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Better care at the end of life: we need to change the conversation

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Far too many people are being denied their right to autonomous decision making at the end of their lives. This stubborn reality seems hard to shift, despite years of guidance supporting professionals to elicit and respect people's wishes, and despite the best efforts of educators and campaigners to encourage better conversations about death and dying.

This is evidenced by the thousands of phone calls and emails that the charity *Compassion in Dying* has received in recent years. The charity analysed these responses to better understand what gets in the way of doctors, nurses, or care home managers from following the wishes of a dying person.

The report published recently makes for difficult reading.¹ It finds that people do not understand that they need to write down their wishes for their end-of-life care in order to ensure these are followed. Relatives report that their loved ones were subjected to invasive treatments that they had explicitly said no to. People are being actively discouraged by their doctors from having a conversation about their preferences at the end of life.

As a small organisation tackling a truly knotty problem this leaves them with a difficult question to answer: how do you affect the change you work towards?

For years there has existed guidance about doctors needing to ensure their patients fully understand the implications of interventions at the end of life. For this, dying people obviously need to understand that they are terminally ill, the likely trajectory of their illness, their treatment and care options, and what decision maximises their chances of maintaining good quality of life for as long as possible—if that is their priority.

Health and voluntary sector organisations have run various “let's talk about dying” weeks and charity initiatives. People have used complaints processes and Patient Advice and Liaison Service (PALS) services to try to be heard. But still, far too many people experience a denial of their right to a conversation, to be heard, and for their wishes to be followed through on. The consequence of this is concerning. Polling² shows that one in four people say the last close friend or family member they know who died received medical treatment their loved one would not have wanted.

Charities who work towards change (and obviously all charities should) have some choices to make. Firstly, they could decide that their services alone are the answer. This idea is unrealistic for all small charities, but even large ones cannot reliably *provide services* to patients and families at the scale that is required for near universal coverage. The solution for charities to achieve change can't ever really be

“just services.” It has to be a service, plus influence, leverage, insight, and advocacy.

But influencing the super tanker that is the health and social care system (and sadly the report shows that it is *also* the care system which sometimes denies people their right to autonomous decision making about the end of their lives) is by no means a trivial challenge. How do you tackle “systems change” at the required level, where everything from medical education, to training of care workers, to inspection frameworks, and obligations placed on individual clinicians has to change?

There seem to be two schools of thought. One of these views the system essentially as a machine, where if you pull the right lever, different outcomes appear. It seems to me—and to *Compassion in Dying*—that this theory of change has been tried and tested to destruction, and it doesn't deliver. The health and social care systems are too complex, there are too many decision makers in the process, and everyone from a care assistant to a consultant can scupper your efforts if you rely solely on mechanistic tools for change.

The other approach foregrounds “culture.” It acknowledges that system change is complex, and that you need to tackle the beliefs and assumptions of the workforce and of users to affect change. Is it fair to say that far too often this approach remains entirely aspirational? It suggests that if only we talk enough about change, about “flipping the culture,” and about “transformation” then it will somehow magically happen. Maybe some of the wider sector activity around death and dying falls a bit into this trap too—being too easily satisfied with having had some good conversations about dying, but not making sure people have actually documented their wishes in ways that clinical teams are then compelled to enact.

Compassion in Dying adopts an approach that rightly recognises we need both. Yes, we need to change the conversation. But we also need to re-examine how end-of-life decisions are made and communicated. So, we need to improve education and training, how we enable people to record their wishes, and introduce a duty of candour for someone reaching the end of their lives. Taking the General Medical Council's Good Medical Practice guidance as a blueprint, this would include a duty to provide clear, jargon-free information to a person about their condition, likely progression and prognosis, their options for treatment (including declining it) and the benefits and risks for each. This will help instil a greater culture of openness and transparency in end-of-life conversations, so that people can fully weigh up treatment decisions and provide properly informed consent or refusal.

But we also need to enable people to see that they can—and should—tell their families what they do and don't want and record this, and that clinical staff need to feel safe and confident to know when to transition from active treatment to comfort care only.

This change can't be led just by "the State," or just by "society." Because the organisation paying for care, and regulating and inspecting it, is probably not the right one to lead a hearts and minds communications campaign on changing the conversation about death and dying. And the organisation supporting professionals in how to engage in better conversations can't be the one that then inspects them. We need partnerships that enable all the different actors to lean into their assets and strengths, and to coalesce around a shared mission of autonomy for people at the end of their lives. The new Labour government's commitment to giving power to patients is refreshing, but as encouraging as these noises are, we need cross-sector and multi-level collaboration to ensure it becomes reality for people at the end of their lives.³

Competing interests: Charlotte Augst is a freelance consultant, mostly working with voluntary and community organisations. She has helped Compassion in Dying develop their policy response to the issues raised by the many callers to their helpline services. She has no other conflicts to declare.

- 1 Compassion in dying. Rethinking the UK's approach to dying. <https://compassionindying.org.uk/resource/rethinking-uk-approach-dying/>
- 2 Compassion in dying. End of Life Care. https://ygo-assets-websites-editorial-emea.yougov.net/documents/CompassionInDying_EndOfLifeCare_240304_W.pdf
- 3 Mahase E. Palliative care: People are dying in pain and without the support they need, report warns. *BMJ* 2024;386. doi: 10.1136/bmj.q1928.