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**OPPORTUNITIES
FOR CHANGE**

In end of
life care.

Better Endings

Areas of Opportunity

1. No one is lonely

Recognise and make the most of people's desire for human connection as they come towards the end of life. No one who is dying, or is caring for someone who is dying, should feel alone.

2. A good death away from home

Draw on the ideas, energy and capacity of family, friends and the wider public to improve and enhance care for people dying in institutions.

3. Focus on legacy

Find new ways to talk about and make sense of dying and loss through the idea of 'legacy' rather than endings, so that we can feel more at peace with these experiences.

4. Allow loved ones to care

Make it much easier for informal carers, families and wider support networks to provide the right care and support to loved ones who are dying.

5. Value people's sense of self

Provide support at the end of life which means people feel understood, empowered and cared for as an individual in a way that is right for them.

6. See the bereaved as assets

Enable bereaved people to use their powerful insight, experience and empathy to support others that are dying or recently bereaved.

1. No one is lonely

What is the opportunity?

Recognise and make the most of people's desire for human connection as they come towards the end of life. No one who is dying, or is caring for someone who is dying, should feel alone.

What's the problem? Why is this important?

Loneliness and social isolation can be a huge problem for people as they approach the end of their lives, whether we are old, frail or unwell or are caring for someone in these situations.

Loneliness often becomes a problem for us when:

- We are no longer able to be as independent and active as we were in our younger or more 'well' life
- We age and close family or friends die, leaving us without the support network we might once have had
- We move or change where we live because of our changing needs
- We are caring for someone and need to put our lives 'on hold' for an indefinite amount of time or change routines (including taking leave from employment, or moving house), in order to support a loved one.

And, of course, not everyone has a strong or supportive family or social network to begin with – the difficulty of this amplifies hugely at end of life.

What if...

- we all had the opportunity to develop new passions, interests and connections, as we got older and our capability changed?
- every person over 80 had a person who called them regularly or a daily knock on the door from a neighbour?
- every care home was co-located with nursery or a school?
- every carer had a trusted person to help them manage the experience and help them keep their own lives together?

"I've lost all motivation ... I can't do any of the things I loved to do. I can't go to the theatre anymore because I can't hear well ... I'm struggling with my fears of tripping over. This takes all the pleasure out of walking. I watch way too much television... I have given up on the gym recently. My life frightens me. I feel stuck. There's no purpose for me to go on."
(Resident of Lambeth & Southwark)

"I see so much loneliness around me. People are just so isolated and needing support. This does not happen in Nigeria – we are in each other's lives, there is community."
(Resident of Lambeth & Southwark)

2. A good death away from home

What is the opportunity?

Draw on the ideas, energy and capacity of family, friends and the wider public to improve and enhance care for people dying in institutions.

What is the problem? Why is this important?

Most of the people who die in England do so in an institutional setting, either in hospital (roughly 47%), in a care home (21%), or in a hospice (6%). 78% of people who died in England between 2004-08 had at least one admission to hospital in the last year of their life, many of which took place in the last month of life.

For many people who die in hospital, the experience is not a positive one.¹ Whilst many of the contributing factors are perhaps best addressed by changes in professional practice, it is clear that the impact of being somewhere unfamiliar, away from family and friends, and subject to a different daily regime will be challenging for most people. We are likely to feel lonely, lost and frightened.

Even if an institutional setting has become someone's normal place of residence (such as a care home), there is an opportunity for change. Those who are employed to care are constrained in what they can offer by competing priorities, professional regulations and corporate expectations. We know that some family and friends would like to do more. But many of us feel reticent to care for people who are dying, even when presented with the opportunity. We have entrenched understandings that this should be the responsibility and sole preserve of clinical professionals.

What if...

- networks of volunteers were available to connect with people in hospital, deemed to be approaching the end of their life, to offer company, diversion, stimulation and practical help?
- volunteers were available to support isolated family members coming to visit people in hospital - providing lists for visits and supporting them after the death with the many practicalities?
- members of the public were trained to connect with individuals with advanced dementia in care homes on a regular basis, offering friendship, hand massage and time?

"I think the biggest problem that we've got is that death and dying has become the business and the responsibility of professionals and that society and the public don't recognise their role or their opportunities to influence it in the way that they might have done historically."
(CEO, Hospice)

3. Focus on legacy

What is the opportunity?

Find new ways to talk about and make sense of dying and loss through the notion of 'legacy' rather than endings, so that we all feel more at peace with these experiences.

¹ See, for example, Dying without Dignity: Investigations by the Parliamentary and Health Service into Complaints about End of Life Care

What is the problem? Why is this important?

We need new ways to talk about and make sense of death. Talking about death is a social and cultural challenge for a number of reasons. These include:

- Death is scary and so many of us find it hard to think about and talk about
- When you know you are dying or approaching the end of your life, or when this is happening to a loved one, it can be really hard to have important conversations and find a route into the subject
- Many people at the end of their lives have a spiritual or emotional need to reflect, find meaning and make sense of the life that they have led. Many of us want to do this with the people we love and will leave behind but we often need support
- In our culture we are lacking rituals of remembrance that go beyond a funeral, rituals that provide a way for people who are grieving to acknowledge the loss and the continued presence of a loved one in their lives.

We have learnt that whilst the notion of endings is difficult, people find it easier to talk about the legacy that they leave. For some this is a positive way of ensuring their impact or presence beyond death; for others it is part of the fear of dying - that they will not be remembered. In other words, 'legacy' is a concept that helps us to see and feel the continuity of life and the impact of a life on the world. It may therefore provide a more accessible route into conversations about death, and some of the more challenging practical preparations.

What if...

- discussions on the part of the public focused on legacy and started by asking us how we wanted to be remembered, rather than how we wanted to die (making space for emotional and spiritual conversations)?
- there was a game you could play with your family to help articulate what's been important to you in life and how you want to be remembered?
- people were invited to complete an app providing details of the legacy they would like to leave?
- artists visited care homes, hospitals and homeless shelters to help people visualise, share and document their lives (for yourself and others)?
- we had festivals or public remembrance rituals for those who had died a 'normal' death?

"I'm not happy it's coming to an end...I'm afraid of missing out when I'm dead; all these millions of years that will come after me!"
(Resident of Lambeth & Southwark)

"Existential questions and concerns can be very real and painful at the end of life"
(Chaplain)

4. Allow loved ones to care

What is the opportunity?

Make it much easier for informal carers, families and wider support networks to provide the right care and support to loved ones.

What is the problem? Why is this important?

We know that being supported by the people we love is important at the end of life. No matter how

good they are, health and social care professionals simply do not have the time to understand or attend to the full set of people's wants and needs, in the way a loved one might do. Family and/or friends are likely to have a better understanding of the person they're caring for and are well placed to notice the subtleties of what people want and need.

Many of us would want to do what we can to make our loved ones last days rich, loving and full of meaning. The role that family and/or friends play can be critical and transformative – it can be the difference between dying well or dying badly. But there are barriers to families and friends becoming more actively involved in care and support that include:

- Knowing you can do it and having timely access to help and support when you can't
- Needing to know what to expect and how to prepare, and who to reach out to for medical and other forms of support
- Needing to learn new skills to support someone who is frail, losing capability, unwell or in pain (such as how to lift and move a person safely, or administer pain relief)
- Sometimes enduring prejudice from professionals and services, if you are not immediate family (though are the person who loves and cares)
- Finding your role amongst multiple professionals/agencies/services

Enabling these networks to be as involved as they would like to be, and enabling them to provide the care they want to, could better support the person that is dying, reduce feelings of helplessness amongst their loved ones and enhance the work of professional services.

What if...

- friends/families/carers sent regular updates to the GP of the person they're caring for and flagged any changes?
- friends/families/carers received a home care kit including equipment and instructional video to enable them to meet basic home care needs?
- hospitals worked like hotels where patients and their families could create a more comfortable and personal environment?
- carers had access to a helpline 24/7 on which they could rely for advice and support?

"The question for me is how you can use experts to empower and enable family?"
(Bereavement Specialist)

"Dying well means being supported by the right relationships with family, friends, carers and professionals."
(Leadbeater and Garber, Dying for Change)

5. Value people's sense of self

What is the opportunity?

Find new ideas and capacity to provide care so that everyone at the end of life feels understood, empowered and cared for in a way that is right for them.

What's the problem? Why is this important?

People sometimes report that their experience of professional health and social care feels impersonal and insufficiently attentive to them as individuals and human beings. We know that stretched health professionals often do not have time to answer people's questions, let alone provide the full range of support people might need and to understand what's

happening to them, what they should expect and how they can prepare for death.

Many people find their sense of self is challenged at the end of life. They might not be able to do what they most enjoy, they might find themselves in new and unfamiliar environments, they might be surrounded by and cared for by people they don't know (and who has no sense of them as a younger or fitter person).

But so much of the support that people want at the end of life - to be listened to, to be understood - requires us to acknowledge people as human beings, not just as patients. And to do this, we need to understand how people see and understand themselves.

What if...

- volunteers in hospitals spent time with people (that professionals might not be able to give) helping them to understand their situation and prepare for what's ahead (and feeding this back into professional analysis and support)?
- every person with terminal diagnosis had access to a supporter who helps them to capture their story, so that when they meet professionals they have an easy and succinct way of explaining who they are and what's important to them?
- family and friends were able to play a bigger role in providing support in institutions of care and at home?

*"There was a lack of humanity in the process right from the start. There didn't seem to be anyone, really, that my father felt he could ask questions to."
(resident of Lambeth & Southwark)*

*"It's when we cease to be inquisitive and become deductive that we cease to see people as people"
(Chaplain)*

*"We have to be much more mindful that people die from a life."
(Palliative Care Specialist)*

6. See the bereaved as assets

What is the opportunity?

Enable bereaved people to use their powerful insight, experience and empathy to support others that are dying or recently bereaved.

What is the problem? Why is this important?

Most people in the UK have very limited exposure to issues related to terminal illness, death and bereavement until it happens in a significant and personal way to them. People have to learn a new vocabulary, find their way around a variety of systems previously unknown to them, and cope with a variety of unexpected emotions and problems. In the early stages of bereavement, people often need reassurance that what they're experiencing is 'normal' grief. Indeed, "I think I'm going mad" is one of the most common phrases in calls to bereavement support lines.

Loss and grief are parts of life that we will all face, but we are not well prepared to support each other through them. Dying and loss are made more frightening by the lack of public understanding and

conversation about what they might look and feel like.

Whilst professionals will want to provide information wherever they can, access to them may well be limited and their vocabulary and approach may not match that of the enquirer. The bereaved have awareness and experience that could help others. Grief after the death of a loved one is normal, and the vast majority of grieving people simply need information, compassion and empathy from others. This doesn't need to come from a specialist or a professional service. It can, and should, come from those around them.

Bereavement support is currently focused around formal counselling and support group services. Whilst excellent for some, this form of support might not best suit everyone. For some, bereavement is a time when they want to use their experience to benefit others or to do something in memory of the person they have lost.

What if...

- bereaved people could join a dog walking group with others with a similar experience?
- bereaved people were given the tools and resources to set up conversation groups with people in their community?
- the loved ones of a person who is dying were provided with mentoring to support them in advance of their loved one dying, and after their loved ones died?

*"Until you go through bereavement, you don't really understand what it means. And having been through it personally, I feel like I'm able to support people better."
(Occupational Therapist)*

*"In bereavement services, what keeps people coming back is the feeling that they can help others, so they're no longer 'just the recipient'. People volunteer because they get something out of it."
(Social Worker)*