-shortening disease come to see this assessment as a 'dying' (Chen et al., 2017; Murray and Amblas 2021; Nwatu, 2021). Some people with this kind of prognosis will persistently view their predicament in terms of a chronic illness that they will need to manage. A medical opinion of their life-expectancy is just that – an opinion. There are also other people who receive a serious but non-life-limiting diagnosis who privately believe they are dying because they hold longstanding pessimistic understandings of some diseases that commonly kill (e.g., 'cancer is a death sentence').

To extend this understanding of the power of personal and social perspective in defining 'a dying', we may also usefully add the experience of people in nursing homes. Despite advanced age and multiple life-limiting diseases in each of the residents of any nursing home, most of these people do not view themselves as hospice patients – they do not view themselves as dying people even though many of these have comparably short life-expectancies (Mathie et al., 2011).

The principle to remember in these examples is that no matter how seriously grim the news conveyed, or how threatening a circumstance may arise, there will always be substantial numbers of people who will seek and adhere to alternative life-affirming or bad news delaying interpretations. The dying identity is not an inevitable outcome of news of an abruptly shortened life. Dying as an identity (and set of needs) is not determined by facts of biology. Unlike death itself, dying is a socially determined experience where biological entropy may be necessary but not sufficient condition to determine subsequent behaviour and experience.

The reverse is also true. There may be no biological decline or disease at all but dying conduct and attitude may be initiated from a sudden change in circumstance. Good examples of this response are those on doomed flights, ships, and buildings (Atkins, 2008; Lesley, 1988) but also those premeditating suicide (Alvarez, 1970; Baril, 2020), those residing on death row or in death camps (Bradford, 2010–11; Frankl, 1946/1964) those in disaster circumstances (Arcaya et al. 2020), and those about to go into military battle (Faust, 2008; McSorley, 2014).

From these quick illustrations it can be readily seen that public health information about causes of death do not reliably indicate whether a dying (identity) had preceded that death. In fact, because many life-limiting illnesses produce lingering forms of dying it is sociologically true that many people 'live with dying' for long periods of their life and therefore have a day-to-day experience of 'managing chronic illness'. Most of these people, for most of their time, are not looking for or engaging in end-of-life care.

From these above examples we can see that people may or may not see themselves (and their needs) as dying people whatever their illness (e.g., cancer), or location (e.g., nursing home), or circumstance (e.g., trapped in a mine), or intention (e.g., suicide). Furthermore, much dying in the UK is sudden, for example, in work, hunting, or traffic accidents, homicides, drownings, and in catastrophic medical events such as cardiac arrests and aneurisms, strokes, or drug overdoses for examples. For most of these examples of dying, palliative care is not a suitable response because few of these conform or able to fit the social requirements of a good death. But these variations to dying populations do not end even here.

There are other forms of dying that go beyond even these above diverse expectations and attitudes. Two further examples may be described as (1) people in 'endangerment' and; (2) those who consciously anticipate but resist having a drawn out dying at all. Endangerment is often identified with people who experience life-threatening risks where death is a significant likelihood. The common stereotype of these populations includes risk-taking sports such as climbers and racers, or bomb disposal workers. Other more common examples include refugees and the homeless (Walter, 2020).

However, far more common examples of endangerment exist in our hospitals as patients in coma, persistent vegetative states, or brain death (Owen et al. 2006; Veatch, 2005). Other examples can be found among the variable levels of awareness of dying associated with states of advanced dementia, or the cultural sanctions against open awareness in African and Asian populations of the terminally ill (Ayane and Kadimo, 2020; Liao et al. 2020)). In all these examples, people exist in states of in-between-ness. They are in significant danger of death and 'dying' and yet from moment-to-moment some may safely return, recover, or shun the risk. These populations lie in an ambiguous, perhaps liminal position in relation to death, and therefore the model of care at the end of their life – should it come suddenly – is not appropriately palliative care.

A final example comes from those who may face and accept death (for whatever reason) but eschew a conscious dying. Typical examples of this approach to the encounter with death are premeditated suicides and those who seek euthanasia or assisted dying (Richard and Krawcyzk, 2021). Healthcare is not required in the first example and is only required as a single episode intervention in the second.

In summary then, it is not the public health pattern of death alone which permits us to evaluate the efficacy and appropriateness of our end-of-life care policies but rather the living identity politics within the experience of dying. When we examine this pattern of identity formation and expression at a national level, we observe a diverse range of awareness of dying, a diverse range of circumstances that restrict or eschew preparation and companionship, and a diverse range of motivations, attitudes, needs, and anticipations toward death. So, although many people may look forward to a good death (in

the sense of *kalos thanatos*) a great many more – most people in fact – will have to settle for 'doing dying' the best way they can. In other words, they will mostly try to die well (in the sense of *eu thanatos*), steered by their own values or constrained by their end-of-life circumstances, or both.

These patterns suggest that the social origins and personal sources for a contemporary art of dying are more numerous and diverse than our palliative and end-of-life care policies currently address. The palliative care policy vision of the 'good death' not only falls well short of addressing this biological and social diversity it also often fails to even acknowledge it. These diverse populations are overlooked and often denied end-of-life care policies that are inclusive of their needs. This denial strikes at the heart of any fair and inclusive policymaking process, but more seriously, is antithetical to any fair minded, inclusive democracy.

To die well in a democracy

We often link the idea of democracy to citizenship, and from there focus on access to social opportunities (economic and cultural resources) and political participation (access to power and decision-making). The early academic and policy narratives on these two topics have sought to highlight the plight, disadvantage, or exclusion of traditional social positions such as gender, class, race/ethnicity, or age for examples. To these we have recently added categories of social experience as additional social determinants of exclusion: mental health, sexual orientation, immigration status, disability, and so on.

The principle being advocated (and assumed) in these cases and more, is the core democratic ideal that 'all those effected by a decision should have the right to participate in making that decision, either directly or through chosen representatives' (Arthur Lewis quoted in Lata, 2016). This is sometimes described as the inclusive character of democratic systems with 'inclusion' here being political code for participation, equality, social justice, and recognition (Zilla, 2022). Open and inclusive democracies are linked to prosperity and resilience and are therefore viewed as both positive and desirable in advanced democracies (OECD, 2020).

In this context, dying is an overlooked and under-recognized social determinant of exclusion. The privileged (and dominant) social group in end-of-life care are those who live with a life-limiting illness that will likely end their lives in the next 12 months, who are aware of this prospect, and who wish to avail themselves of the social, psychological and medical care offered by hospice and palliative care. This good death is the resource they wish to access, and palliative care is keen and committed to provide it.

However, as we have seen in the earlier review of dying, there are a good many other dying people. To recap only three examples with significant populations: there are people with life-limiting illness who deny their short-life expectancy because they choose to view themselves as chronic illness managers, seekers of cure, simply 'old', or wish merely to get on with life and continue 'the fight'. Palliative care is 'giving up'. They desire another form of support and care. There are other people who know they may be dying very soon but simply refuse the prospect of dependency in care facilities such as hospices or nursing homes, or don't wish to receive care that will moderate

the severity of their illness because they don't wish to encounter that severity at all. These too desire another form of support and care.

There are yet others who will become dying people quite suddenly and who would seek a quick source of support and advice, but they are about to enter intensive care, be caught up in an unfolding disaster situation, or are homeless and old and sick, and palliative care is either inappropriate, unconnected, or unwanted. They too desire another form of support and care.

For those unwilling, undesirous, or ineligible for a good death, dying as best as you can – i.e., dying well – is the only hope. But unlike those who aspire to a good death, current palliative and end-of-life care policies exclude populations looking to die well in any other way. Good death for the willing and eligible is easier to stage. Open awareness, long dying, and compliance make this kind of dependency eminently serviceable. *Withdraw just one of these characteristics*, and planning and delivery of a service becomes inadequate, unlikely, or inappropriate.

Lack of participation from this diverse range of dying populations must also be viewed as a barrier to policy understandings of end-of-life care but this is compounded and reinforced by a lack of acknowledgement of the social differences in dying in the first instance. This barrier is not helped by offering opposition and dissent when some groups publicly express a desire for alternative forms of end-of-life care that marginalize palliative care (e.g., assisted dying lobbies). Without an inclusive democratic approach, conflict is inevitable.

There are two recurrent problems that stem from being non-inclusive when developing palliative and end-of-life care policies. The first is the practical problem of consistently creating policy boards that do not include the people who will be affected by these decisions. The second is the ideological problem of creating marginalisation processes that view different end-of-life care models as competition and threats to resource acquisition. Consequently, if the dominant healthcare groups consistently maintain their presence by ignoring or dismissing dissenting and marginalized groups then the claims of these smaller groups will be overruled (Gherghina, Mokre &Miscoiu 2021). We have seen this repeatedly in gender and race politics.

It is crucial to be inclusive at recruitment, deliberation, and output/outcomes stages of the policy making process. There are many arguments for an inclusive approach to democratic processes including policy making. Some of these approaches emphasize institutional design (representative composition of parties and organisations), culture wars against elitist norms (critique, dissent, and counter-cultural claims), and equality and redistributive approaches to background and conditions (affirmative actions). However, disaggregating of organisational membership/composition and the idea of presence/voice are two of the key devices for inclusive practices most agree upon (Garcia- Espin, 2025).

In a national end-of-life context then, a commitment to an inclusive democratic path to future policy and planning reveal only two choices for the future. Regrettably, none of these choices seem currently in evidence. The first choice is for future commissions and policy committees in palliative and end-of-life care to accommodate a diverse array of membership beyond those committed to that singular vision of a good death for all British citizens. This will mean inviting the widest possible accommodation of those

whose end-of-life needs are not currently considered. This would necessarily include the assisted dying lobby, intensive care interests, public health interests, those representing marginalized groups such as prisoners, the homeless, and those with humanitarian and disaster experience. Such inclusive disaggregation of current policymaking bodies within palliative care circles would necessarily mean an inevitable shift from a one-size-fits-all policy to one reflecting a diverse vision for the end of life.

This first choice seems unlikely given hospice and palliative care roots in Chistian traditions and values. Furthermore, the recent record of dismissal and conflict over the topic of assisted dying does not bode well for future collaborations or cooperation with other end-of-life groups advocating different choices from those currently offered by hospice and palliative care. This lends greater possibility to the second choice for end-of-life policymaking in the UK.

This second choice would see hospice and palliative care viewed as a social movement and health service with a vested interest in one choice at the end-of-life. Political (and healthcare) recognition of this vested interest would mean that to develop an inclusive democratic vision of care for British people at the end-of-life a policymaking agency should be assembled that reflects the pluralism of contemporary dying in the UK today. Only with an inclusive gaze toward the art of dying will we develop an equally inclusive approach to its care. This option would logically lead to decentring the (now dominant) palliative care policy voice in favour of a more representative end-of-life care one.

In other words, end-of-life care policy would be driven by a national authority, such as the National Health Service, Department of Health and Social Care, or a similar authority. This agency would be responsible for assembling the main representative groups currently supporting Britons at the end of life. In turn, a federation of these groups would develop policies and strategies together for all types of end-of-life care. Just as there are numerous discreet services and products offered at the beginning of life – from contraception, abortion, IVF, and family planning, to adoption, fostering, and parent education – the end-of-life will inevitably see a similar proliferation of services and supports.

There is now, more than ever, a growing need to develop policies on quality, access, regulation, co-ordination, and education about these different end-of-life care offerings. In this second policy scenario, palliative care would simply become one player among others, requesting its own resources to service their own client population. Palliative care would not be the lead service and policymaker as it now currently positions itself.

However, both policy choices will necessarily require that all players in the health and social care fields recognize their own biases and interests both contemporary and in historical legacies. These biases and interests may be derived from religious organisations and ideologies, businesses, or political elites within a particular health service tradition, for examples. This is sometimes described as the political economy of health (Doyal, 1991; Hart, 2010). Political, ideological, and financial benefits can accrue to these less obvious, background interests if certain policy outcomes are realised in their favour. Often, these interests can drive strategies behind the arguments and evidence about the apparent needs of the client populations that they publicly serve.

Historically, for example, most democracies recognize the importance and value of a separation of State and religion. However, this separation has been an easier task in theory

than in practice. Religious ideologies and organisations have commonly and regularly opposed decisions, arguments, or appeals for outcomes made on public health (risk and safety), humanist (rationalist), legal (human rights), or scientific (evidence-based) grounds. Examples of this specific influence are replete in the history of policymaking in the drug and alcohol field, abortion, contraception, and family planning, literary, educational, and cultural production, as well as most recently in end-of-life care.

In this cloaked policy context then, ideological influencers and stakeholders can benefit by helping set strategic agendas in the end-of-life care marketplace of competing ideas – many of which might threaten, impede, or diminish their own power and influence. To help mitigate against these influences we can employ the sociology, epidemiology, and politics of dying as a guide to accountability, as we have done in the present review. These maps of social diversity in dying experience will cast a revealing light on what coverage is being privileged and what coverage is being denied or marginalized in our future care policies for the end of life.

Only by maintaining a steady gaze on these maps of human experience shall we be alerted to the vested interests who would distort or reduce our encounter with mortality to a narrow handful of outcomes. This methodological comment is no passing observation but rather a crucial tool of policy evaluation, particularly at a national level. Now, as ever in the past, it is valuable to remind ourselves of the axiom that secular freedoms and human rights–as with democracy itself–are won or lost on a daily basis, and not just at the ballot box.

Summary and conclusion

In this essay, I have offered a critical sociological analysis of the mismatch between contemporary experiences of dying with current palliative care policies. The privileging of long dying accompanied by awareness and a desire for healthcare ministrations is a major form of life at the end-of-life, but it is only one path among many. Current policies with a vested interest in servicing this form of dying view any diversity in dying as competition or threat. This leads to an undemocratic tendency to exclude other forms of dying from the policy gaze, and logically, other models of care and support. In this context, different personal experiences at the end of life are a significant social determinant of exclusion.

Fifteenth century Europe saw a published practical guide to dying entitled *Ars Moriendi* – meaning the art of dying (Aries, 1981). This was a guide to help people to achieve a good death – one that provided a blueprint on how to navigate the physical and spiritual ravages and temptations of the final days of life before surrendering to divine judgement. Such a guide, intended for the aristocracy and middle classes, emerged from a time when life expectancy and dying were brutally short, and God and the afterlife were self-evident. Not so today.

Modernity has transformed dying, making it vastly different – diverse in length, in the range of possible causes, in the range of socio-economic backgrounds, in fluctuations of personal awareness, and in the ascribed significance of death itself. Individualism, gentrification, secularization, and internationalisation have fragmented public cosmologies and personal value systems. Nowadays, the art of dying is no longer the singular cultural

project that it was but rather a personal one continually born from the mixed character of modernity and democracy. Any future development in end-of-life care policy must now respond–and be accountable to–these new constituencies of diverse populations meeting their end. For contemporary Britain, this will mean looking afresh at the art of dying in a democratic society.

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Addendum

The writing of this report did not use AI. AI was used solely to generate the diagrams in the report.