

### 3.5 End of Life Care and Bereavement

#### Key Points

Creative health supports people at the end of life, providing relief from symptoms and pain, improving quality of life, and providing psychological and spiritual support for the individual and their friends, family and carers. Creative health approaches are used as part of bereavement support and can help to normalise conversations around death, dying and bereavement.

With demand for end of life care increasing, a high level of unmet need, and inequalities in

access, policies and frameworks are moving towards a more personalised, integrated and community-based approach. Creative health can be a valuable resource, improving the quality of service and relieving pressure on acute services.

Creative health is also an important component of a public health approach to end of life care and bereavement, fostering community-based and social support.

#### Challenges in end of life care and bereavement

There are longstanding inequities in access to end of life care and quality of care. It has been estimated over 100,000 people that could benefit from palliative care die each year in the UK without receiving it<sup>374</sup>. Due to an ageing population and an increased number of people living with complex and multiple long term conditions, demand for palliative and end of life care is expected to rise by at least 25% by 2040<sup>375</sup>. The increased cost for hospice services alone could rise to £947m per year over the next ten years<sup>376</sup>. The majority of deaths take place in hospitals, and the majority of end of life care takes place in acute settings, which struggle to provide a 24/7 service<sup>377</sup>.

Outside of acute and hospice settings, provision of end of life care can be limited and there are inequalities in access particularly for those from deprived or minoritised communities<sup>378,379</sup>. Persistent inequalities have been observed in hospice care for people aged over 85, ethnic minorities, people with non-cancer illnesses, and people living in rural or socially deprived areas. Barriers include institutional cultures, particular cultural needs, and a lack of public awareness of available services<sup>380</sup>. Although community care at the end of life can be more cost-effective than hospital provision, and many people express a preference to remain in their own homes, adequate infrastructure and workforce capacity is currently lacking<sup>381</sup>. A large proportion of home-based care is provided by unpaid friends and family members.

Policies and frameworks including the National Palliative and End of Life Care Partnership Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026<sup>382</sup> (hereafter National Framework) and the NHS Long Term Plan emphasise the importance of personalised care and empowering patients to improve the quality of end of life care. Creative health has an important role to play in this approach.

The National Framework recognises that good end of life care must incorporate family, friends and carers and include bereavement and pre-bereavement care, and that this should also be personalised to individual needs. The UK Commission on Bereavement identified barriers to accessing formal bereavement support either through lack of knowledge of what support was available or how to access it, or because the required support was not available. This could be due to a lack of funding for statutory bereavement



*Artists have an important role to play here, because they can offer a different kind of language, a language of metaphor, perhaps a non-verbal language, a visual vocabulary, that can express something of this emotional landscape”*

*Anna Ledgard, End of Life Doula, End of Life Care and Bereavement Roundtable*



“*Creativity is a profoundly important part of what it is to be human. For many of the people we see at Pilgrims their sense of self has been stripped away by illness. They often come to us feeling like they are a diagnosis, a set of symptoms, defined by their treatment, or lack of it. Often they are unable to engage in activities that gave their life meaning and helped form their self-image. So I believe that engaging in creativity can help give them back a sense of themselves as a whole human being, that sense of agency...and hopefully a little joy”*

*Justine Robinson, Therapies and Wellbeing Manager, Pilgrims Hospice, End of Life Care and Bereavement Roundtable*

services, lack of training, lack of data on need and service provision or insufficient coordination between VCSE and statutory services<sup>383</sup>.

### **Creative health at end of life**

People nearing the end of life often experience pain, fatigue, anorexia, shortness of breath and anxiety<sup>384</sup>. Palliative care in the form of medical interventions and rehabilitative approaches can reduce symptoms. The WHO scoping review ‘*What is the evidence on the role of the arts in improving health and wellbeing?*’ cites studies that have found music and arts therapies can also help to alleviate physical symptoms and decrease pain, as well as regulating heart rate and assisting with troubled breathing. Arts participation has been linked to lower levels of fatigue<sup>385</sup>.

End of life care incorporates elements of social, psychological, and spiritual care. The APPG on Arts Health and Wellbeing inquiry report ‘*Creative Health*’ provides a wealth of evidence and examples of the ways in which creativity has been used as a means of communication, often non-verbal, to facilitate the expression of difficult emotions, to help people come to terms with their own mortality, or that of a loved one, and to find meaning amid suffering, loss and death. Creativity can provide a sense of control and self-determination. It can provide people with the tools with which to reflect

on their lives, and also provide a lasting legacy, which can provide comfort to friends, family and carers<sup>386</sup>. More recently the use of digital technologies for legacy-making has also been explored<sup>387</sup>.

According to the WHO scoping review the arts ‘provide opportunities for communication and emotional expression and facilitate a cognitive reframing of the illness experience<sup>388</sup>’. Arts engagement can enhance social interactions, fostering a sense of community within care settings and improving relationships between those at the end of life and their family members and carers. In terms of spiritual satisfaction, the arts can provide comfort and meaning. Arts therapies, in particular, have been shown to have mental health benefits for people at the end of life, resulting in lower levels of distress, sadness, anxiety and depression and improved wellbeing<sup>389</sup>. A subsequent systematic review of artist-facilitated arts engagement in palliative care also found beneficial effects including a sense of wellbeing, a newly discovered, or re-framed, sense of self, and connection with others<sup>390</sup>.

Arts and music therapies are used widely in end of life care settings, particularly hospices. According to the International Handbook of Art Therapy in Palliative and Bereavement Care, the broad aims of arts therapy in this context are to facilitate the process of adjustment for the patient following diagnosis, to promote the process of rebuilding a new or renewed sense of self, and to provide the patient and those around them with the resources to cope<sup>391</sup>.

The benefits of creativity in end of life settings are not limited to patients. A number of studies have shown that the positive impacts can also be felt by families and end of life care staff<sup>392,393</sup>.

The ‘*Creative Health*’ report sets out the importance of hospital and hospice architecture and design in relation to end of life care<sup>394</sup>. Providing space for patient-produced artworks to be displayed can also add to a sense of identity and agency. Sensory rooms have been used with people at the end of life and have been shown to improve wellbeing by enabling reflection and reconnection<sup>395</sup>, whilst therapeutic gardens and horticultural therapy are important in improving wellbeing in hospices<sup>396</sup>.

### Advance Care Planning

Advance Care Planning (ACP) allows people to communicate their wishes as part of a personalised and holistic approach to end of life. According to a co-produced set of Universal Principles for Advance Care Planning it is 'a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversation about these'<sup>397</sup>. The National Framework emphasises that although participation in advanced care planning must be voluntary, the offer should be universal. There are barriers to ACP including public understanding and awareness, patient engagement, and knowledge and competency of healthcare staff<sup>398</sup>.

Creative and arts-based approaches have been used to improve access to advance care planning in populations that face inequalities in end of life care. The No Barriers Here approach, originally developed to improve access to end of life care for people with learning disabilities, uses co-produced creative workshops to guide people through the advance care planning process and conversations about end of life, with less focus on verbal interaction<sup>399</sup>. A community-based action research project is now underway to explore its use with minority ethnic groups<sup>400</sup>. The process also incorporates training for healthcare professionals.

### Creative health and bereavement

In addition to creative engagement in end of life, which can support both patients and their loved ones to process a life-limiting diagnosis, arts and music activities for families following bereavement can support coping, support the maintenance of stable mental health, help in the development of support networks, facilitate the continuation of bonds with the deceased, enhance meaning-making and reduce sadness<sup>401</sup>. These activities can also support staff in providing empathetic and compassionate care. Music therapy has been used with people who have experienced bereavement to facilitate the expression of emotions and explore concepts of grief, to provide emotional release, to foster a sense of reconnection with the self or with the lost loved one, to facilitate reminiscence and as an opportunity for social support<sup>402</sup>. Within this, activities such as group singing have been used to

### End of Life Care and Bereavement – The Weston-super-Mare Community Network

The **Weston-super-Mare community network project**, led by the Palliative and End of Life Care Research Group at the University of Bristol, and part of the Mobilising Community Assets to Tackle Health Inequalities research programme, harnesses creative and community assets to tackle inequities in end of life care and bereavement support and mitigate social isolation and loneliness. The project, which recognises that those living in the poorest areas of the country are less likely to access end of life care or bereavement support, consists of several workstreams of activity supporting collaboration between the local integrated care system, people with lived experience and people providing community assets, including arts and culture initiatives. Outcomes include generating community knowledge, commitment, capacity and outputs that will help counter these inequities.

Through a series of creative workshops participants have explored techniques to facilitate discussions on death and dying and received training in techniques such as **No Barriers Here**, which uses arts-based methods to facilitate conversations about death, dying and advance care planning, and **Grief Gatherings**, small, free informal discussion groups about grief and loss.

As part of the project, collaborators coproduced events and activities for **Good Grief Weston**, a festival held in May 2023 in partnership with **Super Culture**. The festival draws on the approach of **Good Grief Festival**, founded by project lead Dr Lucy Selman in 2020, which aims to open up compassionate conversations around death and bereavement. In Weston-super-Mare, the event included a range of creative workshops and performances including a 'grief rave', film, music, comedy and theatre, and a large-scale community arts project of more than 800 forget-me-not flowers created by members of the community in tribute to those they have loved and lost.



help people to process grief as part of bereavement support therapy services, and have been shown to improve mood, and provide social connection<sup>403</sup>.

The UK Commission on Bereavement report, *'Bereavement is Everybody's Business'* finds that increased awareness of bereavement in society can help people to share their experiences and support each other through loss<sup>404</sup>. Informal networks of support such as death and grief cafes

and compassionate community initiatives, as well as awareness-raising initiatives such as the Good Grief Festival help to bring people together<sup>405</sup>. Creative approaches are often a key part of such initiatives.

### **Public health approaches to death, dying and bereavement**

Public health approaches to palliative care place a focus on community-based and social support

## **Still Parents – Life after baby loss**



The Whitworth Art Gallery and Manchester SANDS (Stillbirth and Neonatal Death Society) have partnered on an award-winning project, providing a creative outlet for parents who have suffered the loss of a baby during pregnancy or just after birth. It is estimated that one in four pregnancies end in loss during pregnancy or birth. However, the subject is not often spoken about, and this can lead to stigma and shame for those who experience loss. [Still Parents](#) aims not only to support parents through their bereavement, but also to open up conversations about baby loss more widely.

Participants come together monthly at the Whitworth Art Gallery in Manchester, drawing on the museum's collections and using creativity to explore and express their feelings in a supportive community. The sessions, led by professional artists in a range of media, focus on making rather than talking, and conversations arise as a result of the art-making.

*"There comes a point where you've talked about it so much that you need something else. So having that physical thing to hold onto, to make something once a month, it made a huge difference to me."* - Participant in Still Parents, End of Life Care and Bereavement Roundtable

The programme led to a public exhibition *'Still Parents: Life After Baby Loss'* - an honest and powerful portrayal of baby loss told by those who have experienced it first-hand. It

displayed artworks produced by participants alongside pieces from the collection, selected by participants, which resonated with their stories. These stories and the participants voices helped to personalise the statistics around baby loss and raise awareness. The exhibition helped break the silence surrounding baby loss and has become a catalyst for open conversations. Visitors have described the space as a positive, healing space, essential for building empathy.

The Whitworth is situated opposite Manchester's largest maternity unit and Tommy's, the largest stillbirth research centre in the UK. Throughout the project there has been regular contact with the bereavement midwives and counsellors at the hospital who advocate for the workshops and regularly refer bereaved families to the Still Parents programme. In 2023 the Whitworth was awarded funding from the Rayne Foundation to develop a new strand of work called Still Care focussing on midwives and other health professionals and their experiences of baby loss.

Still Parents and Still Care model a new, collective and creative approach to bereavement support that expands on and complements traditional, clinical provision. For the partners Manchester Sands, Still Parents has enabled the charity to scale-up their work, to increase public awareness and understanding of the role of arts in health and to embed more creative practice into the support mechanisms they currently use.



for end of life care. Creative health providers and cultural institutions can be integral.

*By community, we mean not merely community services or volunteers but members of neighbourhoods, faith groups, workplaces, schools, local government agencies, as well as sporting clubs, and cultural organisations such as galleries and museums. Death, dying, loss, and caregiving are experiences that occur within these kinds of community contexts, each providing love and support, practical care, policies for support, or educational experiences<sup>406</sup>.*

The 2022 Lancet Commission on the Value of Death proposes a new vision for death and dying, with greater community involvement alongside health and social care services, and increased bereavement support. The five principles of the vision are: the social determinants of death, dying, and grieving are tackled; dying is understood to be a relational and spiritual process rather than simply a physiological event; networks of care lead support for people dying, caring, and grieving; conversations and stories about everyday death, dying, and grief become common; and death is recognised as having value<sup>407</sup>.

Creativity can be used to raise awareness and spark discussion around death, dying and bereavement. This could be through an exhibition or event, or a participatory intervention. For example, storytelling has been used as an intervention in schools to explore conversations around end of life<sup>408</sup>. Creative approaches can also be used with specific populations facing inequalities, providing culturally appropriate ways to address death, dying and bereavement, thereby beginning to address inequalities.

### **Maximising the potential of creative health**

In shifting towards such an approach, more people will be able to access the care and support they need in the community and will be empowered to make decisions about their end of life care, and how they wish to spend their time. Creative health, as a personalised approach to end of life care and bereavement, will support services to meet the aims of the National Framework, and may reduce the burden on acute care settings.

In order to achieve this, sufficient resource must be available for community and hospice care, and people must be able to access creative opportunities when and where they need it. Currently, with community-based end of life care services experiencing funding cuts, and inequalities in provision, there is a risk that creative activity, though demonstrably important to people at end of life, can become an add-on rather than part of a core offer.

Integrated Care Systems offer the potential to embed creative health into end of life care pathways, bringing together the NHS, local authorities, the VCSE, cultural institutions and creative practitioners as part of a collaborative approach which will allow people to be easily directed to the kind of support they may most benefit from during end of life or bereavement.



*When you are in this space, it's hard to know which way up you are, let alone what might be beneficial as some sort of activity. Any offer has to be made incredibly easy to access: it needs to be signposted by the places we might already be finding support (e.g. Cruse, Maggie's Centres, Counselling); it needs to be accessible (right across the country); it needs to be funded, and there should be a menu of options - group or individual"*

*Phillipa Anders, Lived Experience Speaker,  
End of Life Care and Bereavement Roundtable*