RAISING AWARENESS OF VOLUNTARILY STOPPING EATING AND DRINKING

Talk VSED response to the publication of BMA guidance: Caring for patients who elect to voluntarily stop eating and drinking (VSED)

An important development

Talk VSED welcomes the publication of the British Medical Association (BMA) guidance: Caring for patients who elect to voluntarily stop eating and drinking (VSED). https://www.bma.org.uk/advice-and-support/ethics/decisions-about-nutrition-and-hydration/caring-for-patients-who-elect-to-voluntarily-stop-eating-and-drinking-to-hasten-death-vsed

This is an important development. Although BMA guidance is not regulatory guidance, the BMA has considerable professional standing, and we hope its clear explanation of the law and doctors' responsibilities will give healthcare professionals greater confidence when responding to people who are considering or have chosen VSED.

Talk VSED was invited to contribute to the BMA's targeted consultation on the draft guidance. We are pleased that the final version reflects a substantial proportion of the points we raised during the consultation, including several matters that we consider particularly important.

Talk VSED provides information about VSED, not guidance or legal or medical advice. We are a citizen-led initiative bringing together people with a range of relevant backgrounds and lived experience united by a commitment to making clear, accurate and compassionate information about VSED more widely available and this is the basis on which we have prepared this statement. We are currently reviewing and updating the information on our website in light of the BMA guidance.

What follows are some of our observations on the guidance, including the aspects we particularly welcome and areas where we believe further consideration or clarification may be helpful.

Clear confirmation of the legal position

We especially welcome the guidance's unequivocal confirmation that:

- an adult with mental capacity has the legal right to refuse food and fluids with the intention of hastening their death;
- a person does not have to be terminally ill — or ill at all — to exercise that right;
- doctors may lawfully provide information and answer questions when a person asks about VSED;
- doctors must respect an informed decision to VSED;
- doctors can agree in advance to provide symptom relief and palliative care without this constituting unlawful assistance with suicide;
- providing appropriate symptom relief is part of a doctor's duty of care.

People who are exploring VSED

We welcome the recognition that a person may approach a doctor while still exploring VSED, rather than only after making a firm decision.

Mental capacity and mental disorder

The guidance is clear that a decision to undertake VSED is not, in itself, evidence of either a mental disorder or a lack of mental capacity.

It distinguishes understandable low mood arising from illness or a person's circumstances from diagnosed clinical depression. It also confirms that dementia does not automatically mean that somebody lacks capacity: capacity must be assessed in relation to the particular decision and at the relevant time.

Conscientious objection and continuity of care

We particularly welcome the section addressing conscientious objection.

A doctor who does not feel able to provide support must ensure that the person's assessment and care are transferred, without delay or detriment, to another doctor who is willing to provide that support. Appropriate care must continue until alternative arrangements are in place.

Advance care planning

The detailed emphasis on anticipatory care planning is also valuable.

The guidance recognises the importance of agreeing in advance:

- how symptoms will be managed;
- how and whether food and fluids will be offered and where a patient refuses the offer, how a doctor will ensure that the patient has the opportunity to change their mind, and
- what should happen if the person later experiences delirium or loses capacity.

It confirms that an Advance Decision to Refuse Treatment (ADRT) or advance directive referring to VSED, even if not legally binding in relation to oral food and fluids, can provide a strong indication of the person's wishes. It should have an important bearing on decision-making and be considered alongside the person's care plan and other relevant circumstances.

In practice

Mental Health

Although we welcome the guidance's clear warning that a decision to undertake VSED is not, in itself, grounds for referral to mental health services, we remain concerned about how the term 'mental disorder' may be interpreted in practice and about the possibility of inappropriate referral for compulsory mental health assessment.

Understandable psychological responses to serious illness, frailty or declining quality of life, such as low mood, distress, anticipatory grief, and demoralisation, should not automatically be characterised as indications of a mental disorder.

Our previous lived experience and that of others indicates that in some circumstances there have been referrals for a mental health assessment even when there is no previous history or current indications of a 'mental disorder'.

Death recording

In relation to recording deaths, to ensure consistency in practice, further clarification on when deaths do and do not need to be referred to the Coroner would be helpful.

The need for practical and clinical guidance

The guidance provides a legal and ethical framework rather than comprehensive clinical and operational guidance.

Although its appendix offers some basic information about the stages of VSED and possible symptom management, more detailed practical guidance remains necessary.

A legal framework alone cannot ensure appropriate care if healthcare professionals do not understand how VSED may unfold or how to plan and coordinate care across primary care, palliative care, community nursing, out-of-hours services and the person's close network.

A significant and welcome step

Overall, we regard the publication of this guidance as a significant and welcome step.

It provides a significant professional point of reference for conversations that have too often been met with uncertainty, fear or avoidance.

We hope it will enable people considering VSED to receive accurate information and compassionate, non-judgemental care and ensure that no person is left without appropriate support or symptom relief because of misunderstandings about the law.

What we would like to see next

We would welcome consideration by the relevant governments and legislatures of the changes required to the Mental Capacity Act 2005 and its Code of Practice so that a person's advance refusal of orally offered food and fluids can be recorded and legally respected through an Advance Decision to Refuse Treatment (ADRT).

We would also value relevant professional and regulatory bodies, including, but not limited to, those representing or regulating doctors, psychiatrists, nurses, social workers and occupational therapists, to develop their own guidance, policies and professional practice.