

Compassion in Dying – Written Evidence (LBC0193)

Rethinking Dying

Summary

"My father died in a care home during lockdown. The experience of his death reminded me the importance of control, advance planning and self-determination in respect of one's own death... I feel with lockdown I will have even less freedom of choice about my own end-of-life options."

People are often not listened to when it comes to decisions about their end-of-life care. The pandemic has exacerbated this problem. The unprecedented pressures on the healthcare system and clinicians have heightened anxieties, created new obstacles for people to overcome and deepened the power imbalance that often exists between healthcare professionals and their patients.

Compassion in Dying is a national charity that helps people prepare for the end of life – how to talk about it, plan for it and record their wishes. We have supported over 56,000 people to consider and record their end-of-life wishes. Since the pandemic began we have spoken to 4,492 people about their end-of-life decisions.

Many people have told us that they have had decisions about their care imposed on them without being asked their wishes or priorities. Considerable numbers of people have told us that coronavirus has compounded existing fears that their wishes will be overlooked or not known about when it matters, which has in turn negatively impacted their quality of life. For many, not being able to physically be with their loved ones in hospital has left people with no one to advocate for them and consequently their wishes have been overridden.

Others have been told explicitly that they will not be taken to hospital if they become unwell during the pandemic, but have been given little or no information on what support they will get at home. These people are not demanding admission to an intensive care unit, rather they have not been asked about their wishes, preferences or expectations for their end of life and have therefore been deprived of the opportunity to plan for their last days or receive care tailored to their needs and priorities. Importantly, the pandemic has exacerbated existing health inequalities at the end of life.

Put simply, dying has been made worse in ways that could have been avoided.

In 2018 we published a report which found that people approaching the end of life often do not feel supported to make the decisions they are faced with; are not always given an honest prognosis; do not know what options and choices are available; and do not know the right questions to ask their doctor. Reports by the Royal College of Physicians (2018), the Care Quality Commission (2016) and the Health Ombudsman (2015) have uncovered similar problems. These problems are still persisting.

In considering what needs to change as a result of the pandemic, it is clear that we must seek to make coronavirus a catalyst for a much-needed and overdue transformation of end-of-life care. Policy initiatives intended to promote personalised care when dying are clearly not having an impact on a large scale and are not given weight in crisis situations, which are the very times that person-centred care should be

paramount. Attempts to chip away at a culture within medicine, which too often leaves people approaching the end of their lives feeling disempowered or overlooked, have clearly not worked.

It is time for a more ambitious and purposeful rethink of how our healthcare systems support dying people. We must forge a more patient-focused way forward so that people see themselves as the leaders in decisions about their care, and are recognised by healthcare professionals as such.

The pandemic has prompted many people to consider and record their end-of-life wishes for the first time. It has enabled families to have important conversations that they have previously not been able to broach. These positive developments are evidence that, right now, we have a powerful opportunity to improve dying in this country.

Lessons from the pandemic

All the quotes included here are from people Compassion in Dying has supported and worked with since the pandemic began.

More people are thinking about end-of-life wishes and planning ahead

The coronavirus pandemic has thrust death and dying into the spotlight like never before. It has prompted an unprecedented number of people to consider and document their end-of-life wishes, many for the first time. At its peak during lockdown, calls to Compassion in Dying's information line increased by 48% and the number of people making an Advance Decision to Refuse Treatment – a document given legal force by the Mental Capacity Act, also known as a 'living will' – rose 160% compared to the same period the previous year. The pandemic has also been a catalyst for many people to discuss their wishes with both their family and healthcare team.

I have been identified as extremely medically vulnerable and I found the letter spelling this out to be upsetting (weirdly). But it prompted me to discuss my wishes and finally move on to writing things down.

Covid opened up the opportunity to have a frank and honest conversation with my mum and allowed her to communicate her wishes to me.

I knew I would be clinically very vulnerable to covid as I'm immunosuppressed. I wanted to make plans in case I did get it, so I made a living will in March and the pandemic was the nudge I needed. Having done it, I am hugely relieved. Everyone knows what the situation is. I don't think so much about dying anymore.

I have discussed my clinical wishes with my GP, stating clear instructions as to the limits of my treatment. I have no desire to live with a seriously damaged quality of life following treatment of the acute phase of Covid-19. This was by far my most important conversation I've had since the pandemic.

This growing public demand for support to plan ahead and for having important end-of-life conversations is a huge step forwards in improving people's experience of dying in the UK. We know that considering what you want at the end of life and recording those wishes reduces unwanted and invasive treatments being given, reduces unnecessary

hospital admissions and makes it more likely people will have care aligned with their priorities and goals^{1 2 3}.

However, during the pandemic, this drive from patients to have greater control over how they die has been met with many examples of health and care professionals ignoring patient preferences and making decisions *for* people without considering what's right for each person or consulting them.

Decisions have been made on a blanket basis and not based on people's needs and priorities

We have spoken to many people since March who have had DNACPR (Do Not Attempt Cardio Pulmonary Resuscitation, also known as DNR or Do Not Resuscitate) forms placed on their record with no communication or consideration of their individual needs and priorities. What's more, several people have told us that Advance Decisions to Refuse Treatment have been unlawfully completed in a blanket way by care home staff, on behalf of residents who lack capacity to make the decisions within them. This blanket decision-making has also been backed up by experiences shared widely in the UK media during the pandemic.

Such unlawful decision-making by healthcare professionals on behalf of patients completely overlooks what matters to each person and is the antithesis of person-centred care at the end of life. Despite recent national policy which clearly asserts the importance of care and treatment being person-led, these principles have not been fully embedded into clinical practice.

For the people we support, this leaves them feeling confused, abandoned and distressed.

Inside the folder I found a document which said Do Not Resuscitate. It was dated the day my husband went into the hospital. I was just overwhelmed when I saw it. At no point did someone explain that his disease was progressing and this was normal. We felt completely adrift. I felt such guilt about the DNR. If I had tried to lift it would he have lived? I now understand the rationale for one being in place, but what I don't understand is why no one thought to phone me and talk to me about it, particularly when I couldn't be with him in hospital because of lockdown.

People have been told they will not be given emergency treatment but with little information on what support they will receive

Some people have been told explicitly that they will not be taken to hospital if they become seriously unwell during the pandemic:

Me and my husband have been told if either of us gets Covid we will not be admitted to hospital. So, as we are both suffering from significant conditions we are expected not to survive. Will we die at home, who will look after us, what about our comfort? We are both frightened about this.

The surgery telephoned me at the beginning of the pandemic to say that I wouldn't go into hospital if I was ill, but would be looked after at home. I have COPD and I'm 87. Will I automatically be given a morphine driver at this stage?

To convey a decision not to admit someone to hospital or offer certain treatments without providing information or support to understand how that person will be cared for is frightening and disempowering and leads to anxiety and concern. Dying people who do not know where or how they will be cared for cannot plan for their final weeks or days. They cannot make the decisions or choices they might wish to make at the end of life without being fully informed about what options are available to them. This means that any care they receive is far less likely to be tailored to their needs and priorities, because they have not been given the opportunity to think about and express what matters most to them.

The pandemic has led to anxiety that wishes will be ignored, which reduces people's quality of life and makes their end-of-life experience worse

A significant proportion of the 4,492 people we have spoken to have told us that coronavirus has created or exacerbated significant anxiety that their wishes will be overlooked or not known about if they are too ill to communicate them. This anxiety makes people's experience at the end of life worse because they do not feel in control. People worry that what matters to them as an individual will not be taken into account when treatment decisions are being made.

People are fearful that the pandemic makes it less likely that a clinician will have time to consult their records and understand their recorded wishes before commencing treatment. Crucially, anxieties stem from the current lack of a universal system for documenting and sharing a person's wishes and preferences for treatment and care.

If I were to get coronavirus and be on a ventilator, how would the hospital staff know about my advance decision? It is registered with my GP, but would they look for it? Would they bother to read it? It makes me feel that I wouldn't be looked after in the way I set out, in the way that's right for me. It makes me feel frightened for my wellbeing.

My only worry might be that if I was hospitalised with Covid the doctors may not have the time/resources to check my records and act accordingly to the wishes I have made.

I am concerned that my wishes as expressed in a living will might get administratively overlooked in a crisis.

I remain concerned that, whilst my family and GP know my wishes about declining organ support, there is no central database for my wishes.

At present there are a number of localised systems for sharing end-of-life wishes but not all are available between care settings or across geographical boundaries. We often hear from the people we support that they gain peace of mind by recording their wishes. However, this is offset by the fear and anxiety that emerges when people learn there is no certainty that those wishes will be accessible to all clinicians in all circumstances.

As frequently happens on our information line, some people have raised the current prohibition of assisted dying, unprompted. They tell us that being denied this option adds to their fears about how their end of life might unfold, for themselves and for others.

It has not been clear to me how I would access care should I suddenly become very ill [during the pandemic]. I would also like to see the law concerned with assisted dying revisited as it is unnecessarily cruel... Please use this opportunity to have a good look at the options.

I have already assigned a Lasting Power of Attorney to my sons and also completed an Advance Decision form. I have reiterated my desire not to 'drag it out' if I succumb to illness with little or no prospect of returning to a meaningful life. If I knew there was a solid plan for assisted dying in this country, I could get on with the rest of my life knowing that, if I became seriously ill, I could have an exit that would not cause a great deal of pain to me and my family.

The pandemic has meant that people have been admitted to hospital alone, without a loved one to advocate for them

For many, not being able to have loved ones physically present with them in hospital has left people with no one to advocate for them and consequently their wishes are not known about.

Dad is 97 and discharged himself from hospital last week after his wishes to come home were ignored by clinicians. He is now receiving palliative care in the community. Not being able to visit him in hospital made it especially difficult to ensure his wishes were listened to. I felt frustrated, angry, and like he needed to be heard.

No contact was made when my dad was admitted and there was no awareness of his advanced directive. He was deemed to lack capacity when he was there and I am his Lasting Power of Attorney, but no one contacted me. I couldn't speak to a doctor about him at all despite trying. No one asked about his wishes or if he had written anything down. They gave him medication to extend his life that he wouldn't have wanted. I feel that his stay may have been more like what his wishes were if they'd known about the advanced directive, as it was he came home after a highly stressful 13 day stay, having suffered delirium and seemingly aged 20 years. I felt excluded and frustrated. It's scary enough when your folks go into hospital, so the lack of contact I was shocked at. I know they're all really busy but communication needs to be better. You need to be asked about advance directives.

The experiences shared with us during the pandemic suggest it is very likely that those with low health literacy or additional communication and/or support needs have been disproportionately impacted. For these people, the consequence of having no one accompany you to hospital is that it is much more difficult to ensure your voice is heard and more difficult to make informed decisions. The fact that there is no universal system for sharing end-of-life wishes means that advance care planning documents are not always known about, particularly if a family member is not present to alert the medical team to their existence. This results in care that is less likely to be person-centred.

Groups that are more likely to experience health inequalities are less likely to plan for the end of life during the pandemic

Coronavirus has meant that people who are already at risk of health inequalities are now even less likely to consider their wishes for the end of life and subsequently less likely to receive care aligned with their values and priorities.

We know that many communities who experience health inequalities also face additional barriers, such as structural racism, which can prevent people from accessing mainstream support. In addition, language barriers and lower levels of health literacy mean that some communities are less likely than the wider population to be able to document their wishes without support. Communities likely to experience this marginalisation include Black and minority ethnic communities and people with learning disabilities.^{4 5 6} We also know that people with higher levels of support needs require much more help to consider and record their end of life wishes, but unfortunately this support is not always available. This means that people from certain communities or who need more help to plan ahead have a worse experience at the end of life.

During the pandemic, we have found that services designed specifically to tackle these issues have been underused due to the option of face-to-face support being taken away. The 'Lambeth Advance Care Planning Consortium', a three-year initiative led jointly by Compassion in Dying and Healthwatch Lambeth, works specifically with local communities known to be at risk of health inequalities by creating community-led services tailored to their needs. These groups include people who speak Portuguese as a first language, informal carers and people with learning disabilities. During the project's scoping phase, around 400 local people said they were supportive of the culture change needed to talk about death and dying, and agreed that there was a need for local support to have conversations about how people would want to be cared for at the end of their life. However, the newly established service has supported only six local people via phone or Zoom since lockdown began, as people have said they would prefer to wait until they can talk with someone in person.

"The restrictions associated with Covid- 19 have led to a change from face-to-face sessions to virtual online groups. This has narrowed who we can engage with to those with digital resources but also limited our engagement with those who prefer to have face to face conversations." Community worker, local carers' organisation from the Lambeth Advance Care Planning Consortium

This finding is in stark contrast to the steep rise in demand for phone-based support from Compassion in Dying's information line, which is mainly used by white people with lower levels of support needs and higher levels of health literacy. When it comes to end-of-life decision making, it is clear that people who most need support or who could benefit from a service tailored to their individual needs are being disproportionately affected by the lack of face-to-face contact that the pandemic has necessitated.

We have found, however, that when community, peer-led support to plan for the end of life is already established, then people within that community will continue to consider and document their end-of-life wishes and access the support available. For example, in the Portuguese community in Lambeth an advance care planning service provided by Portuguese people themselves (as part of the Lambeth Advance Care Planning Consortium), has been well-established for two years, and the project has seen almost no reduction in demand for help to document end-of-life wishes.

"When there is really good support that is integrated into our community and delivered by people the community know and trust, then a crisis like this can be easier to deal

with because the support people need is on their doorstep and they know where to find it... My community has been able to keep planning ahead for the end of life because there is the right local support, without the need for an interpreter, and it has already been normalised." Portuguese-speaking community worker, local advance care planning and community support service from the Lambeth Advance Care Planning Consortium

Rethinking end-of-life beyond Covid

The pandemic offers a powerful opportunity to reframe how we approach dying in this country. People have to now be given more power over their end-of-life decisions. These decisions must be made *with* and *by* patients, not *for* them. People must be listened to. This will ensure more people have a better death.

The fact that the pandemic has prompted so many people to consider what matters to them at the end of life, have conversations about this with the people close to them, and record those wishes, demonstrates the growing appetite from people to make decisions about and plan their end-of-life care.

This growing public awareness must be nurtured and, in parallel, met with the right information, support and systems to ensure people can feel in control and have their wishes known and respected.

Reorienting medical practice and culture around the needs and wishes of the individual

During the pandemic, decisions have been made on a blanket basis instead of being based on people's needs and priorities. It is clear that much more needs to be done, urgently, to make sure this does not happen again.

Healthcare professionals need more support to improve their knowledge and confidence of DNACPR decision-making, shared decision-making and advance care planning. We know through our extensive work with clinicians that many are reluctant to start a conversation about someone's end of life wishes because they fear they lack the skills to do it well⁷.

Cues that people could benefit from or might be open to a conversation about their end-of-life wishes need to be recognised and acted upon. Dying is now everyone's business and opportunities to encourage someone to consider and document their end-of-life wishes should not be missed. Such opportunities also should not be deferred to the next clinician along a person's treatment pathway because of a misapprehension that another clinician may be better suited to having the conversation. This is everyone's responsibility across the health and care sector.

Capturing public mood and creating a culture which normalises considering how you might die

There is extensive evidence that planning ahead has a positive impact on the quality of a person's end-of-life experience. We need a culture where considering *how* you might die is commonplace and making an end-of-life plan is as normal as making a birth plan.

There is still an enormous disparity between the large proportion of people who have clear views on the kind of treatments they would or would not want at the end of life, and the relatively small proportion who have taken practical steps to record their wishes. There is no greater opportunity than now, during the coronavirus pandemic, to think about this. We need much greater awareness amongst the public of why it is important to consider end-of-life wishes and document them, how this can help, and how to go about it. Alongside this increased awareness of planning for the end of life, there must be information and support to do so which meet the needs of each individual.

Revolutionising end-of-life records so people's wishes can be shared and accessed with ease

Treating people in line with their wishes should not depend on a family member or friend being present to advocate on behalf of their loved one. We must develop a safety net. This means creating an effective system which enables treatment preferences to be documented and shared between clinicians, but it also means developing a culture in medicine in which people are actively encouraged to consider their wishes in advance of a decline in health and to document these accordingly.

End-of-life records must be accessible and shared seamlessly between care settings and across geographical boundaries so that if someone's family member can't be by their side to advocate for them, or if they don't have someone to play that role, their wishes will still be known about and followed.

In order to address the significant anxiety that many dying people feel about their wishes being overlooked, this system should also enable them to check and amend their wishes and preferences themselves. Parity of access and the seamless sharing of end-of-life data – and consequently the confidence that any treatment in the future will align with what they want – will make a significant difference to the quality of dying people's life and death.

Addressing health inequalities in end-of-life care

We must ensure that people who are already at risk of health inequalities are not disproportionately affected by the pandemic and consequently even less likely to make decisions about their end-of-life care and plan ahead. If we allow this to happen then ethnic minority communities and people with lower levels of health literacy will continue to have a worse experience at the end of life.

To prevent this happening, we need to work alongside people in their communities to provide support that recognises their distinct experiences and meets their needs. The role of communities in enabling more dying people to plan ahead must be recognised.

Ensuring that nobody is unable to plan for their deaths because of a lack of information about their options or a lack of support to make decisions

During the pandemic many people have been told they won't have access to certain treatments with little or no information on what support they will have in their final months or weeks. This is unacceptable. Without information on what people's options are or what support is available, they cannot hope to make decisions about what's right for them or plan their care in advance. We must ensure that dying people have the information *they* need to be able to make decisions that are right for them.

What happens next?

These are ambitious aims, but their scale is matched by the impact that the current culture around end-of-life care has on dying people and their families. The unprecedented pressures that the healthcare system and clinicians were under as a result of the pandemic has exposed the fragility of past attempts to make care more person-centred. It has also highlighted the need to urgently implement new ways of thinking.

There are efforts underway in some of these areas. NHS England are looking at overhauling the way end-of-life records are documented and accessed. NHS England and Improvement has announced it will publish new national guidance on DNAR (Do Not Attempt Resuscitation) orders. This came after campaigner Kate Masters, supported by Compassion in Dying, threatened legal action against Matt Hancock over a failure to provide the public with clear and accessible information on this subject.

But a fragmented approach will be incapable of bringing about the holistic improvements the people we speak to want and need. We ask that Parliament grasps this opportunity and takes a rounded look at end-of-life care in the UK today. Legislators and policy-makers need to be aware of evidence that sheds more light on the problems we have identified here. They need to be provided with a forum in which they can explore the ways in which these problems could be addressed. Questions that need answering include how we encourage more people to plan ahead, how we can better embed a person-centred culture in medicine and how we empower people to die on their own terms, including exploring the possibility of shortening the dying process as so many of the people we support raise this with us. Dying people and their families were asking these questions before the pandemic, and now they are more relevant than ever.

A transformation of end-of-life care is much-needed and long overdue, and coronavirus can and should be seen as a catalyst to forge a more compassionate, patient-centred approach.

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¹ Literature review on the impact of Advance Care Planning – produced by the International Longevity Centre on behalf of Compassion in Dying, 2016.

² Advance care planning: A systematic review about experiences of patients with a life-threatening or life-limiting illness, Zwakman, 2018.

³ The effects of advance care planning on end-of-life care: a systematic review. Brinkman-Stoppelenburg, 2014

⁴ Care Quality Commission, A Different Ending: Addressing inequalities in end of life care - People with a learning disability, 2016

⁵ Care Quality Commission, A Different Ending: Addressing inequalities in end of life care – People from Black and minority ethnic communities, 2016

⁶ Compassion in Dying, Tie Your Camel First: Planning ahead for the end of life with the Somali community, 2016

⁷ https://compassionindying.org.uk/wp-content/uploads/2019/08/CID_ADVANCE-DECISIONS-GP-REPORT.pdf