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## Voluntarily stopping eating and drinking—lack of guidance is failing patients and clinicians

Patients and physicians need clear information to navigate the complex processes in end-of-life care, say Linda Dykes and colleagues

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The right to make informed decisions, and to be supported compassionately and confidently to do so by your healthcare team, is a cornerstone of excellent end-of-life care. But such care does not happen in a vacuum: understanding relevant legislation and ethical frameworks, recognising the importance of lived experience, and employing clinical expertise all play a key part in its delivery.

Clear, national clinical guidance is what underpins all this, and we each have first-hand experience of how valuable it is in the delivery of end-of-life care. Yet recent research by Compassion in Dying—which has consulted with patients, their families and friends, and clinicians—finds that guidance is often lacking for people who wish to voluntarily stop eating and drinking (VSED) at the end of life.<sup>1</sup> The experiences of people Compassion in Dying spoke to show how patients making complex decisions about end-of-life care lack clear information on VSED, and clinicians are missing standardised, evidence based advice about it.

VSED is when an adult, with the capacity to decide to do so and in the absence of control or coercion, makes a decision to accelerate their death by completely stopping the oral intake of food and fluids. VSED is fundamentally different from the natural loss of appetite that occurs at the end of life, although it may lead to very similar symptoms (for example, thirst, dry mouth, fatigue, pain, confusion), which would need managing in a standard manner.

The Supreme Court has clarified the law in this area,<sup>2</sup> and while some medical organisations—such as the British Medical Association (BMA)<sup>3</sup> and the Royal College of Physicians (RCP)<sup>4</sup>—have made brief statements on the role of clinicians, no nationalised information or guidance exists.

The first-hand experiences of people included within Compassion in Dying's report illustrate the harm that this lack of guidance is causing for people who want to consider VSED. Although calls about the topic make up a relatively small proportion of overall inquiries to the charity's information line, they are increasing, with more calls about VSED in just the first half of 2022 than in any previous calendar year. Some people are not receiving adequate information or support to make an informed decision. Others are not having their symptoms adequately managed. One person interviewed for this research described his mother's experience:

"She was forced to endure not one, but two battles: forgoing food and water, and convincing

professionals that she wished to die the way she lived—on her own terms. As a result of having to constantly state her case, bravely and coherently, to various clinicians who were not listening to her, while foregoing food and water, my mum lost all trust in most of her care team and didn't want to see them anymore."

### Inequitable access to care

The report also exposes how lack of guidance leaves clinicians unsupported and unsure about what is legal and ethical, or how to manage the symptoms associated with dying by VSED. It creates situations where practice depends too much on the ethical judgment of individual clinicians, resulting in the potential for disquiet within clinical teams and inequitable access to quality care. This, in addition to causing a "postcode lottery," undermines the fundamental ethical principle of equality of care provision.

The National Institute for Health and Care Excellence end-of-life guidelines set a new standard for the delivery of personalised care for people who are dying.<sup>5</sup> Guidance from the BMA and RCP on clinically assisted nutrition and hydration,<sup>6</sup> and from the Association for Palliative Medicine on the withdrawal of assisted ventilation at the request of a patient with motor neuron disease,<sup>7</sup> have shown how necessary it is to provide a clear framework to help clinicians navigate ethically complex and potentially emotionally charged end-of-life practices.

We have witnessed how such policy work has led to direct improvements in care for individuals and their families. And we know this is what clinicians want too: a survey of more than 500 health and care professionals revealed that 94% of the respondents would find it helpful to have guidance on the legal, ethical, and clinical aspects of VSED.<sup>1</sup>

We wish to add our voices to this call for guidance. Patient-facing information is needed to help ensure that people are able to make informed decisions and receive the right support and symptom management at the end of their lives. Equally, healthcare professionals need to feel secure in the legal, ethical, and practical aspects of VSED to confidently discuss and navigate this increasingly common request.

The challenges around anticipatory care planning were rightly highlighted during the pandemic.<sup>8</sup> Specific guidance on VSED would support better practice in this area. It would also contribute to a culture where people can have honest conversations

about the choices they wish to make about their own lives and the mode of their death.

The law is clear that the management of symptoms in people wishing to hasten their death in this way is not “assisting a suicide.” Nevertheless we are sympathetic that many colleagues find the concept of dying by VSED challenging, and that supporting someone to die by VSED may conflict with their personal ethical framework. The bottom line, however, is that whatever a clinician’s personal feelings, people are seeking information on VSED and clinicians need to know what this means and how people can be supported. Even when clinicians conscientiously object, it is still essential that they have access to clear guidance to ensure a patient is referred to another doctor and knows what to expect.

**We cannot claim to be supporters of patient autonomy and then close down conversations or veto decisions we don’t agree with. Clear information for patients and physicians alike is inarguably the foundation of good care—and VSED is no different.**

Competing interests: LD is a council member of the Traumaticare charity, advisory board member (voluntary) for EMS World, committee member of RCEM’s Strategic Service Design & Remote and Rural committee, and member of the RCEM Older Persons Special Interest Group. LD has accepted travel and accommodation expenses when speaking at conferences organised by various non-pharmaceutical organisations. SM is a paid employee of Compassion in Dying (clinical lead and services manager).

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