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CHRISTMAS 2024: DEATH IS JUST AROUND THE CORNER

Facing death differently: revolutionising our approach to death and grief

Despite growing public interest in death, support for end-of-life care and bereavement remains inadequate. We urgently need a community centred, public health approach to the social processes of dying and grieving, backed by properly funded palliative care, writes **Lucy Selman**

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Over 600 000 people die each year in the UK,[1] leaving more than six million grieving.[2] On the surface, attitudes to death seem to be shifting: witness the rise of death and grief cafés,[3] festivals and annual awareness events,[4-11] and the formation, in 2018, of a national association of end-of-life doulas.[12] Television shows, films, and books about dying and grieving proliferate. A BBC video by the palliative care doctor, author, and activist Kathryn Mannix, "Dying is Not as Bad as You Think," has had 145 000 views.[13]

But beneath the surface are major gaps in public knowledge and confidence around death, meaning that the practical, emotional, and spiritual wishes of dying people often remain unexpressed and unfulfilled. Meanwhile, futile medical interventions at the end of life persist as a global failure.[14]

Death is as natural a process as birth, yet much of society refuses to see it that way. This discomfort shows in our behaviour: we avoid seriously ill or bereaved people, and we shy away from discussing our own end-of-life wishes with family, friends, and health professionals. These attitudes are deeply intertwined with cultural and systemic issues, from harmful misconceptions about grief to the medicalisation of dying.

Recent debates on assisted dying have put an intense spotlight on the failures of our attitudes towards, and systems for, end-of-life care and bereavement support, and the MP Rachael Maskell has announced a commission to improve palliative care. It's a timely and vital move, but the commission must tackle the wider structural issues that shape how people die and grieve.[15] Just as social determinants—income, employment, housing, education, disability, and social support networks—shape our health in life, they also shape how we die.[14,15] Without a far reaching and integrated public health approach to end-of-life care and bereavement we will only ever be tinkering at the edges of a complex system.

Seriously ill and dying people spend only about 5% of their final year of life in the direct care of healthcare services, with friends, family, and community members without healthcare training providing much of the remaining support.[16] Between 75% and 90% of home based care at the end of life is provided by unpaid carers, often family members.[17]

It is time to shift focus and put families and communities front and centre in the management of dying, bereavement, and grief. But for this role they need comprehensive resources, education, and support.[18]

We need to talk about dying . . .

Covid-19 forced a global reckoning with mortality, deeply personal for many people. A 2021 survey by funeral directors Co-op Funeral Care suggested a shift in attitudes: 20% of adults felt more comfortable talking about grief, 47% reported increased compassion towards people in grief, and 54% felt more conscious of their own mortality.[19] But this awareness has not led to action: only 14% of UK adults have actually spoken to anyone about their end-of-life wishes.[20]

Many people struggle to make informed decisions around end-of-life care because medical jargon and processes are so opaque. Few know what an advance care plan or advance directive is or how and why "do not attempt cardiopulmonary resuscitation" (DNACPR) decisions are made,[21,22] and only 60% of people are aware they have the right to refuse lifesaving treatment.[23]

Mistrust of healthcare providers is another barrier. Nearly a third of UK adults doubt that their end-of-life preferences would be respected, making them less likely to express their wishes.[20] This reflects growing dissatisfaction with the NHS,[24] indicating that much more needs to be done to improve the public's experiences and rebuild trust.

. . . and grieving

Conversations after a death are vital too, but grief is a uniquely challenging topic. Support of family members, friends, and communities is fundamental to coping with bereavement,[25,26] but it is too often lacking.[2,27] Many of us fear "saying the wrong thing" and don't know how to offer support; a quarter of us avoid talking to someone grieving altogether, compounding their isolation.[28]

Embarrassment and fear of causing offence may stem from stigma or misguided ideas about grief. For example, the outdated psychoanalytic idea that grief happens in "stages" and is time limited is often contrary to experience. Cultural norms also shape grief: in the US "prolonged grief disorder" is a diagnosis for intense grief after 12 months,[29] while in Egypt tearful grieving years after a death is considered healthy.[30]

That there is a hierarchy in grief is also a common view. This could reflect societal efforts to control or compartmentalise grief, but sanctioning some forms of loss response while disenfranchising others, as often happens when a baby dies before birth,[31] can lead people to compare their grief to that of others and worry they're grieving too much or too little. Such mixed societal expectations mean bereaved people can believe they are failing, abnormal, or unworthy of support, preventing them from expressing their feelings or asking for help.

Medicalisation . . .

The medicalisation of death has shifted the dying process away from homes and communities and into healthcare.[14 32 33] Dying has become a clinical process, sidelining emotional, social, and spiritual dimensions that were once integral to end-of-life experiences. The loss of religious and communal rituals in the global north has only deepened our distance from death. The funeral business has commercialised mourning, and grief has become professionalised—the remit of trained counsellors.[32 33]

In Hinduism, Sikhism, and Islam death rituals usually include family members washing and covering the body. In parts of the UK it was common until the mid-20th century for families to manage death at home. In Yorkshire villages, for example, women took great pride in "laying out" the dead.[34] Family members took it in turns to sit by the body through the night. One woman, the "bidder," was employed to knock at every house to bid, or invite, the household to attend the funeral. These traditions have faded; at a community level, crucial knowledge and skills have steadily declined. As a result, we may not recognise and accept when death is near and may be more fearful of death and its aftermath.

Healthcare professionals also struggle to face death and the limits of what medical science can achieve, not least because it means facing their own mortality. But, when clinicians avoid discussing death and patients' preferences for the end of their lives, patients and their families lose crucial opportunities to connect, prepare, and ultimately make informed decisions.[35] Clinical education and training must ensure that future clinicians have generalist palliative care skills, know when to consult specialist palliative care, and, crucially, are unafraid and supported to have tender conversations about dying, the bedrock of person centred care.[36]

. . . and deprioritisation

End-of-life care hasn't just been medicalised, it has been deprioritised. Healthcare systems and education focus on cures and life extension, sometimes at the expense of quality of life and compassionate care for dying people.[37 38]

In the UK about 90% of dying people would benefit from palliative care, but 25% don't get it.[39-41] Demand is set to rise 25% over the next 25 years as lifespans increase and health conditions grow more complex, yet the sector is already critically underfunded and overstretched. Just a third of UK hospice funding comes from the state, with the remaining £1bn raised annually through charity shops, fundraising events, and donation.[42] This funding gap sends a clear message: care for dying people is less valued than aggressive treatments and high tech medical advances. (It's surely no coincidence that 9 in 10 of the clinical and care workforce in UKs hospices are women,[43] reflecting a long history of "women's work" being undervalued.)

This patchwork funding model leaves rural and other underserved communities with glaring gaps in care, particularly for children.[44] As demand for palliative care rises, the case for proper government funding for end-of-life care provision in care homes and the community, including hospices, grows ever more urgent.[45 46]

In the meantime, stark inequities exist in access to hospice, palliative, and bereavement services. Marginalised communities face the greatest number of hurdles in accessing support at a time when compassion is most needed.[47-52] Ethnic minority groups, in particular, encounter language barriers, inadequate outreach, and a shortage of culturally competent providers.[48 50 51] Thirty per cent of people from ethnic minority groups but just 17% of white people say they don't trust healthcare professionals to provide high quality end-of-life care.[23]

To close such gaps, hospice and palliative care services and interventions should be co-produced with, and for, underserved communities. Access to advance care planning, for example, can be improved through use of participatory, arts based methods and by collaborating with trusted community organisations to ensure that information and support are culturally appropriate and accessible in multiple formats and languages.[53 54]

Meaningful integration through a public health approach

Access to services and interventions, though necessary, is nowhere near enough. Death, dying, care giving, and bereavement are essentially communal events and need to be reclaimed as such.[14] This transformation requires more than investment: it demands a shift from needs assessment and service provision to genuine cross-sector partnerships with local authorities, social care, the voluntary and community sector, and communities. We must harness and support community assets—the social, cultural, and natural resources already embedded in our communities—and prioritise relationship based approaches to care.[55 56] Through this approach new systems can emerge in which community resilience and networks of support can thrive.[57]

Partnerships between healthcare, social care, local authorities, the voluntary and community sector, and communities aren't new: integrated care has been a core NHS principle for more than two decades.[58] Since 2022 every integrated care board in England has had a legal duty to commission adequate palliative and end-of-life care services, including bereavement support, with a mandate to reduce local health inequities, providing a top-down driver for the public health approach to end-of-life care and bereavement that is clearly needed. But provision varies across boards.[59 60]

Debate continues over what effective integration should look like and what it needs. Critics of integration argue that it risks shifting responsibility for health inequities, rooted in austerity policies, to the community.[61] Others argue that overcoming barriers to integration, such as the funding precarity faced by many community based organisations, improves service provision and reduces health inequities through building neighbourhood system resilience and collective capacity.[62] Within palliative and end-of-life care, compassionate community models such as the Compassionate Cities charter offer a formalised framework to support public health approaches,[63] but it can be a challenge to shift a system to community engagement and development after a prolonged focus on service provision.[64 66] We need a long term government commitment to invest in meaningful cross-sector integration and the reorientation of health services.

Death and grief literacy

The media have a key role in collective sense making and public understanding of death and grief but often sanitise or sensationalise end-of-life experiences. In medical dramas, for example, cardiopulmonary resuscitation (CPR) is often depicted as highly effective, presenting unrealistic outcomes that reinforce misconceptions.[67 68] Rarely shown are the experiences of elderly patients with multimorbidity—the majority in real hospital settings—whose outcomes after CPR are notoriously poor.[69 70] News coverage, often of violent or unexpected deaths, presents death as distressing and fearful but at a distance, as something that happens to other people.[71] Similarly, the vivid depictions of intractable suffering towards the end of life that were recounted in parliament last month during the debates on assisted dying can cause unnecessary fear unless we also tell stories of "ordinary dying."[72 73] Realistic depictions and discussions of death and grief can counter common misconceptions, helping to align public expectations with reality and foster more compassionate societal attitudes and behaviours.

Promoting literacy in death and grief (the knowledge and skills to discuss and plan for death and to support others through their grief) is a key part of a public health approach to palliative and end-of-life care and bereavement. Arts and culture, including festivals, offer vital entry points into what can be challenging topics.[7 8] Most UK children will be bereaved of someone close to them, yet grief, death, and loss are largely absent from the school curriculum.[74] To better prepare children to manage their own grief and support others, grief education should be made a core part of the national curriculum, a move currently under debate in parliament.

Clinicians too have a critical role in reshaping attitudes and so must build their own death and grief literacy. By discussing end-of-life care openly and challenging common misconceptions, healthcare providers can model acceptance of dying, build trust, and show the public that it is safe to ask questions and voice doubts and fears. Care must be emotionally aware, culturally sensitive, compassionate, and person centred—and this must be reflected in clinical education and ongoing support for clinicians. Clinical leaders must acknowledge the emotional weight of dealing with death and grief and support clinicians in this work, encouraging sharing, peer support, and remembrance. By making space for grief and vulnerability in professional life we nurture the human side of being a clinician.

Changing societal attitudes to death and grief demands bold, multifaceted action. We need proper state investment in hospices, palliative care, and bereavement support and a determined effort to close inequities in access. This must go hand in hand with a public health approach that is rooted in collaboration, integration, and the recognition of community strengths. But none of this will succeed without death and grief literacy: the knowledge, skills, and confidence to face mortality with our eyes open. Perhaps the final, and hardest, piece of the puzzle is the courage to reach out to one another when it matters most.

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