

Living a Good Life at Every Stage:

THE ROLE OF PALLIATIVE AND END OF LIFE CARE IN ENABLING A GOOD DEATH

IN ASSOCIATION WITH



Care Talk Magazine's Palliative and End of Life Care Awards ROUNDTABLE DISCUSSION

THE SUPREME COURT LONDON, FEBRUARY 22ND, 2024



Foreword

Why are we, as a society, so reluctant to talk about death?

“You matter because you are you, and you matter to the last moment of your life. We will do all that we can not only to help you die peacefully, but also to live until you die.”

Dame Cicely Saunders, Founder, St Christopher’s Hospice

Palliative and End of life care are a critical aspects of health and social care that require careful consideration and continuous improvement to ensure individuals experience a dignified and compassionate transition into their final stages. This report aims to provide an exploration of discussions and perspectives surrounding palliative and end of life care, drawing insights from Care Talk Magazine’s Palliative and End of life Care roundtable discussion, held at the Supreme Court on 22nd.

15 sector experts took part in the discussion, chaired by Professor Martin Green OBE, Chief Executive of Care England. A wide range of topics were covered, including: **death as society’s best kept secret, public perceptions of death and dying, what it means to live and die well, what a Good Death looks like, and the role of social care** in ensuring this.

This paper synthesises the points that came from the conversation with the aim of foregrounding further dialogue in the areas of Palliative and End of life care.

The panellists:

Julie Armstrong-Wilson, CEO, Gold Standard Framework

Maggie Candy, Deputy Nurse Manager, Cavendish Homecare

Debbie Day, End of Life Lead, Canford Healthcare

Professor Martin Green OBE, Chief Executive, Care England

Anna Holdstock, Deputy Manager, Canford Healthcare

Mairead Liston, Founder and Registered Nurse Manager, Cavendish Homecare

Nuno Santos Lopes, Director of Research and Innovation, Nightingale Hammerson

Joanna McCabe, Huntington’s Disease Nurse Consultant, Exemplar Healthcare

Nicola Payne, Best Practice Manager – Dying to Talk, Macintyre Charity

Paula Plaskow, End of Life and Palliative Care Lead, Jewish Care

Karen Rogers, Director, Herefordshire Care Homes

Claire Sutton, Transformational Lead: Independent Health and Social Care Sector, Royal College of Nursing

Professor Deborah Sturdy CBE FRCN, Chief Nurse for Adult Social Care, Department of Health and Social Care

Anne Trotter, Assistant Director of Education and Standards, Nursing and Midwifery Council

Society's best kept secret: public perceptions on death and dying

Why are we, as a society, so reluctant to talk about death?

The Experts' perspective

Understanding death and dying as a natural part of life emerged as a crucial theme in the discussions. The need to approach death with care and compassion and acknowledge it as an integral aspect of the human experience was highlighted. This perspective challenges societal norms that often shy away from discussing or confronting the reality and inevitability of death and dying.



A hidden death is hidden grief. We talk openly to residents when a fellow resident and friend dies so they are able to say 'goodbye'.

Debbie Day, End of Life Lead, Canford Healthcare



The challenges and opportunities

There is a persistent lack of understanding amongst the public and families about what constitutes good practice in palliative and end of life care. This lack of awareness can lead to disagreements between families and care providers about the necessity of certain treatments and what a palliative or end of life care pathway may look like.

The lack of conversations about end of life care, particularly for people with learning disabilities and / or autism, children and young people, and those living with dementia or other cognitive and / or physical impairments, was also stressed, along with the need for targeted initiatives and support systems to ensure that these individuals are fully supported when facing death and dying.



For years people with a learning disability and autistic people have been sheltered from end of life and advanced care planning, when actually they flourish when they are enabled to contribute.

Nicola Payne, Best Practice Manager - Dying to Talk, Macintyre Charity



The solutions

Above all, death needs to be divorced from its societal taboo. We need to encourage more honest, open and frank discussions about death in our wider culture.

A more generalised acceptance of death in our culture will help foreground more specific conversation on the nature of palliative and end of life care.

A key point that emerged was the significance of careful terminology use when discussing palliative care and end of life, and the distinction between them. It should be stressed that individuals can receive palliative care for a number of years, where end of life is usually considered as the last 6 months a person can expect to live.



*The term 'palliative' can sometimes seem aggressive...
it doesn't mean that death is imminent.*

Claire Sutton, Transformational Lead: Independent Health and Social Care Sector,
Royal College of Nursing



The potential for confusion about an end of life prognosis necessitates clear and empathetic communication between care providers, service users and their families. Effective communication is not only crucial for providing accurate information but also for ensuring that individuals receive the support and care aligned with their preferences and values.



*We need tender and compassionate conversations.
The individual's rights must not be overruled by their family.*

Paula Plaskow, End of Life Lead, Jewish Care



Furthermore, the social care sector must continue to champion a person-centred approach to palliative and end of life care and seek funding for initiatives targeted at groups often underrepresented in these discussions.

What does a *Good Death* look like? How do we live and die well?

The Experts' perspective

Once death is accepted as a natural part of life, we can move toward establishing a praxis for living and dying well.

A *Good Death* is, first and foremost, centred on the wishes of the person in receipt of care. A recurring emphasis is placed on a familiar, comfortable environment and the presence of family and loved ones. Thus, care environments and community are the most crucial foundations of a *Good Death*.

However, end of life and palliative care should not only focus on ensuring a *Good Death*, but also on fostering a good life leading up to that point. This perspective advocates for a paradigm shift in our views and challenges the traditional narrative surrounding end of life care, encouraging a more holistic approach that considers the overall wellbeing of individuals in their final stages.

The challenges and opportunities

Again, lack of awareness and communication on the nature of death and dying features as the most crucial obstacle to ensuring we all live and die well.

A popular cultural narrative is that moving toward a palliative / end of life pathway constitutes care professionals 'giving up.' This perspective is largely informed by societal reticence to speak on death, the perceived absence of death in our lives, and thus the prevalent belief that modern medical interventions can in some way 'beat' death, that death is a 'failure', or that prolonging 'time on the clock' (over quality of life) is the optimal route to pursue.

'Giving up' not only alludes to the over-medicalisation of death in our culture, but to the idea that a palliative prognosis is a death in itself, that robs the individual of any meaning to the life they have yet to live.

This commonly-held, yet misinformed view of palliative / end of life pathways as 'giving up' stands a major hurdle to ensuring we all live and die well.

The solutions

The 'over-medicalisation' of death was cited as a specific point of contention that should be addressed. Over time, other medical / care facilities have become more prevalent sites of death and dying, with nurses, doctors or other medical professionals as the chief providers of care. This is in contrast to more traditional models, as well as those outside of the UK, which prioritise the home / residential environments and care and support administered by family and loved ones.





The main cause of death is dementia. Hospices are not as prepared for people living with dementia whereas care homes are. Care Homes are the hospices of the future.

Nuno Santos Lopes, Director of Research and Innovation, Nightingale Hammerson



In practice, this 'over-medicalisation' of death can lead to sub-optimal outcomes, with those in receipt of care oftentimes left in want of pain medication (due to the lack of practitioner availability), and unhappy with their clinical environment.

Time and time again it emerges that dying in a familiar, comfortable environment surrounded by loved ones is optimal. Thus, care and support that prioritises these factors moves toward a foundation of best practice in this area.

Providers should focus on creating an environment that fosters meaningful connections, activities, and support systems for those in receipt of palliative or end life care. By prioritising the wellbeing of individuals in their twilight years, care providers can contribute to a more compassionate and dignified end of life experience, that allows those in receipt of care to die peacefully, having lived well up until this point.

Further, more awareness and education on palliative and end of life pathways is required to ensure the public are informed of what constitutes best practice and what type of care (residential, domiciliary, hospice, hospital etc) may be most appropriate. Communication on these points is essential in ensuring that the person in receipt of care, their loved ones and care practitioners can all work together effectively and ensure the best outcomes.



What is the role of social care in ensuring our health and social care systems are structured to protect the right to a *Good Death*?

The Experts' perspective

Having outlined the need for death to be accepted as a natural part of life, and detailed what a *Good Death* should look like, experts moved toward a more practical understanding of how this can be achieved across the sector.

The importance of collecting and collating data on death and dying was emphasised. Experts questioned how a *Good Death* is measured, and the need for more qualitative data and benchmarks to determine this. This emphasis on data underscores the need for a comprehensive understanding of end of life care patterns to inform resource allocation decisions, training and development to ultimately foster an improved service.



*Data is important and is currently lacking and totally fragmented. There are some wonderful examples of where people are living and dying well but no data of a **Good Death**.*

Karen Rogers, Director, Herefordshire Care Homes



Education for care and support professionals was also particularly highlighted as a crucial factor for improving services, with a need for further incorporation of palliative care into the curricula stressed across the board. Additionally, more structural support for those working in palliative and end of life care was called for, to ensure staff wellbeing and the continued provision of high quality care.



If we want people to care we have to care for the people who are caring!"

Julie Armstrong-Wilson, CEO, Gold Standard Framework



The value of interdisciplinary collaboration across health and social care was also stressed, to ensure integrated working and the cascading of best practice across the sector.

Regulation also has a crucial part to play in identifying sub-standard practice, as CQC should move away from apportioning blame and toward dissecting what can be learnt and improved upon.

Finally, the value of recognising and awarding exemplary palliative and end of life care practices was underscored, serving as a means to incentivise and acknowledge care providers who go above and beyond in ensuring a dignified end of life experience for their service users. Additionally, showcasing positive examples of palliative and end of life care was recognised as a way to educate the public and counteract negative narratives often perpetuated by the media.

The challenges and opportunities

Data

The first major obstacle to overcome is collecting and synthesising data related to palliative and end of life care. At present there is a lack not only in the volume of data but the quality of this information. Information about where people are dying, how often emergency services are being called and how often people are being sent to hospital was stressed as particularly important. Experts questioned the metrics that are being measured and whether these benchmarks actually consider what a *Good Death* looks like, emphasising a lack of qualitative data especially. There is also a lack of dissemination of the data we currently have, which limits the ability of providers to benchmark their service against others in their local area.

Education, training and support

Another major obstacle relates to education, training and support within the workforce.

Experts highlighted a lack of thorough palliative and end of life learning within the curricula and onboarding process, leaving staff not fully equipped with the knowledge necessary to deliver high quality care in this area. This lack persists with respect to ongoing training on the job, as the professional skills necessary are not being taught and revised. Furthermore, the sector is lacking in robust pastoral systems to support staff who work in end of life and palliative care, a particular point of contention given the mental and emotional toll care provision in this area can take.



We need to acknowledge that there is a lack of good carers and nurses for end of life in social care.

Mairead Liston, Founder and Registered Nurse Manager, Cavendish Homecare



The current lack of education, training and support can oftentimes leave staff unequipped with the knowledge, skills and confidence to deliver high-quality care. Further, this lack can also contribute to acute distress and miscommunication not only for staff, but the service users and families they interact with. This further compounds the negative effect of the more general lack of publication awareness on palliative and end of life care.



*Nurses in social care need resilience training.
They deal with more deaths than nurses in hospital.*

Professor Deborah Sturdy CBE FRCN, Chief Nurse for Adult Social Care,
Department of Health and Social Care



Collaboration across the sector

Fragmentation across the sector was also highlighted by the experts as a serious factor impeding the provision of high-quality end of life and palliative care.

There is a sense of frustration as there are seemingly never-ending roadblocks in communication and collaboration between care providers, the NHS and other partners with a role in improving health and wellbeing. These roadblocks oftentimes result in miscommunication and distress for staff, service users and families, which again compounds the wider problematic at hand.



*The challenge is political - there is a tendency to just throw money
at the NHS.*

Professor Martin Green OBE, Chief Executive, Care England



Regulation

The role of the CQC was also considered by the experts.

The importance of inspections was stressed, but too often providers felt as though there was too much apportioning of blame rather than a focus on improvement. This 'blame and shame' culture contributes to the wider stress felt in the system and by care professionals and impedes the ability of providers to learn from mistakes and improve. Further, 'blame and shame' culture can stoke negative media attention and public attitudes, once more contributing to the wider negative perception of palliative and end of life care.



*We need a story line in popular soap operas around conversations
around dying.*

Joanna McCabe, Huntington's Disease Nurse Consultant, Exemplar Healthcare



The solutions

Data

Ultimately, the sector needs higher quality data, and more of it.

Providers stressed the need for new metrics for measuring a *Good Death* focusing on qualitative data especially.

Further, this data needs to be disseminated more effectively, so care providers have better access to the latest information.

Improving the collection, collation and dispersal of data would have an enormous positive impact on the provision of palliative and end of life care, allowing providers to benchmark their service, make more informed resource allocation decisions and find practical methods for improvement.



Education, training and support

Above all, social care requires more thorough palliative and end of life education, training and support for professionals in all roles.

Experts argued that end of life training should be mandated across the sector, in a similar fashion to the recent roll out of The Oliver McGowan Mandatory Training. Further, palliative and end of life training should be consistently reviewed and revised to keep pace with the latest developments and data. This would empower care professionals with the knowledge and skills to effectively deliver end of life and palliative care.

Pastoral systems should also be strengthened to support palliative and end of life care professionals. This would reduce stress, nurture wellbeing and ultimately improve the quality of care provision. A knock-on effect would be the improvement of staff retention, which, in turn, aids continuity of care for service users and families.



The Nursing and Midwifery Council are doing a review of practice learning and are looking to innovate and diversify the way students learn about all standards.

Anne Trotter, Assistant Director of Education and Standards,
Nursing and Midwifery Council



Collaboration across the sector

Fragmentation across the sector can only be tackled by a renewed focus on collaboration.

Care providers, the NHS and other partners with a role in improving health and wellbeing must work together to move toward more seamless care delivery and the provision of high-quality end of life and palliative care.

The passing of the Health and Care Act in 2022, and subsequent creation of Integrated Care Systems (ICS') and Integrated Care Boards (ICB's) demonstrates a promising commitment from the Government to facilitate partnership working across the health and social care sector. ICS' and ICB's must continue to foster collaboration.

Regulation

Regulation has a very important part to play in improving services and ensuring everyone has the right to a *Good Death*.

Experts encouraged a shift from apportioning blame toward dissecting and learning from mistakes with the ends of nurturing a culture of growth. A culture of growth would encourage improvement in care delivery and empower providers with the tools necessary to achieving this.

A paradigm shift in attitudes from, and toward, the regulator is required to ensure this.

Further, the regulator should use its platform to more thoroughly disseminate the lessons to be learnt from sub-standard practice across the sector, so best practice can become the norm rather than an exception.

Recognising best practice

Negative public perceptions can only be countered by the profiling and championing of best practice.

Providers should seek to internally recognise the efforts of their staff, with rewards in turn contributing to workforce wellbeing and improved service delivery.

There is also a need for positive media output, like that of Care Talk Magazine, in tandem with external recognition events such as the inaugural Palliative and End of life Care Awards, new for 2024.

Positive media and recognition events contribute significantly to changing the face of public perception and nurture a shift away from viewing death as society's best kept secret.



Key takeaways

Society's best kept secret – public perceptions on death and dying

- Embrace death as a natural part of life: challenge societal norms.
- Address the persistent lack of public understanding about palliative and end of life care.
- Advocate for targeted initiatives for specific groups, including those with disabilities and dementia.
- Encourage open conversations, clear communication, and a person-centered approach.
- Champion funding for initiatives

What does a *Good Death* look like? How do we live and die well?

- Prioritise individual wishes, emphasising familiar environments and loved ones' presence.
- Challenge societal narratives portraying palliative care as "giving up" and combat over-medicalisation.
- Address challenges through awareness, education, and a shift in cultural perspectives.

What is the role of social care in ensuring our health and social care systems are structured to protect the right to a *Good Death*?

- Emphasise the importance of collecting and analysing quality data on death and dying.
- Tackle challenges such as inadequate data, insufficient education for professionals, and sector fragmentation.
- Improve data dissemination for benchmarking and resource allocation decisions.
- Enhance education, training, and support for care professionals in the palliative and end of life care sector.
- Foster collaboration across the health and social care sector for seamless care delivery.
- Shift regulatory focus from blame to learning and improvement.
- Recognise and reward best practices to counter negative public perceptions.

Conclusions

Care Talk's Palliative and End of life report has therefore outlined some of the key issues, challenges and opportunities facing the palliative and end of life care sector.

Informed by discussions amongst 15 sector experts, we have unpicked crucial topics including: **death as society's best kept secret**, **public perceptions of death and dying**, **what it means to live and die well**, **what a *Good Death* looks like**, and **the role of social care** in ensuring this.

The insights gained from this paper should help foreground further dialogue in the areas of Palliative and End of life Care, and reveal society's best kept secret as one best shared.

Our efforts persist, particularly in the area of recognising best practice, with the launch of the inaugural Palliative and End of Life Care Awards, taking place June 28th 2024 at the London's Marriott Regents Park Hotel.

Please help us recognise and reward best practice, by nominating your colleagues here now: <https://www.palliativecareawards.co.uk/nominate/>

For more information, please contact kirsty@care-awards.co.uk

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