



Dying Well: Wellbeing at the end of life

A summary of practitioner conversations from the
What Works Centre for Wellbeing

THE BIG IDEA

Wellbeing matters for everyone at any stage of life, and the end of life is no exception. We wanted to understand what matters to people with terminal illness and how society can support their wellbeing for as long as possible. The evidence about what matters is spread across academia, policy and practice. We also intentionally sought the knowledge, insight and expertise from people living with a terminal diagnosis. Together we shared learning and identified areas for future research and practice improvement.

In April and May 2021, the What Works Centre for Wellbeing brought together practitioners, academics and individuals to talk about what really matters to people with life-limiting or terminal illness, and how to develop support which puts their wellbeing, and that of their family and close relations, at its heart. Through these conversations we explored how we can support people to live well with a terminal illness, how to value the things that matter, and how to use evidence from across sectors to provide better services for wellbeing.

This briefing provides a summary of three topics:

1. Wellbeing conversations at the end of life.
2. A good place to die.
3. Understanding and measuring wellbeing at the end of life.

Recommendations for practice

We found that more could be done to place advance care planning as part of more general life planning.

Often conversations about dying well occur too late to maximise an individual's wellbeing. This is particularly problematic as an individual approaches the end of their life. Research and practice experience suggest this occurs because health professionals fail to explicitly identify individuals as being in their last year of life, lack confidence to 'have the conversation' and because a lack of system interoperability makes developing and delivering shared care packages, in partnership across a range of organisations and sectors, highly complex. If patients are not identified as nearing the end of their life, it is unlikely they will access palliative support and receive holistic care where there is a wider focus than survival.

"You miss the opportunities to do things well, because nobody tells you early enough to get ready."

Dying well conversations framed to reflect changing needs and preferences across the last 12 months of life, rather than the last few days of life, had the greatest potential to be wellbeing enhancing.

This was especially so, when consideration was given to maintaining purpose, for example where:

- Individuals were supported to continue working.
- Care looked at health beyond diagnosis, for example support with exercise, sleep and nutrition.
- Maintaining social support and connections was given priority.
- High quality end of life care was considered to have a focus on the fact that an individual was still living as much as it was on the fact that they were sick enough to die; and where metrics looked beyond survival.

Approaches that considered the wellbeing of partners, children, family and friends at different time points, as individuals moved towards the end of their life, were wellbeing enhancing.

We heard real world examples of how health professionals learn to have difficult conversations and how this can be enhanced with an understanding of conversation science. Research exploring how people use online platforms to talk about end of life shows they provide comfort, become a repository of collective knowledge, and community to share personal experiences.



AREAS OF RESEARCH INTEREST

The following six areas of research interest were identified to more fully understand what matters to people with terminal illness and how society can maximise their wellbeing for as long as possible.

1. Conceptual review

The evidence on dying well, palliative and end of life care, is scattered and tends to be focused on single population groups. There is a lack of clarity about definitions of dying well, wellbeing and related concepts of quality in care towards the end of life; and how it should be evaluated, measured and applied in policy and practice.

What does wellbeing at the end of life look like? What matters? For individuals? Family? Close partners?

What are the drivers of personal subjective wellbeing at the end of life? What drives differences in these?

What are the unique factors of context at the end of life?

Understanding wellbeing needs at the end of life: what would a wellbeing assessment look like at the end of life?

2. Measures

What are the best measures of wellbeing at the end of life?

What are the best measures for different groups for example individual, family, close relations, non-normative family structures, friends, community?

What are the best ways of collecting this data?

Can we identify standard measures and idiosyncratic measures that can be tailored to reflect an individual's needs and preferences?

What would context specific measures look like, for example assessing the effectiveness of interventions that support someone with a terminal illness to continue in the workplace?

How could measures reflect equity, inequality and different experiences?

3. Cohort identification

What are the best ways to identify the cohort of people who are approaching the end of their life? Is this easier/more possible with some conditions rather than others?

How can we improve prognostication for health professionals and individuals?



4. Care

What are the best ways to embed wellbeing as a goal of end of life care?

What does good end of life care that maximises wellbeing, physical and mental health look like?

How does the implementation of standards for end of life care affect wellbeing?

How is wellbeing affected by palliative care interventions? What works to improve wellbeing in palliative care?

Would a more holistic, less medicalised model of palliative care have greater wellbeing benefits? What would change, for who and in what context?

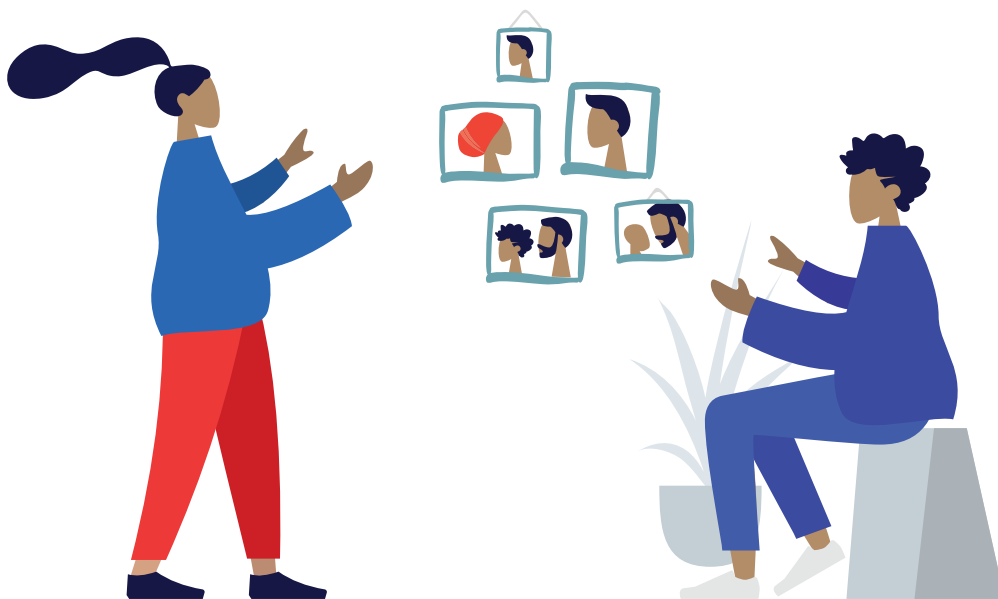
How do we bring symptom management to the fore in treatment plans, and raise people's expectations of working for wellness; not just minimising sickness?

What role does good record keeping/decision making/processes play in maximising wellbeing at the end of life i.e. doing the basics well? Can lessons be drawn from behavioural insight?

What works to maintain social connections and relations at the end of life?

What are the best ways a community can support someone to die? What are the networks that come into play?

How do we reshape public dialogue of what palliative care is? How can we build awareness that palliative care can be wellbeing enhancing and shift perceptions from end of life to symptom management and wellbeing?



5. Wider wellbeing impacts of death, grief and loss

If your life experience is different to that of your peers, for example, you are widowed at a young age, are there different wellbeing impacts?

What is the impact on wellbeing of the experience of loss: understanding acute dips in wellbeing. And what works to start to shift the dial?

6. Advance Care Planning

What's the impact on wellbeing when Advance Care Planning and End of Life Care are decoupled?

What's the impact on wellbeing when advance care plans are followed, and when they aren't followed. What's the impact of doing what matters/bespoke-by-default?

1. WELLBEING CONVERSATIONS AT THE END OF LIFE



Clare Fuller is a Registered Nurse with 30 years' experience in End of Life Care. She founded [Speak For Me LPA](#) specialising in Lasting Power of Attorney consultancy and drafting, Advance Care Planning education, and raising public awareness about planning ahead.

[@ClareFuller17](#)

Advance care planning: just a normal part of life planning

"We should see advance care planning as a more general aspect of life planning which everyone should be encouraged to do - not just as a process in the last year of life. We plan ahead for births, university, jobs; we make wills. We should plan ahead for our healthcare too. Advance care planning isn't a single entity, or a form to be completed, it's a cornucopia of what matters to an individual."

Advance Care Planning includes:

- DNA CPR (do not attempt cardiopulmonary resuscitation).
- ADRT (advance decision to refuse treatment).
- Lasting Power of Attorney.
- Organ donation.
- Digital Legacy.
- Advance Care Plan.
- Anticipatory Care Plan.

End of life care: the last 12 months of life

"End of life care encompasses the last 12 months of somebody's life. So often we focus solely on the moment when someone is dying, missing earlier opportunities to make a real difference, and understand what really matters to an individual. National guidance requires people approaching the end of life to be offered comprehensive holistic assessments in response to their changing needs and preferences."

Advance Care Planning

Progressive disease potentially last year of life

Deteriorating - months to weeks (CHC Fast Track)

Last days of life

"But it's not just important we provide care in this way because it's mandatory. We should do it because people with a terminal diagnosis tell us having high quality, informed conversations about end of life, and what matters, is good for their personal wellbeing."

The numbers of people with advance care plans is very low, and there appear to be three main reasons for this:

- **Recognition:** failure to identify patients as being in their last year of life.
- **Confidence:** of healthcare professionals to 'have the conversation'.
- **Process:** lack of interoperability of health records and systems makes coordination of advance care planning across health professionals and organisations highly complex.

Resources

[NICE guideline \[NG142\]](#)

End of life care for adults: service delivery.

[NICE Quality standard \[QS13\]](#)

End of life care for adults.

Fuller, C., 2020. DNACPR: don't leave it until too late to talk. *British journal of community nursing*, 25(3), pp.109-109.

Fuller, C., 2021. End-of-life care: perspective of a relative rather than a professional. *British Journal of Community Nursing*, 26(4), pp.176-178.



Ruth Parry is Professor of Human Communication and Interaction at Loughborough University (having been an NHS physiotherapist in an earlier career). She leads 'RealTalk' – a programme of research and training which aims to capture and pass on ways in which highly experienced clinicians and patients navigate conversations on end-of-life issues.

@CACEnotes

How conversation science can enable better conversations about dying

"Learning how to have difficult conversations is often acquired on the job. If you, and your patients are lucky, it happens by a kind of osmosis from other practitioners. Unfortunately, much of it we learn through really painful trial and error. Conversation Science unpacks what we know about how we have very difficult, challenging, complex conversations. Through knowledge transfer, we aim to speed up the time it takes to bring our learning on having better conversations about dying from bench to bedside."

Research shows practitioners talk about end of life:

- By encouraging the dying person to volunteer the topic, as one already on their mind.
- By encouraging the patient to elaborate on something they've said, or via a pivot from symptoms to concerns/implications: "you've been really short of breath - what goes through your mind?".
- In a cautious, stepwise manner.
- Using fishing questions.
- Following the patient's lead.



There is promising evidence on the effectiveness of conversation based interventions shaped by core principles:

- Whose topic is this?
- Volunteered > coerced.
- Ask before tell – so I can fit what I say and how.
- Offers and invitations – risk rejection, distress, drop out.
- Don't point too hard at the painful thing.
- Indirect ≠ ambiguous.

Resources

RealTalkTraining.co.uk
Blogs and 'in a nutshells'

Online workshops:
bit.ly/RegisterRealTalkWorkshops

Book – 'How we talk'
by Nick Enfield

BBC Sounds Podcast Word of Mouth
Michael Rosen & Liz Stokoe

W what works wellbeing

Clare Fuller MSC

Dying Well: Wellbeing Conversations at the end of life.

LIVE ILLUSTRATION
Katie Chappell



The Internet, and the End of Life

Ciaran Cummins (DEMOS)

Themes: CARE Pets as grief companions

Meeting needs online: Recurring themes...

- comfort
- Capability
- Community



Advance Care Planning = better wellbeing



RealTalkTraining.co.uk

Discussion



What about FAMILY?



Continuing the Conversation





Ciaran Cummins is a Research Trainee at the Centre for the Analysis of Social Media at Demos, Britain's leading cross-party think-tank. His research focuses on democratic innovation and the future of the web.

@CiaranCummins1

The Internet and the End of Life

"My work at Demos focuses on bringing people's voices into policy debates. Working with the University of Sussex we have explored how people are using the internet to talk about end of life."

People using these spaces are seeking:

Comfort

Capability

Community

"We have used a suite of natural language processing tools to examine large datasets: 110,000 posts collected from 7 forums. This volume of online content would overwhelm human comprehension, so we have trained an algorithm to look for patterns of language as an analyst would, which we then analyse more closely."



The themes identified included: care and the care system, experiences of grief, discussions around mortality and life after death. We also found people reflecting on the value of these online spaces, as well as prominently, how pets had been grief companions to them.

- **Comfort:** people feel they have nowhere else to turn to, sharing advice on how to cope, seeking validation of others with shared experiences.
- **Capability:** spaces become a repository of collective knowledge, voice frustration at not being listened to, lack of communication during COVID-19.
- **Community:** people share intensely personal experiences, conversations about many different aspects of life (not only death), better support in times of COVID-19.

"Online spaces are clearly meeting a need that people have - whether that's advice, solidarity, or companionship. However, it's also clear that while people can use online spaces to share their experiences, and gain emotional support, they cannot provide everything needed to improve people's experiences at the end of life, or for those who are supporting them. "

2. A GOOD PLACE TO DIE



Clair Fisher is a retired Public Policy Professional and associate of the What Works Centre for Wellbeing. She has been writing about her experience living with terminal illness, and her interest in discovering how wellbeing evidence can help inform and improve life for those living with terminal illness.

@pashleyfisher
@dyingwell_uk

Living, dying and the spaces inbetween

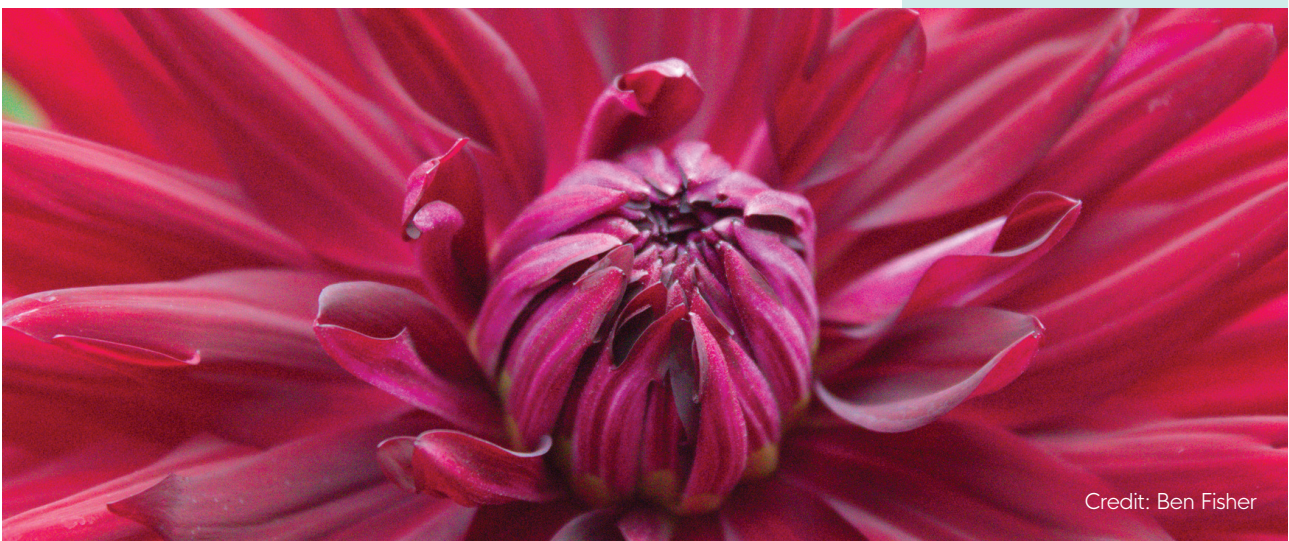
"As someone living with a stage 4 cancer diagnosis I have come to realise that many people seem to think that surviving is the same as being well and that dying is the same as being sick - when actually neither are true. There should be more to life than simply not dying."

What matters for wellbeing at the end of life?

- **Purpose** matters - why isn't there better support for people diagnosed with terminal illness to keep working?
- **Health beyond diagnosis** matters - could the tried and tested wellbeing services, for example exercise, and nutrition, be offered more routinely to those living with terminal illness?
- Our **physical environment** matters - could wellbeing home visits become part of a community care package.
- Our **support and our connections** matter. System failures and avoidance of important conversations means that people die in hospital when they don't want to, which is not good for the wellbeing of the patient, nor the family.
- A **sense of community** matters and community care should not be reliant on charitable donations, this leads to inequalities in accessible care.

"It seems so sad to me that because of failings in our system, sometimes an unwillingness to have these conversations, people end up dying in hospital when it's the last place they want to be. Acknowledging that death is coming is not something that should be thought of as a failure or a lost fight.

Let's rethink end of life care by using wellbeing evidence to inform and improve services. I'd love to see more focus given to living well, designing in wellbeing and properly holistic person-centred care."



Credit: Ben Fisher



Dr Miriam Colleran is a Consultant in palliative medicine in Kildare and West Wicklow. Miriam works mainly in St. Brigid's Hospice which is currently a 9-bed inpatient unit with a community palliative care team, and also in Naas General Hospital.

@miriamcolleran2

What makes a good place to die?

"A good place is about our environment. We need to be in a good place physically, emotionally and spiritually. Our healthcare professionals need to bring excellent communication and clinical skills. Dying well is not about a location. It is about the care given, the people in the room, around the bed and giving care."

- While interventions are important, particularly for pain and symptom control, we also need to reframe the narrative, and empower people through education and understanding about death and dying.
- Optimised patient care is about helping patients live well through their end of life care: the focus needs to be as much on the fact that they are still living as it is on the fact they are sick enough to die.
- At the end of life, addressing someone's spiritual and emotional needs is just as important as their medical needs.

Dr Ira Byock talks about giving the best care possible through the end of life.
"Dying is a part of life. So we need to give the best care possible throughout the journey. I routinely use the Patient Dignity Question on my ward rounds, and ask my patients what matters most to them"

The Patient Dignity Question

From a **caregiver perspective**: What do I need to know about you as a person to take the best care of you that I can?

Source: Prof Harvey Max Chochinov

From a **patient perspective**: What do I need my clinical team to know about me as a person to take the best care possible of me?

Resources

Byock, I., 2014. The Four Things That Matter Most-: A Book About Living. Simon and Schuster.

Dr Ira Byock's website
<https://irabyock.org>

Chochinov, H.M., 2004. Dignity and the eye of the beholder. Journal of Clinical Oncology, 22(7), pp.1336-1340.

A short video of Prof Chochinov describing his experience of using the Patient Dignity Question
<https://www.youtube.com/watch?v=zlgtpqZ2sPA>

The Palliative Care Outcomes Collaboration (PCOC)



Erica Borgstrom is a lecturer in medical anthropology and end of life care at The Open University, where she leads the group Open Thanatology. She has been researching palliative and end of life care for the past decade with a particular interest in the juxtapositions between policy, health and social care practice, and people's everyday lived experiences. She is also the current co-editor of the international interdisciplinary academic journal *Mortality* and sits on the councils for the Association for the Study of Death and Society.

@EricaBorgstrom

Family, community and design for wellbeing

"As an anthropologist, I'm particularly interested in the notion of place in dying. My ethnographic research involves spending time with people in their homes, or in care homes or in hospitals, when they are approaching or living the last year of life. I get to see how policy translates to practice. Many of our national policy guidelines promote person centered care, and a focus on the individual at the end of their life and their expressed choice. My research explores how this plays out in practice, and has revealed a more complex, interconnected picture:

- When a patient makes a decision about dying, it is often not solely their preference, but a consideration of how their decision and choice might impact a partner, or their family: some sort of negotiated middle ground.
- The 'unit' of decision making wasn't constant during the last year of life; it changed and flexed to reflect personal preference, needs as a couple, accommodation of close/wider family needs and wants.
- Patients shared how it can be really difficult to express to their family, friends or healthcare providers that what matters most to them has changed, from when a previous care plan had been prepared.

"If we are truly interested in understanding what dying well looks like, it's important we don't make assumptions about 'who' matters to a patient, or assume this is constant throughout the time we are providing care and support. We need to have flexibility in our systems, and when what matters to a patient changes, that change should be welcomed and accepted. Our challenge is to think about death more broadly, and about people more broadly than just as individuals."

Resources

Henry, C., Findlay, H. and Leech, I., 2015. *What's important to me: a review of choice in end of life care.* London: Choice in End of Life Programme Board.

Dying Well: A good Place to die - family, community and Design for wellbeing

LIVE ILLUSTRATION
Katie Chappell

Claire Fisher

www.dyingwell.uk

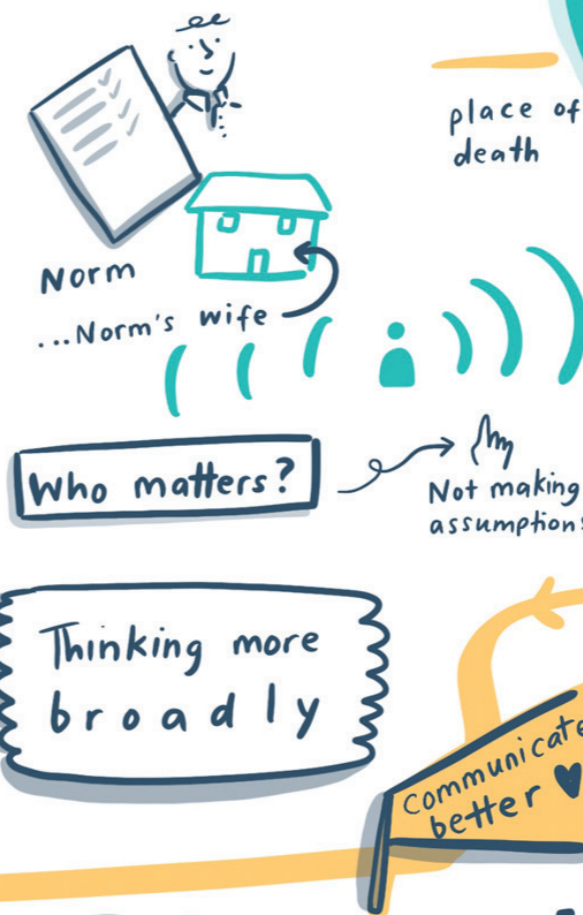


Miriam Colleran



Dr Erica Borgstrom

Open University



It is v. difficult to care @ home



Discussion Time...

Sick enough to die.

#In A Good Place

How + Where



3. UNDERSTANDING AND MEASURING WELLBEING AT THE END OF LIFE



Deborah Hardoon leads the What Works Centre for Wellbeing's research. She leads a team with evaluation and analytical expertise and is responsible for the centre's evidence approach and standards.

An economist by background, she was previously Deputy Head of Research at Oxfam GB.

@DeborahHardoon

Measuring wellbeing

"Before we can think about measuring wellbeing and understanding wellbeing at the end of life; we need to consider wellbeing more broadly. At the very general level, wellbeing means different things to different people; we don't presuppose what is important to you. At the Centre, we define wellbeing as everything in life that's important to us both now and in the future. It's very holistic, and takes into account all the things that happen to us through our lives, our personal characteristics, the environment in which we live. And often this can be thought of alongside concepts like social value, public value, quality of life, thriving and happiness."

- Since 2011, there's been a [national framework](#) for measuring the holistic concept of wellbeing, with 10 different domains that takes into account everything from our relationships, our health, personal finance, the economy.
- Personal wellbeing is critical to measuring wellbeing and there are [four subjective questions](#) in the national framework. They ask about your overall life satisfaction, the extent to which your life is worthwhile, how happy you felt yesterday, and how anxious you felt yesterday. These questions are important because they ask individuals directly how they are doing.
- These measures are [not constant across our life](#): we know that average wellbeing is lower for people between 45 and 55 years old, compared with people that are younger or older.

Wellbeing is...

"How we're doing" as individuals, communities and as a nation, and how sustainable that is for the future. It is sometimes referred to as social welfare or social value.



"Quantitative measures for measuring wellbeing are things that can neatly fit into surveys that can be used for comparisons, and for understanding the relative impacts of other factors on this quantitative outcome, which is really great for decision making. But for understanding context, and mechanisms, how things improve wellbeing; what really matters to individuals - qualitative understanding and measuring of wellbeing is just as important."



Sam Royston is Research and Policy Director at Marie Curie, who support palliative and end of life care research. He was previously Policy Director at The Children's Society, and is also a former chair of the End Child Poverty coalition. Prior to that Sam completed his PhD in the Social Policy department at the University of York, at which point he was also an adviser at a Citizens Advice Bureau. He is also author of the book "Broken Benefits: What's gone wrong with welfare reform."

@sam_royston

Measuring what matters

"Too often end of life care focuses on treating individuals as patients, rather than people. We rarely pause and take time to understand what really matters, the differences we could make if we tailored our care to more holistically meet people's needs. If we wanted to develop a wellbeing focused approach to caring support at the end of life, what would we need to do?"

We'd need to ask people what mattered and how they were doing: we'd measure wellbeing. And importantly, we'd act on it. There's no point in measuring if you can't follow through on your actions. We need to ensure the resources are there to deliver services, which can address and respond to the wide range of needs: a public health approach to end of life care."

"We don't seem to have a way of approaching death that allows for a conversation about the quality of life. Too often people find themselves in a system that's driven by survival as the key success metric."

Clair Fisher



Understanding and measuring Wellbeing at the end of life

Deborah Hardon

What matters?
 anxiety
 Sense of PURPOSE
 Overall life Satisfaction?
 How are you doing?
 Workplace question bank
 Qualitative
 Quantitative Data

Measuring wellbeing

Sam Royston

children's wellbeing
 HOW do we know what matters to children unless we ask?
 Same issue
 Beginning AND End of life
 1 Measure
 2 Act
 Public Health approach
 Ask people what matters to them
 then act on that
 Loneliness
 Benefits
 Health needs
 over-medicalising care

3 Qs for Today...

- What needs to change?
- What do we need to know?
- What do you want to do?

Potential

Next Steps

- Map our Knowledge / What we've done
- Asking Well? How do we talk to a wider group?
- Embedding planning in the NHS.

COLLABORATION

LIVE ILLUSTRATION
 Katie Chappell

Who does this apply to?
 Better understand + recognise
 < 6 months to live
 Benefits System
 Personal Health Budget < 4 weeks to live
 Let's stop having referral criteria

Death impacts everybody

Family + Community

Network Mapping

Loneliness

Advance care planning (wellbeing intervention)

Ripple effect
 everybody's wellbeing improved

HUMAN EXPERIENCE
 "medically complex"

Normalise advance care planning as a wellbeing tool.

Holistic

Research Qs

End of Life wellbeing - what does it look like?

Does "wellbeing" matter to the general public? - language?

How often are advanced care plans offered?

DEFINE: advance care planning



ACKNOWLEDGEMENTS

The Centre would like to extend its thanks to all speakers and participants, in particular Clair Fisher who conceived the project and has championed its development. If you would like to work with the centre on Dying Well, [please join our network](#).

The Dying Well network is a group of practitioners, policy-makers and academics who take a 'what works' approach to understand and improve wellbeing of terminally ill people. The network shares knowledge, ideas and challenges collaboratively to find out what works to improve wellbeing at the end of life. The group was brought together by the [What Works Centre for Wellbeing](#) and [Clair Fisher](#) in April 2021.

Read more about our work on Dying Well and how to become a member of our network on our [project pages](#).

You can listen to Tanni Grey Thompson, Clair Fisher and Nancy Hey discuss how end of life care can be made better on The Times [The Red Box Politics Podcast](#).

This briefing was prepared by Viki Taylor-Kidson, Ingrid Abreu-Scherer and Joanne Smithson. The Illustrations were created by [Katie Chappell](#).

To cite this briefing: Taylor-Kidson, V., Abreu-Scherer, I., and Smithson, J., 2021. Wellbeing at the end of life: practitioner conversations. What Works Centre for Wellbeing.

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