Reshaping future experiences of dying, death and bereavement

Summary | October 2020

nesta
People Powered Results

Marie Curie
Care and support through terminal illness

StChristopher's
More than just a hospice

The time is now for collective action

Covid-19 has forced everyone to reflect on dying, death and bereavement in some shape or form. Whilst acting as **a catalyst for significant change and innovation** across the health and care system, and communities, it also **increased pressure on systems, leading to trauma** for staff, people and families.

To better understand these changes, we gathered **insights from a diverse range of perspectives** through 1:1 conversations and hosted an online open event in September 2020.

This document reflects what we have heard so far; what people said needs to change and where the opportunities for change exist, together with some next steps to take towards **reshaping future experiences of dying, death and bereavement**.

'Covid has shown the system can change at pace - this demonstrates an opportunity' **Clinical Lead**

'Let this be the start of the movement... ' **Event Participant**

Who did we interview?

Through the summer of 2020 we undertook 1-2-1 interviews to gather a range of perspectives, from...

- Academia
- Palliative Care professionals
- National charity leaders and staff
- Hospice CEOs & Medical Directors

- Learning disability sector
- Homeless sector
- Care homes
- Local charity representatives
- BAME representatives

- Carers, family members and loved ones
- Community activists
- Care homes and specialists in care of the elderly
- GPs and other general healthcare professionals
- Hospice CEOs & Medical directors

52 people
across England

Including 11 people with lived experience
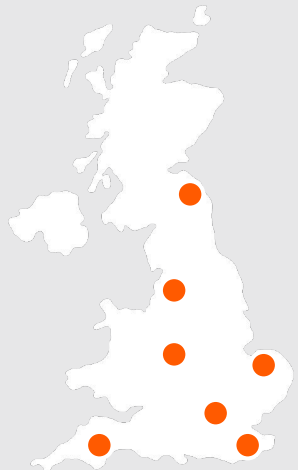
From a range of organisations, including:

11 hospice organisations

6 community and vol. groups

5 NHS Trusts

2 universities

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Who joined the virtual event in September?

In September we convened a diverse group of over 200 people from across England, Scotland & Wales to reflect on the changes through the initial Covid response, and to identify the themes that could reshape peoples experience of death, dying and bereavement.

Around 75% of those who signed up attended, reflecting the collective enthusiasm for change

From a range of organisations and groups:

- Palliative care networks and partnerships
- Adult and children's Hospices
- National and local charities
- Community organisations and groups
- Universities and research partnerships
- Digital health & technology companies

- Care homes
- NHS trusts
- Public health
- CCGs
- Mutual Aid groups
- National health bodies
- Faith based organisations and networks
- Integrated Care Partnerships
- Carer support organisations and networks

With a number of different roles and specialties:

- Palliative and End of Life Care specialists
- End of Life Doulas
- People with lived experience
- Carers
- Commissioners
- Creatives/artists

- CEOs and leaders
- Analysts
- Programme Managers
- Psychologists
- Religious leaders
- Suicide bereavement support
- Academics and researchers

From different sectors and specialities:

- Palliative care
- Dementia
- Homelessness
- Learning disabilities

- Cancer support
- Occupational health
- Mental health
- Care of the elderly
- The arts

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What people told us...

There is a significant opportunity to reframe how we approach death, dying and bereavement

Alongside the challenges that it brought, the pandemic also acted as an **accelerant for innovations and new ways of working**, and systems have demonstrated they can adapt quickly. There was also an acknowledgement that in some instances, the **crisis amplified the cracks** in the current system.

Insights gathered have been grouped into **5 thematic opportunity areas**, as set out opposite and explored in more detail over the next pages.

'If there was ever a moment - now would be the time.'
Palliative Care Consultant

Equitable, person-centred and holistic support

Dialogue and **culture** around dying, death and bereavement

Role of **digital tools and tech**

People's future experiences of dying, death and bereavement

Collaboration and reciprocity

Communities in the lead

Equitable, person-centred and holistic support

People experienced variable access to high standard, holistic care

A snapshot before Covid-19

Access to high standard, holistic care was variable and dependent on several factors including catchment area, eligibility and timing.

Staff often worked to share resources and knowledge through training so patients could have more equitable experiences, but this didn't happen consistently.

Some people were unaware of the options available, struggled to navigate through different services or found services did not chime with their cultural or religious beliefs. This meant that many were left without their physical, emotional, cultural or spiritual needs being met at the end of their lives.

'I can think of an elderly couple – a gentleman was caring for his wife. She wished to die at home. Unfortunately, he couldn't work the washing machine, her bedding etc was then of concern when the district nurse visited.. agencies then decided his wife had to be cared for in hospital as he wasn't 'coping'. His wife died in hospital and her wishes weren't met. He simply needed assistance with the laundry.'
Event participant

'We can't expect a homeless person to come to a shiny outpatient unit and behave in the way we expect them to. They need us to build the model around them rather than how we think we should provide care.'
Hospice Leader

'It is about time decision makers look out for culturally appropriate services and develop a framework to provide these services at scale.'
BAME health community leader

Equitable, person-centred and holistic support

Existing inequalities in access to person-centred and holistic support increased due to Covid-19, and in some cases were exacerbated due to shifts to digital delivery and the removal of choice for some groups.

Shifts since Covid-19

Inequalities and gaps in services were emphasised during Covid-19 for groups that were already marginalised. The Black Lives Matter movement shone a spotlight on privilege and inequalities at a systemic level. People had traumatic experiences of bereavement where they were not able to say goodbye to loved ones. Digital delivery generally improved access but marginalised some groups. Policies around cardiopulmonary resuscitation put in place for some groups are currently being reviewed and investigated.

Some shifts increased access and participation. Hospices providing services in community settings saw demand increase, as people stayed away from formal health buildings. The shift to virtual outpatient services enabled some people who were too ill to leave home to receive support from services they previously couldn't access. Existing services adapted to meet more people's needs as they worked in new partnerships to meet demand during the crisis, including with local faith and BAME groups.

'We don't need to look too far to amplify the voices from the Black Lives Matter movement to ensure that we are not creating something for a certain section of society that already holds the privilege.' **Event participant**

ONE SIZE DOES NOT FIT ALL

'Instead of providing a Rolls Royce service for less people we should provide an Audi experience for all.' **Manager at Hospice Charity**
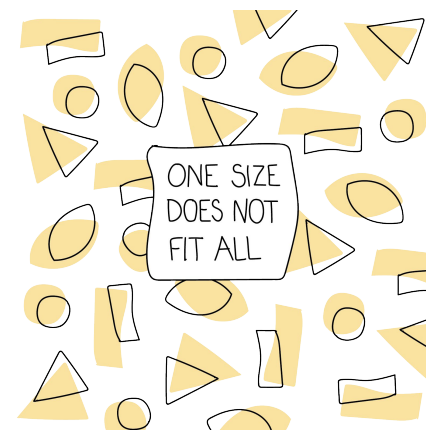
'Access to technology and specialised end of life care is still not equitable despite a great community effort during lockdown. There remains key groups that are disadvantaged in this respect.' **Event participant**

Dialogue and culture around dying, death and bereavement

A snapshot before Covid-19

Society as a whole has been less comfortable talking about death.

Some groups' cultural traditions made them less likely to have conversations about death and professionals were fearful and found it difficult to talk about death with certain groups e.g. people with learning disabilities.

This discomfort meant these conversations are often left to highly trained specialists, resulting in them sometimes happening too late or not at all for some not receiving support from specialist services.

Some organisations and artists had been facilitating more open dialogue through initiatives like Death Cafes and intergenerational approaches.

'Cultural changes and building clinicians' comfort having conversations about future plans and ending curative treatment can support people to have a better experience of End of Life whilst saving money across the whole system.'

National Charity Director

'We found people with heart failure recognised when they were less well and potentially facing death. but their health care professionals didn't want to discuss it with them.'

Event participant

'It (EoL) is everybody's business.. like safeguarding… even though we have negative thoughts about these conversations we need to embrace people having (them), as we all have a right to know.'

GP

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Dialogue and culture around dying, death and bereavement

Covid-19 heightened awareness of death, however, there is more work to do to normalise talking openly about dying, death & bereavement.

Shifts since Covid-19

**The pandemic and media attention on daily death tolls led to heightened awareness of death and dying amongst the general public.** Whilst this encouraged some families to have conversations with loved ones, it also increased a sense of fear and discomfort in many. Staff experienced stress and trauma, exacerbated by a feeling media and politicians were placing blame on them. National pressure on clinicians to ensure patients had Advanced Care Plans or ReSPECT forms meant that these sensitive conversations sometimes felt rushed.

This heightened awareness is pushing people to have conversations with their loved ones about dying and death. As funeral rites changed and caused distress for loved ones, people started looking at alternative ways they can remember their loved one. People bereaved as a result of C19 have also been calling for a national dialogue to ensure we prevent traumatic experiences of bereavement in the future.

'I'm concerned about the impact on people where Advanced Care Planning is not done well, and I have seen that locally. The desire to make sure it is done to respond to a challenge has meant it has been foisted upon patients.' **Clinical Lead**

WE NEED TO NORMALISE TALKING ABOUT DEATH
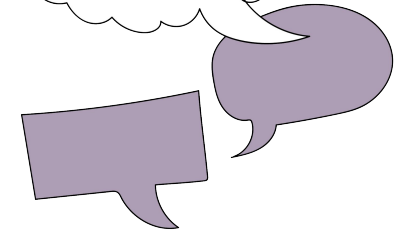
'I've got masses to do – I do voluntary work with the blind; calling people – but one bit in my head doesn't feel right – won't feel right – until [the memorial service] is done…it will be closure, when we are allowed to have it.' **Family member**

'We have seen that we can tolerate talking about it (death) more without society collapsing and relationships are actually better as a result.' **Charity Leader**

A snapshot before Covid-19

Models for community-led support focused on dying, death and bereavement had been tested and campaigned for, but still felt marginal.

They were hampered by public services' concern about the perceived risk around neighbours supporting each other, and the idea that citizens wouldn't be motivated to support each other when facing difficult circumstances.

Some communities already supported each other through death and bereavement, but this didn't happen consistently for everyone. This meant opportunities to connect people to receive support from their local communities were often missed.

'There are 2 parallel worlds spinning.. health & community and family.. What has worked when we have seen excellent deaths is.. often a dance between professional and social networks.'

Palliative Care Consultant and Academic

'We have to accept that 80% of your health is not determined by anything the NHS does – it's your relationship to your home, your environment.'

Event Participant

The NHS is full of people doing their best. But what is equally important as people within the NHS, are the volunteers within the communities.

Palliative Care Physician

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Communities in the lead

Citizens mobilised quickly during lockdown, demonstrating they have the energy and skills to provide vital support locally. More work needs to be done to sustainably harness citizen's energy to support each other.

Shifts since Covid-19

People connected and mobilised support across neighbourhoods as a "community of volunteers" in a matter of days, often enabled by social media.

Communities and local organisations rapidly sprung to action and worked with health and care services to meet vulnerable people's needs. Online communities sprung up, and more funding became available for grassroot organisations.

Families who were shielding or bereaved found that schools, local organisations and faith groups provided helpful support, incl. daily phone calls, delivering prescriptions and food, and adapting funeral processes to meet distancing guidelines as well as people's practical, emotional and spiritual needs throughout lockdown. Some started reimagining their roles in their communities, becoming local Mutual Aid coordinators and leading ceremonies for their loved ones.

'When we found out the temple were getting involved to help us carry out the funeral service, it took so much pain away.' **Family member**

'People are finding ways to engage with their neighbours in ways they never have before.. Never before did people know the names of people on their street, and now they do. That is not going to go away. Those relationships will hold.' **Charity sector leader**
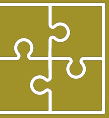
WHEN WORKING TOGETHER COMMUNITIES ARE POWERFUL

'Organisations need to take a more active, intentional role in creating more available time for people to spend in their neighbourhoods.' **Community activist**

A snapshot before Covid-19

Competition, regulatory and funding mechanisms sometimes hampered trust and collaboration between organisations.

There were promising examples of joint-working locally, but different eligibility criteria, funding flows, targets and governance arrangements were getting in the way of scaling joint-working practices.

Leaders were working towards greater integration regionally through Integrated Care Systems, but these cover approximately half of England's population and are still in early development stages.

'When the rest of the system goes through redesign - we don't have the continuity with the people that we are dealing with.
People have to reapply for their jobs - the top down approaches of commissioning create paralysis in the system.'

Hospice Chief Exec

'During our work we bumped up against a lot of hospices and realised that we share values.. it is just our technical knowledge that is different.. We were able to have an exchange of knowledge.'

Learning Disability organisation lead

'Organisations are risk averse, but people aren't. People take risks all the time.'

Community Activist

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Collaboration and reciprocity
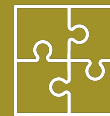
The crisis removed obstacles hampering cross-organisational collaboration, enabling resources and knowledge to flow freely. Without permanently removing these obstacles, there is a risk of slipping back.

Shifts since Covid-19

Pressures of the pandemic changed the drivers within and across organisations, in many cases superseding concerns about competition and funding. A reduction in resource and capacity led to a shift in focus to crisis delivery and a sense of 'one team' working towards a common goal. People said they felt less hampered by concerns around "risk".

Overall staff shared resources and expertise faster and more often, aided by virtual working. This included through virtual training, daily briefing calls and local multidisciplinary whatsapp groups.

Collaborative working was inconsistent. Some families felt abandoned by services, while gaps in medication access were exacerbated. Care homes received less practical support than health services and patients and families felt they were given less information and not involved in key decisions about their care.

'Even before C-19, it was very difficult to get joined up support.. The pandemic has just made everything worse.. So, for four weeks it was just about Covid and everything else got out of control.' **Family member**

'We had an outbreak of Covid among our clinicians.. this actually strengthened our relationship with district nursing colleagues as we were more reliant on them to help us with symptom control.' **Director of clinical services**

'We need to take competition out of services.. money is the thing that upsets people most... We have moved a long way in Covid, but I can see us slipping back.' **Hospice Director**

COLLABORATION IS ESSENTIAL

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A snapshot before Covid-19

Promising examples of using tech and digital tools to support practitioners, patients and families were emerging. These included virtual outpatient clinics, memory-making virtual platforms and technology to support care and planning for a good death.

The spread of digital tools and tech were held back by concerns about equitable access. Some people lack access to equipment or experience data poverty. Staff were also concerned about the potential impact on quality of care, slowing down digital transformation efforts. There was also a lack of sharing of best practice across the sector.

'Telemedicine services were commissioned in the past so we were already equipped to move to digital. Pre Covid, there were about 400 care homes utilising telemedicine. Now there are about 870 care homes using it.' **Nurse Consultant**

'The system was good, but if the family didn't have tech at the other end, or if the patient was too poorly or too old, it didn't work.' **Event participant and retired GP**

'We are fortunate that we have Coordinate my Care, an electronic database that nurses can use. Having a shared record has helped improve patient care.' **Regional Palliative Care Services Lead**

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Role of digital tools and tech

A forced shift to virtual working enabled staff to connect, grow their digital confidence and meet increasing demand. It also further marginalised some groups and shone light on the limits of virtual working in this context.
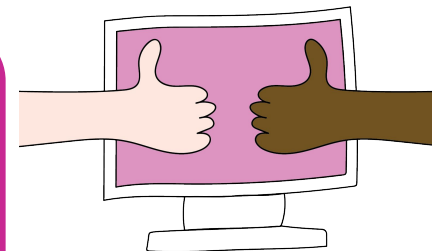
Shifts since Covid-19

A 'forced shift' to virtual working enabled staff to connect more easily and meet increasing demand, particularly with urgent referrals and supporting bereaved teenagers online.

The digital shift led to some having traumatic experiences and being further marginalised. Some people's experience of accessing digital services was traumatic, and in some cases led to serious safety concerns. It also excluded people who were already marginalised because of their condition or their access to equipment and data.

Families and practitioners' confidence in using digital tools grew. Families relied on video calls to stay connected and in some instances this enabled more people to come together, e.g. in online memory-making sessions. Practitioners used digital tools more often to share information, involve loved ones and others incl. priests and imams in people's care.

'Mum's dementia is getting worse, but the GP won't go out. Every 3-4 weeks she gets a Video Consultation, but mum has no idea. I can see the real benefits of video or telephone consultations, but not for an 83-year-old woman.' **Family member**

TECHNOLOGY MUST BRING PEOPLE TOGETHER NOT PUSH PEOPLE APART

'We saw it (the funeral ceremony) over the internet, live.. It was a relief that we could see it as well.. Our temple played a major role and has done throughout the whole pandemic.. They provided a guided audio ceremony.. We were blessed.' **Family member**

'Myths around digital services have gone away overnight since Covid.' **Nurse Consultant, Digital and Acute Care**

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At the September event we started to think about what action and change is needed to **reimagine how we do things**, break down inequalities and work alongside communities to complement clinical support so that **everyone has a better experience** of dying, death and bereavement.

No one organisation, group or body can achieve this alone and there is work to do at every level, to:
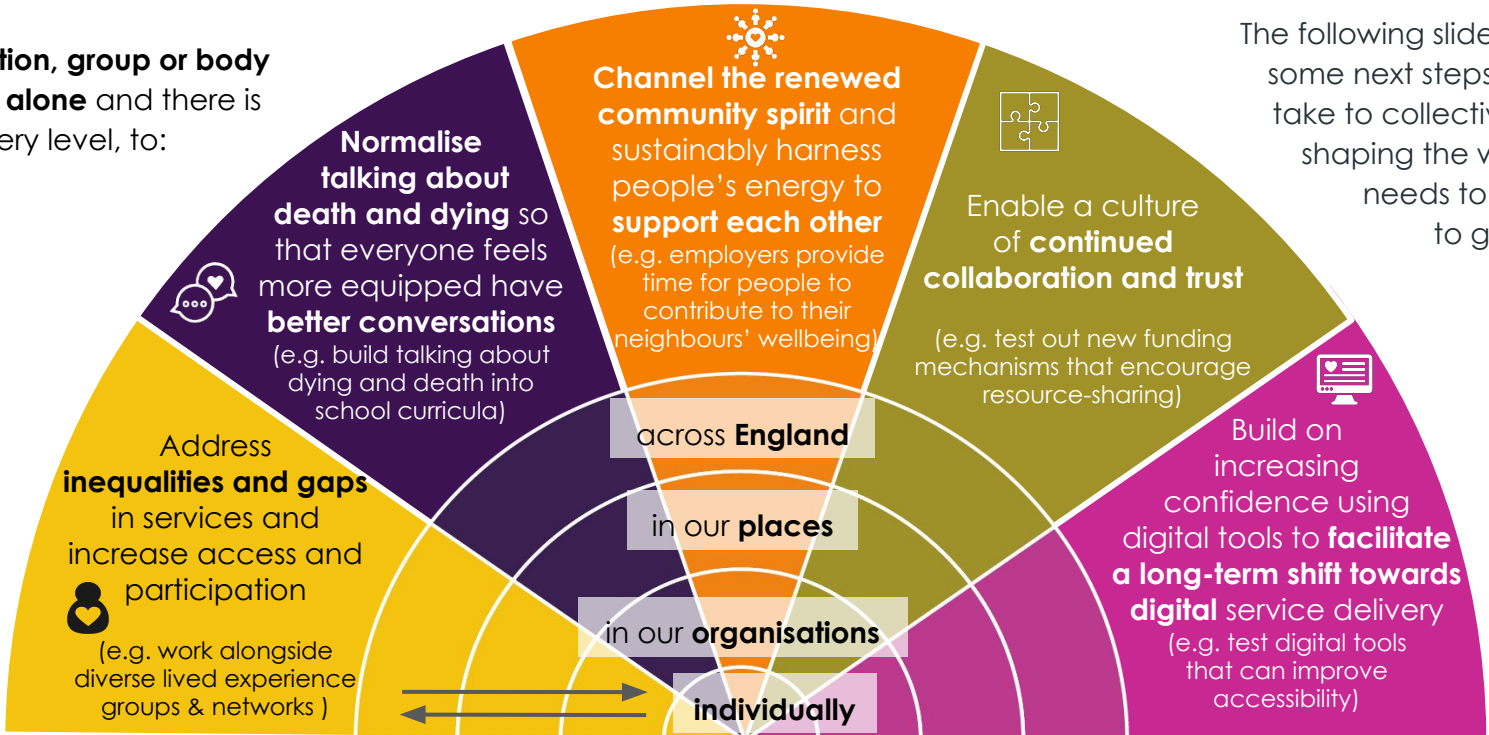
The following slides outline some next steps we can take to collectively start shaping the work that needs to happen to get there.

Normalise talking about death and dying so that everyone feels more equipped have **better conversations** (e.g. build talking about dying and death into school curricula)

Channel the renewed community spirit and sustainably harness people's energy to **support each other** (e.g. employers provide time for people to contribute to their neighbours' wellbeing)

Enable a culture of **continued collaboration and trust** (e.g. test out new funding mechanisms that encourage resource-sharing)

Address **inequalities and gaps** in services and increase access and participation (e.g. work alongside diverse lived experience groups & networks)

Build on increasing confidence using digital tools to **facilitate a long-term shift towards digital** service delivery (e.g. test digital tools that can improve accessibility)

across **England**

in our **places**

in our **organisations**

individually

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And what next..

So interesting to share experiences across the country and **realise the power we have to create change together.**

There is an **openness and a willingness from everyone to listen and learn**. We need to capitalise on that and to build in time to address challenges and **have conversations outside our silos.**

We need to create a movement that isn't organisationally based, it's people coming together with a **shared purpose.**

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Co-creating an uncommon future

A **network is building** of people with diverse perspectives and experiences who are all thinking about the same thing - **how do we do things differently and create a movement for change** so that every person has a better experience of dying, death and bereavement.

Connect on twitter to explore and interrogate these insights, share your stories and offer your views on what needs to happen next **#BetterEndOfLife**

Register your interest to hear about future events and opportunities to connect by signing up here (if you haven't done so already)

Join the dots by connecting the network to great work you know is happening already, e.g. the Hospice UK Future Vision Programme and the NHSE Palliative and End of Life Care Programme

Bring others onboard by sharing these insights or starting a conversation with those who can help us question the way things are done and bring a fresh perspective

WE ALL SHARE THE SAME GOAL
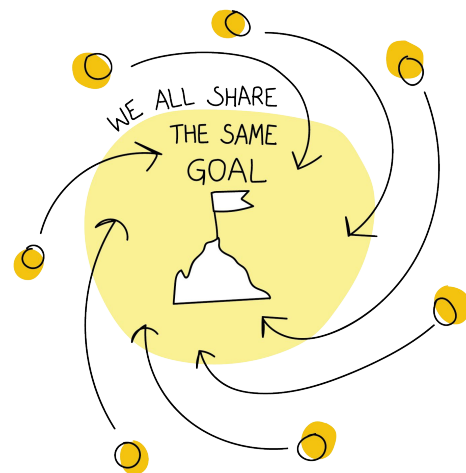
Reshaping future experiences of dying, death and bereavement

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