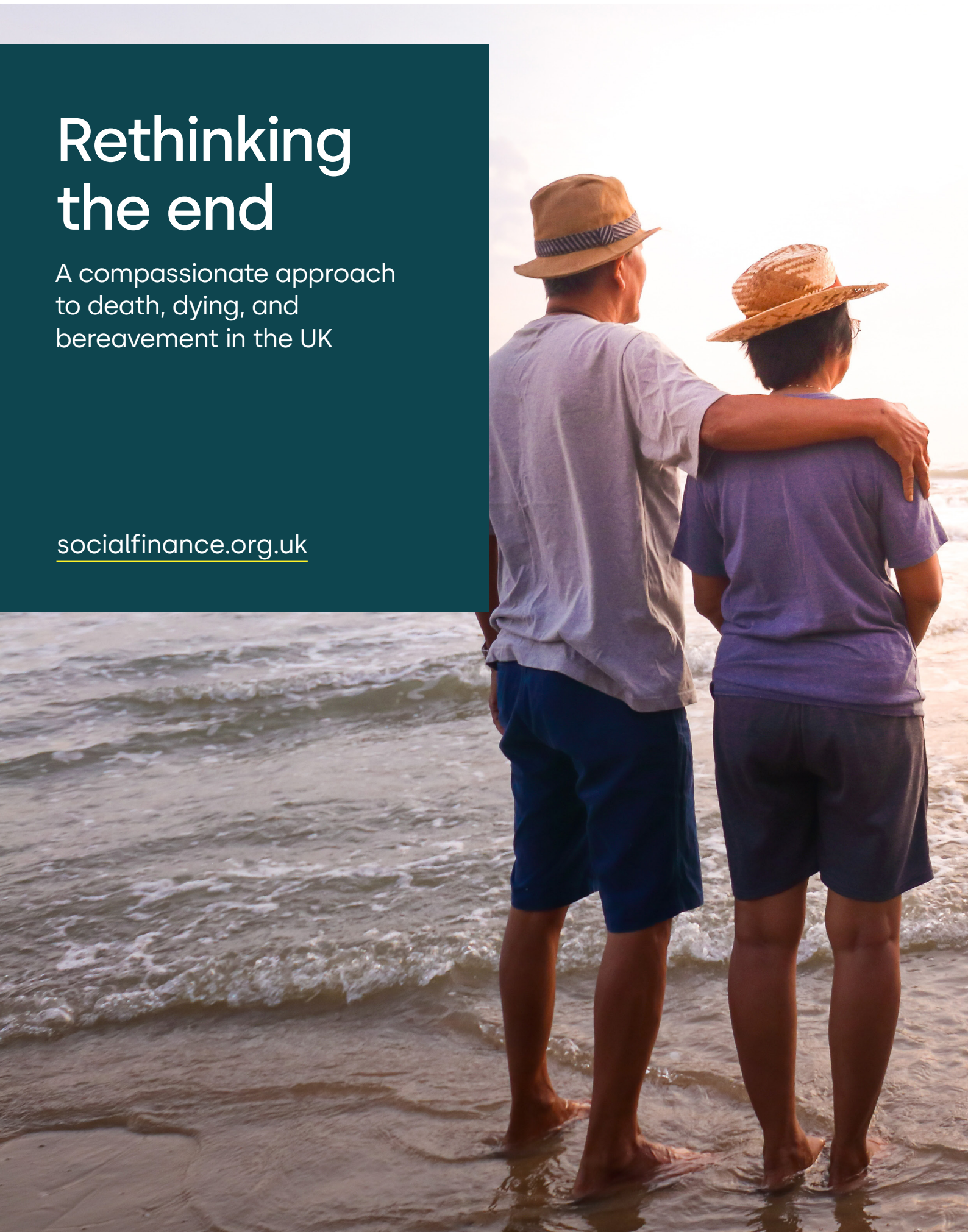


Rethinking the end

A compassionate approach
to death, dying, and
bereavement in the UK

socialfinance.org.uk



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Introduction

This report provides a comprehensive overview of our work at Social Finance around how we can transform society's attitude towards death, dying and bereavement.

Our work has been informed by the ideas raised in the Lancet [Commission on the Value of Death](#), as well as our work on improving end of life care services across the UK.

In this report, we explain why we believe there is a need for change, what such change might look like and what is already being done to bring about such change. We take a deep dive into five different organisations and initiatives, each of which have emerged to address unmet need identified in the current provision for people experiencing death, dying and bereavement. Some provide direct support for those dying, some offer support for those left behind, and others are seeking to shift the wider narrative in society. Nonetheless, they all have a vision for something better.

We hope this report provides a compelling case for change and inspires other new voices who have a desire to make a change for those experiencing death, dying and bereavement. We would welcome any thoughts, reflections or feedback you may have on the ideas discussed in this report. Please get in touch with us at endoflifecare@socialfinance.org.uk.



“ We hope this report provides a compelling case for change and inspires other new voices who have a desire to make a change for those experiencing death, dying and bereavement. **”**

Social Finance is a not-for-profit enterprise that helps organisations and communities deliver pioneering and sustainable solutions to some of society's toughest challenges. We partner with statutory organisations, the social sector and funders to tackle these challenges both in the UK and internationally. Our Health and Social Care team seeks to challenge the status quo by co-designing and testing new investment responses to unmet need in health and social care. We focus on improving outcomes for those at end of life and for those living with dementia.

Rethinking the end

Death is a natural process and a universal human experience. Yet how we understand death, and how we die, has changed remarkably over the past few decades. Death and dying are now predominantly medical events. The customs and traditions that, in the past, prepared us to cope with death have become less common.

Advances in medical science have fuelled an over reliance on medical treatment at the end of life. Not only is this expensive, it also means nearly half of all deaths in the UK now occur in hospital, despite patients overwhelmingly expressing a desire to die at home¹. Avoiding difficult conversations about death deprives individuals and their families the chance to plan, emotionally and practically, for end of life.

In 2022, the Lancet launched a commission called [Value of Death: bringing death back into life](#). It is a global and interdisciplinary exploration of death, dying and grieving. The authors argue that death holds significant value, much of which has been forgotten in today's world; death "allows new ideas... and reminds us of our fragility and sameness"². Rediscovering this value will help us improve

care for those at the end of life and enrich our experience of living.

Social Finance became interested in this area through our work on social investment in end of life care. We have seen how responsibility for preparing individuals and their loved ones for death often falls upon the healthcare system. Holistic approaches to caring that focus on improving wellbeing at the end of life are often missing. Transforming our attitudes towards death necessitates radical systems change, involving interconnected socio-economic, cultural, religious, and political factors that all influence how we perceive, experience, and manage death and bereavement.

Since April 2022, we have been working with Libby Sallnow,

co-commissioner of the Lancet Commission on the Value of Death, and Heather Richardson, Education, Research and End of Life Policy Lead at St Christopher's Hospice, to understand how we can bring about such change in the UK. Over the past three months, we have furthered this work with the support of the Q Foundation.

Under this radical new system, death and dying would be considered part of life and recognised as everyone's business. Families and communities would be the main enablers at end of life, with healthcare playing a supportive role. End of life care services would be co-designed by social, community, and health services to enable people to die well in accordance with their individual preferences. Unpaid carers would access the



In the past few decades, medical science has rendered obsolete centuries of experience, tradition, and language about our mortality, and created a new difficulty for mankind: how to die.

Atul Gawande, surgeon and public health researcher



support they need, and bereavement services would be commonplace.

Advance care planning and widespread death literacy would ensure people feel prepared to face death and the necessary administration that must be navigated following death.

In July 2023, we held a roundtable called The Value of Death at St Christopher's Hospice, London. We brought together a wide range of individuals from both within and beyond the conventional realm of end of life care services, including clinicians, experts in community networks, individuals challenging attitudes and approaches to end of life, and bereavement services.

Several key themes emerged from the initial roundtable discussions:

- Attracting funding for abstract ideas is difficult but necessary. Building an evidence base and making the most of opportunistic moments is essential.
- Connecting unconnected actors through place-based networks or anchor organisations will facilitate co-production, experimentation and shared learning.
- Policy change is required to prioritise end of life and bereavement services and encourage a shift towards more holistic care.
- All actors were keen that death became everyone's business.

We brought this learning to a webinar which we held with the Q Foundation in September 2023. We heard from a wide range of individuals about how they perceive we might start to shift the narrative and do things differently.

We have engaged with organisations from outside the traditional health and social care remit, in recognition that death, dying and bereavement are not purely medical issues, and that the needs of the dying and bereaved cannot solely be met by the health and social care system.

We recognise that there are many exciting initiatives across the world, but in this report, we have focused on the UK landscape. The aim is to inspire other new voices who have a desire to make a change for those experiencing death, dying and bereavement. This report seeks to demonstrate that there are many routes available to facilitate change and scale impact, so that death, dying, and bereavement become everybody's business.

Case study 1:

Untangle

The logo for Untangle, featuring the word "untangle" in a lowercase, sans-serif font. The text is dark blue and is set against a solid orange rectangular background.

An app that supports people through the emotional and logistical challenges that come with a bereavement

The story

When Emily Cummin, founder of [Untangle](#), lost her grandad, she found the subsequent admin confusing and complex, and bereavement support hard to access. Emily found resources were generic and poorly joined up, meaning she spent a lot of time researching what to do and who to go to, instead of grieving. It takes on average about 18 months, or 480 hours, to administer an estate and conduct the necessary practical tasks after a death. This can also cost around £21,000, adding a financial burden to an emotionally difficult time³. As a result, around 10% of bereaved people end up with prolonged grief disorder, requiring psychological intervention⁴.

Emily founded Untangle to help others navigate the extraordinary period after loss. It provides personalised content, care and coaching from peers and vetted professionals. Set up in 2020,

Untangle is a UK-based for-profit organisation with over 40,000 members from 138 countries. Untangle is available to anyone with a smartphone, and subscribers pay a monthly fee for unlimited access to its resources. Its largest markets are in the UK and the US, followed by Canada, Australia and India. By providing emotional and practical resources in one easily accessible place, Untangle aims to save time and money for those grieving, and reduce the mental health impact associated with bereavement.

Catalysts for impact

Significant unmet need

Approximately 600,000 people die each year in the UK, at least three people are affected by each death, and over 40% of those seeking formal bereavement support do not receive it⁵. There is a significant unmet need that might be addressed by Untangle.

Furthermore, Untangle provides an alternative model of support, by means of peer to peer networks, enabling growth in accordance with demand.

Unlock capital

Untangle's financial model is based on individuals choosing to self-finance their own bereavement support. This represents a shift away from reliance on statutory services where they cannot meet demand or cater to individual preferences.

Design for mass reach

App-based support aligns with the current climate in which we increasingly rely on technology to assist us in many aspects of our lives. The app is simple to navigate, can be accessed 24/7 and subscription is relatively inexpensive, making Untangle widely accessible. Future use of AI will make the mass production of customised plans easier.

Case study 1: Untangle

Harness collective effort

Untangle has brought together a range of organisations, including law firms, banks and funeral directors, under one single point of access to streamline the post-death administrative processes.

Barriers to impact

Unlock capital

Private bereavement support is a relatively new market and Untangle will need to secure additional funding to continue to grow. This market is likely more attractive to ethical investors.

Design for mass reach

Subscribers are predominantly female: middle-aged women who have lost a partner or parent. Untangle is working to appeal to and engage with more male subscribers.

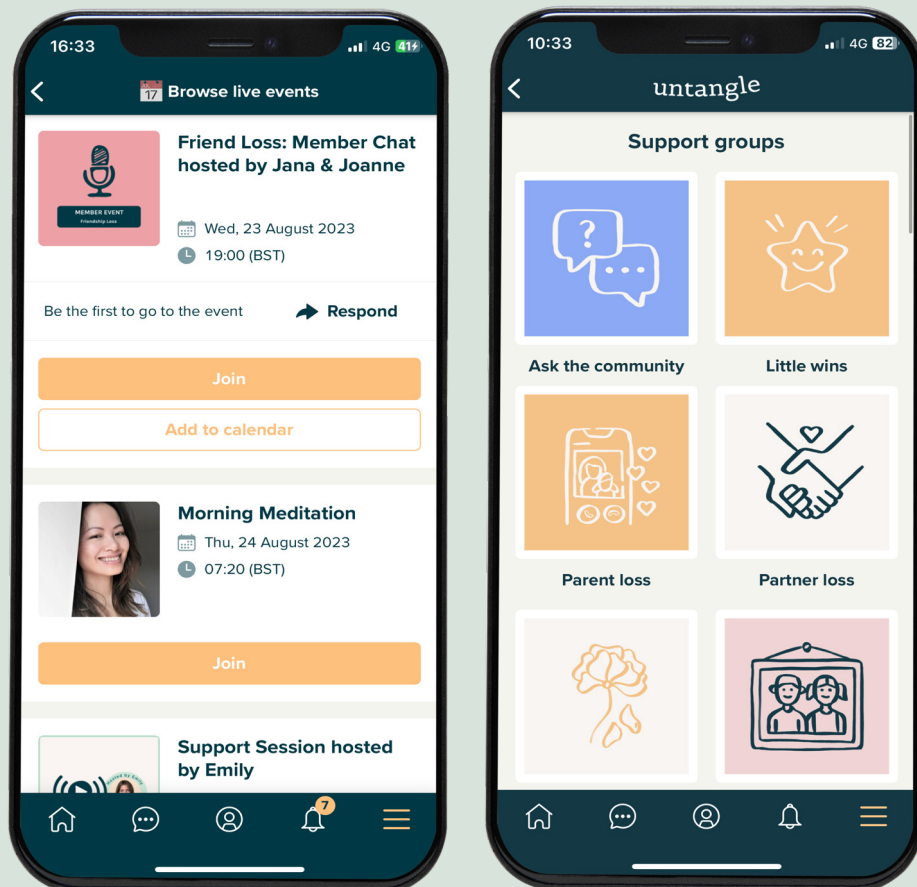
What are Untangle's future plans?

Untangle's immediate goal is to launch an employee benefits programme offering to help businesses support employees going through a bereavement. Over the next five years, Untangle will expand to other challenging life events such as divorce or medical diagnosis,

and will use AI to streamline the creation of tailored support plans and advice.

In their own words: what would Untangle like to see change?

"There is a growing longevity movement trying to fight ageing and death. At the same time, most people are dying in medical settings away from home. As such, death has become a taboo – which makes it more isolating for those who are grieving. Untangle would like to see a cultural shift where we acknowledge death and talk about grief."



◀ Screenshots from the Untangle app

Case study 2:

Legacy of Lives

Free, online independent service dedicated to making funeral planning simple, easy and personal



The story

Rebecca set up [Legacy of Lives](#) following her own experience of loss. When her aunt died, Rebecca and her family were unaware of how to organise a funeral and how much it should cost. 82% of people only get one funeral quote⁶, despite prices for the same funeral differing by up to 46%⁷. They were also unsure of their aunt's wishes, having not discussed them with her before she died.

Legacy of Lives provides two tools: a funeral price comparison tool to facilitate the comparison of funeral packages and a funeral planning tool to allow people to store and share their funeral wishes. Currently it works with over 5,000 funeral directors from a wide range of religious and cultural backgrounds across the UK.

Legacy of Lives aims to protect consumers by bringing transparency to the funeral market. Independent comparison of prices and itemised costing enables customers to make informed decisions around funeral planning. Legacy of Lives also aims to reduce reliance on loans to finance funerals by helping customers plan in accordance with their budget. Alongside this work, Legacy of Lives works to encourage a cultural shift towards more open dialogue around death, dying and planning for end of life.

Catalysts for impact

Shape sector practice

Legacy of Lives' comparison tool has levelled the playing field for independent funeral directors against the largest providers. The online comparison tool

provides a cost-effective means for funeral providers to reach new customers and promote their services without the need for significant investment in bespoke websites and digital marketing. This will contribute towards ending the considerable lack of transparency around pricing in the industry.

Harness collective effort

In bringing together a large number of independent funeral providers from different backgrounds across the UK, as well as working with major end of life care charities to design and promote its services, Legacy of Lives is encouraging the sector to work together to drive greater transparency and choice for consumers. The involvement of the market leaders would enhance this.

Challenge the status quo

Legacy of Lives has partnered with two leading end of life care charities, Hospice UK and Marie Curie. They receive a donation for every funeral planned through its service. These funds are invested in improving care in the sector and to carry out community advocacy work to encourage more open conversation and discussion around death and end of life care planning.

Attract media spotlight

Partnerships with major end of life care charities and significant engagement with mainstream media enable Legacy of Lives to publicise the choice available when organising a funeral. It also encourages the media and media personalities to engage in conversations around death and end of life planning, a key lever to shift the conversation around death and dying.

Barriers to impact

Design for mass reach

The majority of current consumers are over the age of 55. Through its work with end of life care charities and the media, Legacy of Lives hopes to encourage younger customers to engage both with its services and the wider conversation around death, dying and bereavement.

Unlock capital

Attracting sustainable, ethical funding is key to supporting the continued growth of Legacy of Lives. Though there is opportunity through certain funds, Legacy of Lives is keen to provide an ethical finance support to ensure that profit is not the sole driver of growth.

Improve regulation and standards

Current legal restrictions prevent funeral providers from marketing their services in hospitals, hospices, and care homes to protect consumer choice. Legacy of Lives is hoping to become FCA regulated so that it can advertise the choices available when planning a funeral.

What are Legacy of Lives' future plans?

Legacy of Lives is in the process of establishing partnerships with the UK's largest funeral providers, Cooperative Funeralcare and Dignity, who account for 30% of the market⁸. Incorporating these providers into the comparison tool would significantly enhance market representation. Over the long term, Legacy of Lives hopes to support those with limited finance to save for funerals through an ethical money market fund and to establish its own pre-paid funeral plan scheme.

In their own words: what would Legacy of Lives like to see change?

"Legacy of Lives would like to see more supportive policy to promote death literacy in schools. This would be a positive step towards instigating more open conversations about death, dying and bereavement. Legacy of Lives would also like to see the process of death registration digitised to enhance efficiency."

Case study 3:

Ending Life's Taboo

Rapid counselling for young adults who have received a terminal diagnosis



The story

Tracy witnessed firsthand the fear, denial, and isolation her son experienced as he was dying. He was put on a waiting list to access counselling but died before he could access it. Seeing him struggle emotionally at the end of his life was hugely difficult for his family. Reflecting on her son's experience, Tracy set up [Ending Life's Taboo](#) to provide young people with someone to turn to following a terminal diagnosis.

Ending Life's Taboo offers rapid access to professional counselling for people aged 18-45 who have received a terminal diagnosis. It aims to improve quality of life by helping young people process the emotional pain experienced at end of life. Counselling can be given as an inpatient, outpatient, at home or online and the rapid access approach means support is available quickly as and when it is needed.

Ending Life's Taboo currently operates at Colchester Hospital and Ipswich Hospital and typically supports 13-15 people referred from each hospital at any one time. Patients can be referred to its services from hospital, a GP or by self-referral. When a patient does not wish to engage, Ending Life's Taboo works with relatives so they feel better able to support the young person and are better prepared for their death. Ending Life's Taboo also works with clinical staff to better prepare them for

conversations with patients and relatives around end of life and works in the community to encourage more open conversations about death and dying.

Catalysts for impact

Build the evidence base

Ending Life's Taboo has established a new service that caters to a clear gap in unmet need. There are currently no other organisations providing



Tracy, second from right, with her son Ross, second from left.

Case study 3: Ending Life's Taboo

rapid access to counselling for terminally ill young people in the area. After demonstrating service demand and impact initially at Colchester Hospital, Ipswich Hospital has also commissioned the service and Colchester Hospital has extended its service hours.

Adaptability

The service model is flexible and adaptable. Counselling can be delivered in different ways and flexed to individual preferences enabling service expansion to areas with different healthcare settings. This could look like greater use of telephone or online counselling or alternative referral routes for example. The service model is led by the individual with no constraints on frequency or number of sessions. Once a service user has been referred, then no re-referral to access counselling is necessary.

Harness collective effort

Ending Life's Taboo has strong links with other services, particularly hospices and charities, throughout East Suffolk

and North East Essex. This enables it to pull in staff who are already professionally trained and facilitates caseload triage between organisations to ensure individuals access the appropriate service. Partnerships with organisations who have strong links into the community are key to facilitating Ending Life's Taboo's work to break the taboo around death and dying.

Barriers to impact

Unlock capital

Ending Life's Taboo operates as a charity with funding predominantly from fundraising and small grants. Future expansion of service provision will require increased funding to support additional counsellors and administrative functions. Continuing to demonstrate impact to potential commissioners and donors will be key to secure sustainable funding going forward.

Design for mass reach

Ending Life's Taboo has not seen any clear commonalities

amongst individuals accessing its services, but is starting to link in with different faith groups as well as LGBTQI+ groups to understand any barriers they may face in accessing its services.

What are Ending Life's Taboo future plans?

Often young people receive treatment in London and so are missed by the main referral routes from Colchester and Ipswich Hospitals. Over the next year, Ending Life's Taboo will look to establish better connections with local GPs so more individuals can access counselling near to their home. Over the long term, Ending Life's Taboo wants to expand service provision beyond East Suffolk and North East Essex.

In their own words: what would Ending Life's Taboo like to see change?

"Ending Life's Taboo would like to see greater importance placed on mental health care of those living with a terminal illness. The period from terminal diagnosis to death is crucial in supporting someone to come to terms with their mortality and to lessen fear surrounding death. Prioritising the mental health of the individual can lessen complicated grief for their loved ones. We would also like to see greater importance placed on accepting when medical interventions are prolonging death and not prolonging life. Supportive policy in these areas would encourage prioritisation of mental health in end of life care."



Ending Life's Taboo counsellor with a young person.

Case study 4:

Care in Funerals Project



Open access online casebook to support reflection and discussion around what matters about funerals

The story

During the Covid-19 pandemic, academics at the University of Aberdeen held a series of online conversations to share insights into what was going on and explore how collaborative research might help. One conversation led to the formation of a multidisciplinary group of researchers who were interested in the impact of Covid-19 on funerals. They wanted to investigate people's experiences of disruption to death rites and ceremonies during the pandemic, and the adaptations made, to help understand what matters to people about funeral provision today. Their research involved interviews with people who had been bereaved, funeral directors and officiants, secular and religious from across the UK. They interviewed people of different genders, ages, and religious and ethnic backgrounds.

Out of this research, amongst several academic papers, the Care in Funerals Project Team has produced an [open access online casebook](#) which contains 12 case stories that illustrate some practical and ethical concerns that can arise in funeral provision. Each is accompanied by questions and commentaries to support reflection and discussion. This work aims to support the professional development of funeral directors, officiants and policy makers as well as encourage broader conversations about the practical and ethical aspects of funeral provision.

Catalysts for impact

Build the evidence base

This case book encourages multiple actors (including policy makers, people involved in funeral service provision, and

bereaved families) to reflect on what a "good" funeral looks like for different people. The examples and commentaries illustrate both the need to ensure quality funeral provision and the diversity of what can matter for a "good", meaningful funeral. Shortfalls in funeral provision can cause significant distress for the bereaved. The research confirms the need to prioritise safe fulfilment of diverse funeral needs in future emergency planning.

Shape sector practice

The case studies encourage those involved in funeral provision, as well as policy makers, to reflect on different ethical issues and the diversity of experiences and perceptions of death and bereavement. This could facilitate more sensitive funeral organisation and planning that takes into consideration individuals' and communities' values and circumstances.

Mobilise a shared voice

Academic bodies offer a unique way to mobilise a shared voice across different disciplines. The academics started this project organically, bringing expertise from diverse perspectives together as they reflected on the shift in funerals during the pandemic and identified and considered the practical ethics of funeral provision. Though the Care in Funerals project is focused on those engaged with death in the UK today, it sparked conversations about how death is reflected on in wider academic work and has led to wider interest in the value of death across a spectrum of situations.

Barriers to impact

Consistent funding

The pursuit of further research requires funding, which will involve competition with other issue areas. Making the case that death studies are an important avenue of research is essential. Garnering the interest of professional organisations, including those associated with funeral provision, but also archaeology, museum work and others, is key. The importance of the issue also needs to be stressed to research councils and philanthropic funders.

Attracting media spotlight

Finding effective ways to publicise and disseminate the casebook is necessary to ensure relevant actors can benefit from it. The team needs to work to identify effective dissemination avenues.

What are the Care in Funerals Project's future plans?

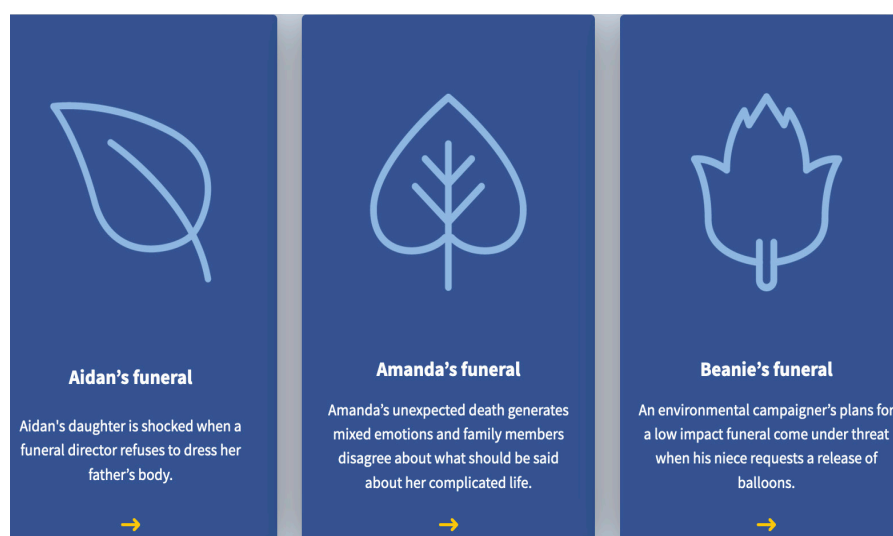
The Care in Funerals Project has ended, but the team is looking to develop further interdisciplinary research around death studies and the ethical issues associated with death. They are currently planning several projects, but continued work is dependent on securing funding. In May 2023, one member of the Team was awarded a research fellowship by the Leverhulme Trust to explore 'grave goods'; what people put in their coffins and why, and what are the implications, for example for the environment and future archaeological work.

In their own words: what would the Care in Funerals Project like to see change?

Vikki Entwistle, lead investigator for the Care in Funerals Project:

"I would like to see it become much easier for people to access funerals that are meaningfully respectful of the person who died and supportive of those left behind. This would involve, among other things, tackling poverty and improving the financial safety net around funeral provision for those with limited resources, and ensuring that diverse religious and cultural traditions are more readily accommodated at the point of funeral need. To support the latter, community and public conversations that consider diverse perspectives on death and funeral provision could be useful, and we need to consider how well death literacy is promoted in various educational curricula."

▼ Snapshot of the online casebook



Case study 5:



The Child Bereavement Network's Grief Education Initiative

A campaign to integrate death and bereavement literacy into the statutory curriculum across the UK

The story

The [Childhood Bereavement Network](#) (CBN) has long advocated for the statutory provision of grief education in the curriculum. With at least one child per class bereaved of a parent or sibling, and three quarters of 11 – 16 year olds bereaved of someone close to them, grief education is a necessary topic in schools and other educational settings. Grief education equips children with knowledge about death, loss and bereavement, normalising conversations around death, preparing them for lifelong experiences of change and loss, and promoting compassion for others. A recent confluence of initiatives, the Covid-19 pandemic and an upcoming curriculum review in England

have provided a unique window of opportunity.

The restrictions in place during the Covid-19 pandemic disrupted usual rituals around death, 'saying goodbye' and grieving. Along with a substantial increase in bereavements, the circumstances spotlighted the need for a more compassionate response and a full review of the bereavement experience in the UK. The independent [UK Commission on Bereavement](#) (UKCB) heard from children, young people, adults and over 130 organisations, subsequently publishing 27 recommendations in October 2022, including:

'All schools and other education settings must be required to provide age-appropriate opportunities for children and young people to learn about



I knew my teachers all knew, but no-one spoke to me about the fact they knew, so it felt like an unspoken secret?

Young person, aged 13-15 .



coping with death and bereavement as part of life’.

In England, a key opportunity to introduce grief education lies in the relationship, sex and health education (RSHE) curriculum. For many years, CBN advocated for the inclusion of coping with grief and loss in this and the wider curriculum, without success. With the news that a review of the RSHE curriculum would take place by the end of 2023, CBN saw a key opportunity to implement the UKCB recommendation. More broadly, it felt timely to bring together the rich range of initiatives and resources across the country into a powerful joint campaign.

Alongside this work, CBN continues to advocate on behalf of bereaved children and young people, providing resources to families, schools and services, and supporting childhood bereavement services to deliver quality provision.

Catalysts for impact

Supportive policy

The school curriculum provides a key opportunity to introduce and teach children about death, dying and bereavement, how to recognise and manage feelings and where to turn for help. Introducing a statutory requirement to provide grief education at an appropriate level throughout all Key Stages would help equip children with a healthy understanding of death and better coping strategies. Enabling children to talk openly about death, dying and bereavement will help initiate a ripple effect to normalise

conversation around death and dying in wider society. Policies for grief education need to be carefully integrated with pastoral support for students who have experienced bereavement, in a whole school approach.

Shape sector practice

The case studies encourage those involved in funeral provision, as well as policy makers, to reflect on different ethical issues and the diversity of experiences and perceptions of death and bereavement. This could facilitate more sensitive funeral organisation and planning that takes into consideration individuals’ and communities’ values and circumstances.

Build resources and the evidence base

There is now a significant range of quality [lesson plans and training resources](#) available to educational professionals, equipping them with the tools needed to address death and grief in their school communities. The curiosity of children and young people to learn about death and positive evaluations of different death and grief literacy initiatives in Scotland and England help make the case for change and provide examples of effective interventions for adoption by other schools. Case studies show grief education can be successfully implemented and embraced by educational professionals, parents and children. They can also provide a clear avenue for more specialised support for young people when needed.

Harness collective effort

Many have been working towards a vision of a grief literate curriculum over the last few years. Recent initiatives include a [public petition](#) led by John Adams, while he was President of the National Association of Funeral Directors; a [powerful summary](#) of the arguments for inclusion led by Lesel Dawson and Rachel Hare at the University of Bristol, accompanied by a Good Grief Festival [panel discussion](#) including Michael Rosen and guests; and a growing range of resources and initiatives from organisations. CBN has realised that bringing people together to advocate for change offers better chances of success and will create new links and stronger connections across and beyond the bereavement sector.

Barriers to impact

Challenge the status quo

Statutory provision of death education would signal a commitment from policy makers to encourage more open conversation around death, dying and bereavement. CBN and others are aware that our general reluctance to talk about death, dying and bereavement may hamper the implementation of policy into practice. However, using the resources and case studies mentioned above, along with key messages, can help to shift attitudes and beliefs. Supporting teachers through teacher training, engagement with parents & acknowledgement of sensitivities within different communities will be key to successful implementation.

Design for mass reach

Even with the introduction of statutory grief education, the inherent nature of the subject and differing levels of confidence in addressing it mean that provision and support across the country will remain inconsistent. Teacher training and clear communication of expectations to teachers, for example that they are not expected to be subject experts, will be key to enhance confidence and help educational professionals to feel comfortable handling these sensitive but important conversations.

What are CBN’s future plans for its Grief Education Initiative?

CBN has identified five key audiences who will be pivotal to the successful implementation of

grief education: policy makers, teachers, future teachers, parents and carers, and children. Statutory provision is an important first step. If introduced, CBN will engage and work with the other key audiences: teachers, future teachers, and parents to ensure they can confidently engage with important conversations around death, dying and bereavement and interpret statutory guidance. Enhanced confidence should encourage greater acceptance of the need for grief education, facilitate more effective implementation of curriculum requirements and ensure more consistent provision throughout the country.

In their own words: what would the CBN like to see change?

“We know that grief education is vital and important. The experiences of bereaved children and young people highlight that their trusted adults and friends are still confused, uncomfortable and reluctant to support them at a time of critical need. Grief education would help classmates to thoughtfully support a bereaved friend. It will allow us to acknowledge and normalise the end of life, now so often hidden away in a hospital or hospice – spaces unknown or restricted to many children and young people. Finally, it will build a compassionate society, where we easily offer kind words and gestures to bereaved friends, neighbours or colleagues.”



Building routes to scale

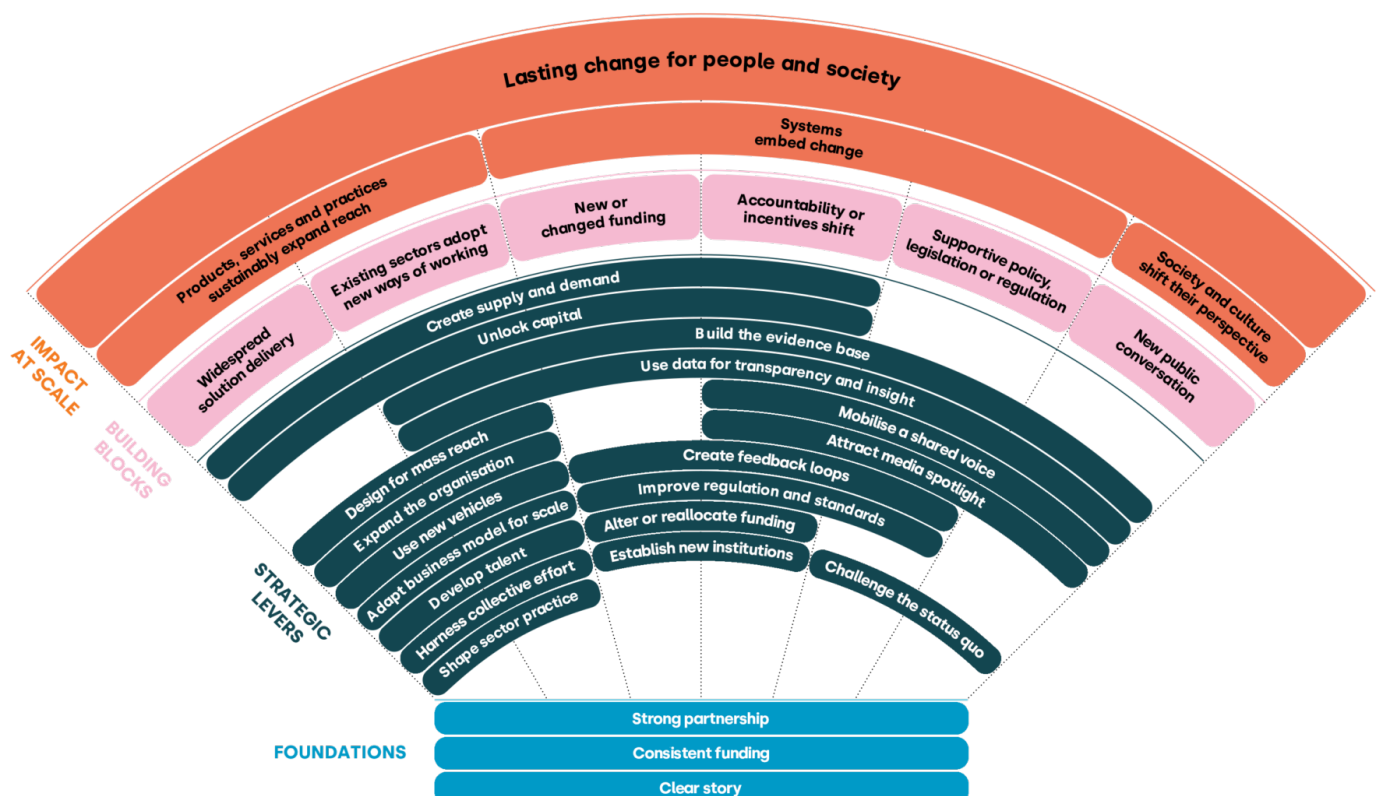
Structure of the case studies

Social Finance has extensive experience in scaling impact for long term change in many different issue areas, from reducing loneliness in older people to tackling domestic abuse.

In 2021, we launched our [routes to scale framework](#) which maps out different approaches that can be used to scale impact and generate system wide change. It outlines the key foundations, strategic levers and building blocks that are needed to underpin such work (see below):

- Impact at scale: understanding what it is and how you can tell when you get there.
- Building blocks: the milestones that help you understand whether you are heading in the right direction.
- Strategic levers: different strategies that can be used to put in place the building blocks of impact at scale.
- Foundations: the foundations on which the most effective change is built.

We have applied this framework in discussions with each of the five case studies to understand the landscape, how they operate and their ambition for scaled impact, where applicable. All five initiatives are focused on the strategic levers for change rather than the larger building blocks but we have sought to highlight the interplay between these levers to demonstrate how progress is unlikely to be made by pulling them in isolation. Strategies will often need to be used in parallel to generate impact at scale.



Comparing the case studies

The final section of the report compares the five case studies to identify their commonalities and differences.

Each case study demonstrates which key strategic levers are necessary to shift the narrative around death, dying and bereavement in society. Not one of them is a silver bullet nor are they an exhaustive list of solutions. Instead, they highlight ways in which conversations, systems and funding can be shifted to improve the experiences and outcomes for the dying, bereaved and affected communities.

Below you can see (in dark green) the nine specific strategic levers demonstrated across the five case studies to amplify the value of death.

Two levers stand out:

Build the evidence base

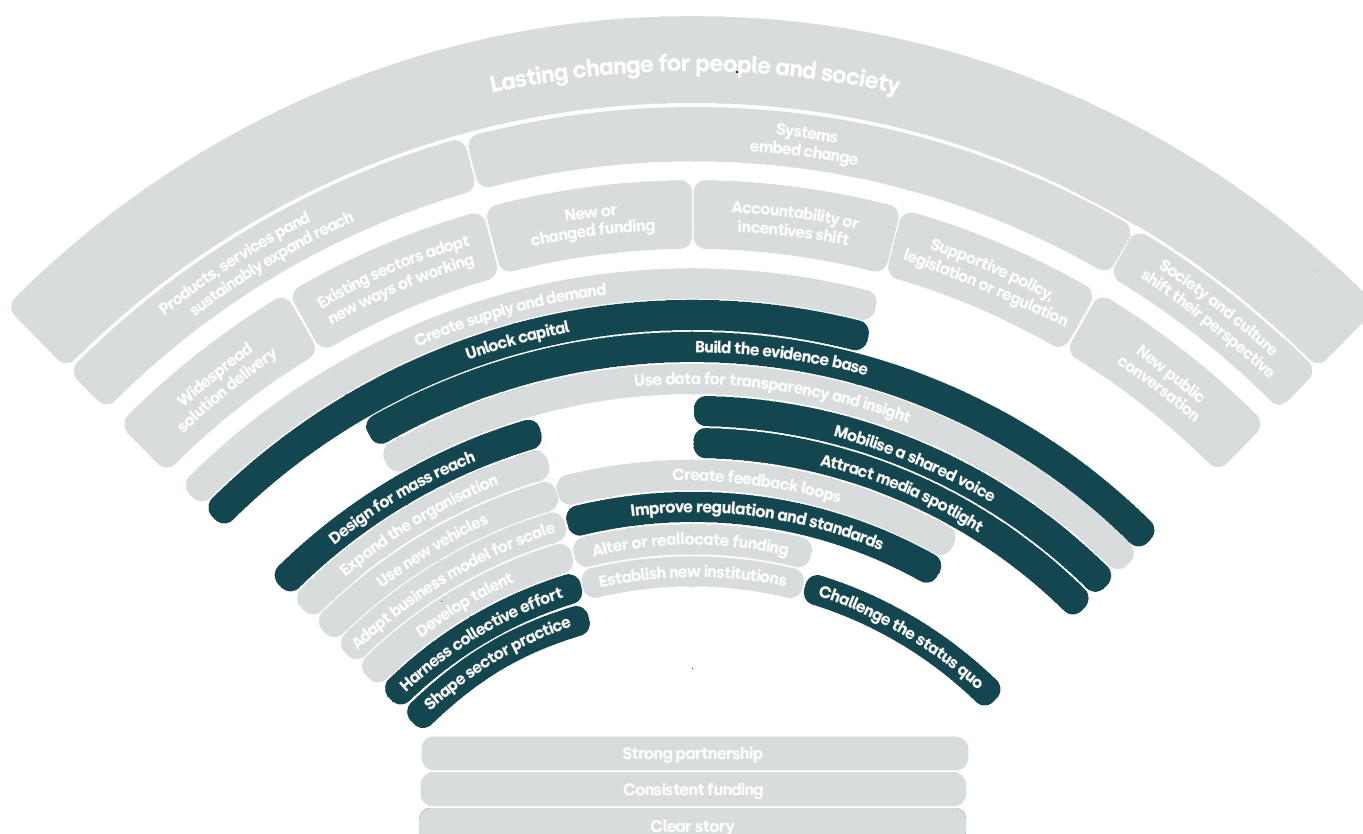
The five initiatives vary in size, but they all collect data to evidence the need for their service and evidence the impact of their intervention. Collecting evidence is important to make the case for government policy changes and influence the flow of both public and private capital towards community based, holistic support for the dying and bereaved.

Challenge the status quo

All five initiatives developed in response to an identified gap in unmet need and a desire to improve the experience for others. They operate at different scales; Ending Life's Taboo wants to improve the experience for those at end of life, whereas

Grief Education has ambition to challenge the status quo at the widest scale by encouraging all children and young people to engage with death literacy. They all operate from different positions, ranging from Ending Life's Taboo which works within the end of life care system, to the Grief Education initiative which operates outside the system.

Taking a step back, each of these case studies forms part of a wider drive for impact at scale. More effective coordination of these initiatives could be realised if anchored to one organisation. This would facilitate better cross fertilisation of ideas and impact across different initiatives.



Broader theme analysis of case studies

Plotting their zone of influence on the value of death timeline

The organisations and initiatives we spoke to are all working at different stages along what we could consider the 'death, dying and bereavement journey'. Ending Life's Taboo supports those who are facing death whilst Untangle and Legacy of Lives support those who have been bereaved. The Care in Funerals Project and Grief Education Initiative take a broader view across the journey to encourage more open conversations in society so that we are better prepared when faced with death and bereavement .

That all five organisations are working at different stages of this journey highlights the level of unmet need at all stages. It also reflects the need for a whole systems approach that includes all the different stakeholders involved in the death, dying and bereavement journey.

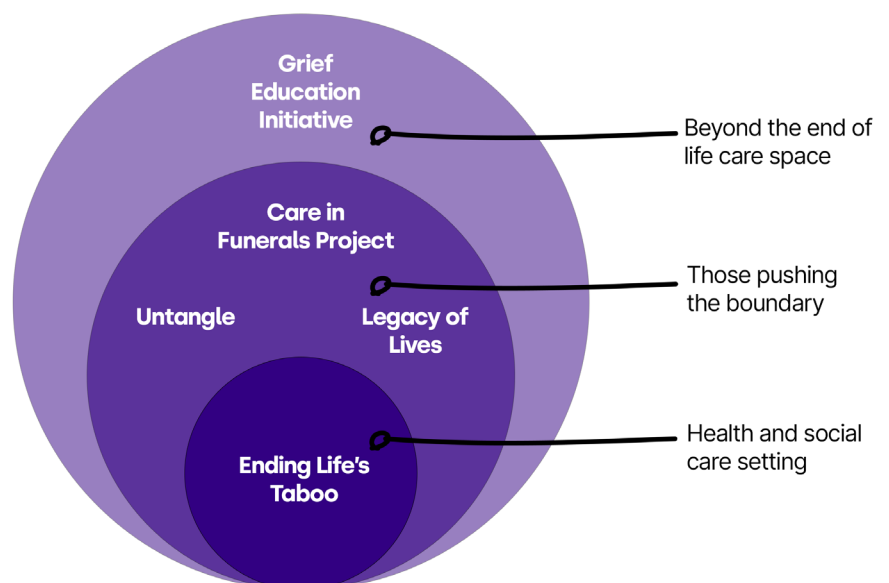
Working outside the conventional end of life care remit

End of life care and bereavement services typically sit in health and social care settings. Though Ending Life's Taboo is unique in providing rapid counselling for young people facing the end of their life, it sits in a conventional end of life care setting: a hospital.

Untangle, Legacy of Lives and the Care in Funerals Project exist

outside of the health and social care setting, however alignment to funeral services doesn't seem that unusual at first glance. They do push the boundary by providing impartial support for those planning funerals.

The Grief Education Initiative is undoubtedly acting furthest from the health and social care system by aiming to bring death literacy into schools. System change will not be realised solely by actors operating in the conventional realm of end of life



care, or even health and social care. It will require action from the many different actors that influence how we perceive, experience, and manage death, dying and bereavement.

Understanding the opportunity of extraordinary moments

The five organisations and initiatives covered in this report have all emerged in response to the extraordinary period that follows death. Ending Life's Taboo, Legacy of Lives and Untangle were all created in response to personal experience. They've sought to meet a gap in need and provide the kind of support and direction they lacked during and after the death of a loved one. The Care in Funerals Project emerged out of the Covid-19 pandemic, whilst the pandemic and an upcoming curriculum review have provided the Grief Education Initiative with a unique opportunity to push for implementation of the UKCB grief education recommendation. The Covid-19 pandemic provided a window of opportunity to advocate for change in this space, given that death, dying and bereavement were brought to the forefront of the media and people's everyday lives for the first time in a generation.

That all these initiatives have emerged out of the extraordinary period following death may reflect societal taboo around death, dying and bereavement, which are not openly discussed and addressed until we are directly confronted by them. Disruption of the status quo may be driven predominately by

passionate individuals motivated by their own experiences. Or it may be driven by latching onto extraordinary events that make death everybody's business, and therefore provide a prime opportunity to re-examine current norms.

Storytelling is central to the value of death

All five case studies draw on the power of storytelling to make a case for change. In our conversations, the Care in Funerals Project, Grief Education Initiative and Legacy of Lives all reflected on the dilemma of conveying the scale of unmet need through numbers. Case studies bring a human element to statistics which is key to engage others and foster empathy.

The importance of storytelling was pivotal for all the case studies in conveying why they started their work. In particular, the personal experiences of the founders of Ending Life's Taboo, Untangle and Legacy of Lives are a compelling tool used to highlight the gap in unmet need and consequent need for their service. Care in Funerals explicitly uses stories to help professionals and the wider public to reflect on what a "good" funeral is. The Grief Education Initiative aims to use stories to normalise talking about death and dying, for pupils and teachers and ultimately for children and parents.

Stories are key to shift the narrative around the Value of Death. Stories help to engage people; they help us to reflect and evaluate our own feeling

around death. They are also a key communications tool; the telling of powerful and relatable scenarios has often helped attract finance.

Financing the work

Work around the Value of Death does not sit neatly in a single funding stream. The five case studies draw on different funding mechanisms to support their work, reflective of the need inherent in the nature of the work across stakeholders and funding flows to enable real systems change. Untangle and Legacy of Lives have tapped into the private market, through private investment and payment for services. On the contrary, Ending Life's Taboo fundraises to support the majority of its work. Whereas organisations funded through private capital will see growth fuelled by demand, any scaling up of the services provided by Ending Life's Taboo's work will be limited to the funding it can raise, regardless of the demand for its services.

Nevertheless, these five case studies highlight the limited availability of statutory funding for innovative services. At present, statutory funding is largely limited to more conventional end of life care and bereavement services provided by the health and social care sector. Statutory funding cannot provide sufficient and sustained resource to meet the gap in unmet need. Additional capital, be it through private investment, charitable fundraising, or philanthropic funding, is required if we are to generate radical and sustainable transformation of death and dying at scale.

Summary

This report is a summary of our initial horizon scan of projects, networks and organisations pushing to elevate the value of death into new spaces. We suspect this is only the start and look forward to seeing how they develop in the future.

Social Finance is keen to ensure these discussions continue, both with the those working in a conventional health and social care setting, and those working on the outside.

This report has mapped out catalysts, barriers, and future aims of each of the case studies. We are keen that they, and others, find a space for such discussion within the Q Community to continue the work towards developing more holistic support for the dying and bereaved. The burden must not fall solely on the health and social care sector.

If you are interested in engaging with these groups and with the wider discussion, please sign up to the [Value of Death Network](#).

We hope this report has inspired people, organisations and projects to reflect on the value of death, and how your work can better support those faced with death, dying and bereavement. Death is everyone's business.

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