

There's a problem with VSED (in Scotland).

Abstract

VSED has been available for decades (at least) to those Scots who wish to end their lives, and especially for those who wish to accelerate a likely unpleasant death and intractable suffering due to any number of chronic morbidities. Ending one's own life is not illegal in Scotland, and VSED specifically operates on the principle of a right to refuse (any form of treatment, including sustenance). Proponents of VSED have argued that it can be a process without anxiety or suffering where appropriate palliative support is provided. It can be acknowledged that this has been true in some cases. It has also been the case that some deaths via VSED have been considerably more traumatic. However, the experience of VSED may still be shorter and less traumatic than the end of life that would have been experienced otherwise if various chronic conditions had carried on to their inevitable conclusion. In many states, including Scotland, in the absence of Assisted Dying, VSED is the main alternative for autonomously accelerating death that can involve medical support. There are however a number of issues that deserve examination within the Scottish context:

1. VSED's similarity to Assisted Dying.
2. A lack of data.
3. A lack of standardised national guidance and inequality of provision.
4. A lack of standardised protections against malfeasance.
5. The degree of suffering that may be experienced by some patients.

Introduction

The Scottish government has observed that

[i]n 2016/17 there were about 57,000 deaths in Scotland, a figure set to rise slightly to just over 60,000 by 2037. Around 75% of these people will have needs arising from living with deteriorating health for the years, months, or weeks before they die.¹

Scotland has long been regarded as the 'sick man of Europe'. Scotland appears to have the widest health inequalities in Western Europe² (linked to inequality and

¹ Scottish Government (2018) Palliative and End-of-Life Care by Integration Authorities: advice note. <https://www.gov.scot/publications/strategic-commissioning-palliative-end-life-care-integration-authorities/pages/5/>

² Mercer SW, Blane D, Donaghy E, Henderson D, Lunan C, Sweeney K. Health inequalities, multimorbidity and primary care in Scotland. *Future Healthc J.* 2023 Nov;10(3):219-225. <https://pmc.ncbi.nlm.nih.gov/articles/PMC10753226/>

deprivation^{3 4 5}), an ageing population⁶, and with many of these additional years spent with health problems, often multimorbidities^{7 8 9}. Multimorbidity “is increasing in prevalence in Scotland. It has several negative outcomes including higher mortality, decreased quality-of-life, decreased functional status”.¹⁰ Multimorbidities are already present in under 65s within the population, the proportion of the Scottish population suffering from more than one health condition is on the increase and is more prevalent among disadvantaged groups¹¹, with onset from the age of fifty in deprived areas.¹² Scots aged over 70 years are living with an average of three chronic health conditions.¹³ Personal and family scenarios where an individual will wish to end their life - due to intractable suffering, or due to an experience of ‘social death’ where their health has removed any sense of autonomy or social experience that could make life feel it is worth living - will likely increase in the years to come. In such cases, palliative care will continue to be insufficient for, and/or unpalatable to, some chronic sufferers.^{14 15} The position of a majority of British medical institutions

³ Scottish Government. Health and Social Care Strategy, as above. 2022.

⁴ Cezard, G., Sullivan, F. & Keenan, K. Understanding multimorbidity trajectories in Scotland using sequence analysis. *Sci Rep* **12**, 16485 (2022). <https://doi.org/10.1038/s41598-022-20546-4>

⁵ Miall, N; Fergie, G; Pearce, A. Health Inequalities in Scotland:trends in deaths, health and wellbeing, health behaviours, and health services since 2000. University of Glasgow. November 2022: 139. <https://eprints.gla.ac.uk/282637/1/282637.pdf>

⁶ Government Office for Science. Future of an Ageing Population. 2016. <https://assets.publishing.service.gov.uk/media/5d273adce5274a5862768ff9/future-of-an-ageing-population.pdf>

⁷ Gondek et al (2021) Prevalence and early-life determinants of mid-life multimorbidity: evidence from the 1970 British birth cohort. *BMC Public Health* volume 21, Article number:1319. <https://doi.org/10.1186/s12889-021-11291-w>

⁸ Healthcare Improvement Scotland: More about multimorbidity and diabetes. <https://rightdecisions.scot.nhs.uk/type-2-diabetes-mellitus-quality-prescribing-strategy-a-guide-for-improvement/polypharmacy-in-diabetes/more-about-multimorbidity-and-diabetes/>

⁹ Mercer, Stuart Prof. Multimorbidity. Advanced are Research Centre. https://edwebcontent.ed.ac.uk/sites/default/files/atoms/files/acrc_briefing_3_v.1.pdf

¹⁰ ADRUK. Multimorbidity and the use of health and social care. <https://www.adruk.org/our-work/browse-all-projects/multimorbidity-and-the-use-of-health-and-social-care-71/>

¹¹ Miall et al. ,Health Inequalities in Scotland:2022: 139, as above.

¹² Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study. *Lancet*. 2012 Jul 7;380(9836):37-43. <https://pubmed.ncbi.nlm.nih.gov/22579043/>

¹³ Scottish Government. Health and Social Care Strategy for Older People: Analysis of Consultation Responses, 2022. <https://www.gov.scot/publications/health-social-care-strategy-older-people-analysis-consultation-responses/>

¹⁴ Cookson et al. Unrelieved Pain in Palliative Care in England. National Institute for Health Research. 2019 <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

¹⁵ Riley, L & Hehir D. The Inescapable Truth About Dying in Scotland. Study conducted by the Office of Health Economics for Dignity in Dying. 2019 https://www.dignityindyingScotland.org.uk/wp-content/uploads/sites/2/2025/02/DiD_Inescapable_Truth_Scotland_WEB.pdf

on assisted dying (AD) has currently settled at neutral,¹⁶ although a recent attempt to legislate on the subject in Holyrood failed. Assisted Dying, as it is understood in the McArthur Assisted Dying For Terminally Ill Adults (Scotland) Bill (2024), remains without formal legislation in Scotland. Nonetheless, as the range of options that Scots seeking to accelerate their death continue to implement demonstrates, a significant degree of legal ambiguity persists in relation to assisting another person in ending their life. There are a number of practices extant in Scotland that lead to an accelerated death, each with its own issues¹⁷:

palliative support only - which may prove undesirable to some individuals or incapable of sufficiently ameliorating suffering in some cases ;

suicide attempt - not illegal in Scotland;

suicide with 'amateur' assistance (not assisted and monitored by a medical professional) - unlikely to lead to a prosecution or a custodial sentence under certain circumstances;

Dignitas or a similar foreign facility - highly unlikely to lead to any legal action; denial or withdrawal of treatment and sustenance by medical staff - legal;

double effect - common within end-of-life treatment, regarded by some as a form of euthanasia;

heavy dosage drug administration short of inducing a coma - common within end-of-life treatment;

heavy dosage drug administration involving an induced coma (Continuous Deep Sedation (CDS)) - common within end-of-life treatment); and

Voluntary Stopping of Eating and Drinking (VSED) - legal. It is this latter process, often accompanied by administration of drugs by medical practitioners, that is the focus of this document.

There is no legal ambiguity in relation to the assistance and support provided by Scottish medical staff for individuals who have opted for VSED, despite VSED being possibly the closest analog to assisted dying (AD). Unlike 'double effect' where at least lip-service can be paid to the claim of death being 'foreseen but not intended', death is understood explicitly to be both foreseen AND intended in VSED. Within the context of an increasing number of Scots likely to experience conditions which can lead to a desire to end their lives, and in view of the continuing lack of legislation to enable AD, it is worth examining AD's closest analog, VSED.

Voluntary Stopping Eating and Drinking (VSED)

Also known as Voluntary Refusal of Food and Fluids (VRFF), this is a process which often involves medical staff (although it can also be carried out and supported independently) where an individual can end their life. Pope & Anderson argue that

¹⁶ Robertson, J. Legal Rulings, Legislation and Social Change in Scotland Relating to Assisted Dying.2026: 19-21.

<https://www.academia.edu/166289694/>

Legal Rulings Legislation and Social Change in Scotland Relating to Assisted Dying

¹⁷ Robertson, J. Legal Rulings 2026: 32-38, as above.

“VSED is a method of hastening death that dates back thousands of years”¹⁸ and that “[t]here is a good amount of anecdotal evidence that a death incident to VSED is peaceful, painless, and dignified.”¹⁹ Ivanović et al concur with the perception that VSED is a peaceful process, describing it as a process that stops poor quality of living and greater suffering where “palliation or symptom management is ineffective and cannot relieve discomfort”²⁰ and offers the patient a greater feeling of autonomy, (although the length of time take to die can be a disadvantage).

The right to refuse food or hydration in Scotland predates *Law Hospital NHS Trust v Lord Advocate* 1996 SC 301²¹, but the case result may be the first time the Scottish courts had made this explicit:

It is not in doubt that a medical practitioner who acts or omits to act with the consent of his patient requires no sanction or other authority from the court. The patient's consent renders lawful that which would otherwise be unlawful. It is not for the court to substitute its own views as to what may or may not be in the patient's best interests for the decision of the patient, if of full age and capacity.²²

In England and Wales, *An NHS Trust v. Y*, and *Briggs v. Briggs*, previously supported the permissibility of withdrawing constant artificial nutrition and hydration, (as the *Law Hospital Trust* case did in Scotland). The Supreme Court in relation to the ruling on *R (Nicklinson) v Ministry of Justice*²³, subsequently clarified that mentally competent adults can refuse food and water, and that medical staff should comply with such requests and can manage any resulting discomfort without fear of prosecution.

The process is not restricted to terminal patients, and is supported by the principle of a “right to refuse” any intervention. It is commonly carried out in conjunction with deep/terminal sedation and continuous care provided by medical staff. Jox et al define VSED as the intention and act of causing the shortening and ending a life: “VSED is a form of suicide by omission – the person’s omission of eating and

¹⁸ Pope, Thaddeus & Anderson, Lindsey. Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life. *Widener Law Review*, Vol 17. 2011: 388. https://www.researchgate.net/publication/47354408_Voluntarily_Stopping_Eating_and_Drinking_A_Legal_Treatment_Option_at_the_End_of_Life

¹⁹ Pope & Anderson. 2011:389, as above.

²⁰ Ivanović, N., Büche, D. & Fringer, A. Voluntary stopping of eating and drinking at the end of life – a ‘systematic search and review’ giving insight into an option of hastening death in capacitated adults at the end of life. *BMC Palliat Care* **13**, 1 (2014). <https://doi.org/10.1186/1472-684X-13-1>

²¹ Robertson 35-36

²² *Law Hospital NHS Trust v Lord Advocate* SC 301 1996 paragraph 1, The Function of the Court. https://www.bailii.org/scot/cases/ScotCS/1996/1996_SC_301.html

²³ *R (Nicklinson) v Ministry of Justice* [2014] UKSC 38, para 255, <http://www.bailii.org/uk/cases/UKSC/2014/38.html>

drinking directly causes death.”²⁴ However, Mentzel et al argue that “[a]lthough the outcome is both predictable and expected, the palliative care worker is not complicit, merely prioritising his or her duty of care as far as the law will allow”²⁵ and that “[i]n cases where a condition is terminal, it can be seen not as facilitating suicide but as facilitating a better death.”²⁶

According to Wechkin et al:

VSED is a deliberate, self-initiated action by a patient with decision-making capacity (DMC) to hasten death in the setting of suffering refractory to optimal palliative interventions, prolonged dying that the person finds intolerable, or expected deterioration or suffering due to an irreversible illness, that the person regards as unacceptable. This action is typically undertaken by a patient with a serious illness associated with a life expectancy of months or years. VSED is characterized by the exercise of a specific choice at a specific time and is dependent on the patient having sufficient decisional capacity at the time that VSED is initiated.²⁷

According to Wax et al,

Individuals who consider VSED tend to be older, have a serious but not always imminently terminal illness, place a high value on independence, and have significant illness burden.²⁸

VSED is practiced within Scottish palliative care as a best available option where a patient seeks to end their life. It is most commonly performed in conjunction with medical staff supporting the patient by inducing a coma and continuing to administer sedation, monitor the patient and provide care. The sufferer will starve and dehydrate to death or succumb to an overdose, whichever occurs first as the body weakens.

It is generally accepted within palliative care that medical involvement in Voluntary Stopping Eating and Drinking remains at ‘arms-length’, thereby removing any direct causality in the death of a consenting and competent individual who is seeking to end their own life. Supporters may argue that a degree of facilitation exists, but this is not analogous to causality. Pope²⁹ argues that there are key

²⁴ Jox, Ralf J, Black, Isra orcid.org/0000-0001-5324-7988, Borasio, Gian Domenico et al. (1 more author) (2017) Voluntary stopping of eating and drinking: is medical support ethically justified? *BMC Medicine*. 186. ISSN 1741-7015 <https://doi.org/10.1186/s12916-017-0950-1>

²⁵ Mentzel, PT. Ethical Issues, chapter in Quill, TE et al Eds. *Voluntary Stopping Eating and Drinking: A Compassionate, Widely Available Option for Hastening Death*. 71 https://www.google.co.uk/books/edition//Q30_EAAAQBAJ?hl=en&gbpv=1&pg=PA60&dq=VSED+coercion

²⁶ Mentzel, PT. Ethical Issues: 73, as above.

²⁷ Wechkin H et al. Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED) *Journal of Pain and Symptom Management*, 2023; 66, e625-e631 [https://www.jpmsjournal.com/article/S0885-3924\(23\)00565-1/fulltext](https://www.jpmsjournal.com/article/S0885-3924(23)00565-1/fulltext)

²⁸ John W. Wax MD, Amy W. An MD, Nicole Kosier MD, Timothy E. Quill MD. Voluntary Stopping Eating and Drinking. *Journal of American Geriatrics Society*, Volume66, Issue3 March 2018, Pages 441-445. <https://agsjournals.onlinelibrary.wiley.com/doi/full/10.1111/jgs.15200>

²⁹ Pope, T.M. Voluntarily stopping eating and drinking (VSED) to hasten death: may clinicians legally support patients to VSED?. *BMC Med* 15, 187 (2017). <https://doi.org/10.1186/s12916-017-0951-0>

differences that differentiate palliative care in the context of VSED, as the level of active medical support simply does not qualify it as an assisted suicide. Unlike an assisted death (AD), any medical support provided in VSED is argued to be very specifically an act of care. Providing and even administering drugs to alleviate suffering within the VSED process, even where the level of dosage may cause death, is regarded as within the ‘doctrine of double-effect’ where death is foreseeable but not intended. Most commonly, VSED in Scotland is supported by medical staff, and is carried out in conjunction with deep sedation. The patient is placed into an induced coma which continues until death. It can be argued that although the level of sedation is potentially lethal as the body weakens from starvation and dehydration, death is foreseeable but not intended (the doctrine of double-effect) by the provision and maintenance of the dosage. An argument can be made that ‘double effect’ applies and that medical staff are simply tending to the comfort of an individual who is dying by their own hand, and that any drugs administered are purely to soothe discomfort, and that any contribution of drugs administered is intended to be purely palliative. Quill et al note that:

[i]n a 2015 guidance document, the GMC advises that no prohibition prevents a doctor from “agreeing in advance to palliate the pain and discomfort involved for such a patient should the need arise for such symptom management” (General Medical Council 2015). The GMC subsequently confirmed that symptom management includes the symptoms which arise from VSED which progresses to that individual’s death. “Doctors may agree with their patients in advance to provide medicines or treatment to alleviate pain or other distressing symptoms, should the need arise” (General Medical Council 2018). Notably, there have been many high-profile VSED deaths in the UK, yet no liability or sanctions (Culzac 2014; Savulescu 2014).³⁰

Quill & Byock note:

When unacceptable suffering persists despite standard palliative measures, terminal sedation and voluntary refusal of food and fluids are imperfect but useful last-resort options that can be openly pursued.³¹

The process has indeed been a ‘useful last-resort option’, not only for those expected to die within a specific period of time (let’s say six-months), but remains legally available to those who suffer conditions that are not imminently terminal.

Despite an overall lack of research and data on the subject of VSED in Scotland (and in general), one thing that consistently emerges is the lack of consensus on VSED and the potential issues therein. As death is intended from the process as a whole, and the contribution of the dosage to either effective pain-control or indeed

³⁰ Quill, Timothy E.; Menzel, Paul T.; Pope, Thaddeus; Schwarz, Judith K.. *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death*. Kindle Edition. Oxford University Press 2021: 90-91

³¹ Quill, TE. & Byock, IR. Responding to Intractable Terminal Suffering: The Role of Terminal Sedation and Voluntary Refusal of Food and Fluids. *Annals of Internal Medicine*. Volume 132·Number 5. March 2000. https://www.acponline.org/sites/default/files/documents/clinical_information/resources/end_of_life_care/intractable_suffering.pdf

overall cause of death remains open to debate. The purpose of VSED, as supported and understood by Scottish medical staff, is for the individual to end their life, an outcome that is both foreseen and intended. As Quill et al confirm “[d]eath is definitely intended with VSED”³², clarifying that “[i]n suicide a person intentionally aims at her own death and directly causes it; in a typical VSED, too, a person intends to die and directly causes the death. As a matter of descriptive fact, then, VSED is a form of suicide.”³³

A key assumption has been that the process occurs over a short period, with any discomfort ameliorated by palliative care. This remains a convenient assumption. The extensive lack of studies to establish just how smooth, or otherwise, the process is for individuals remains an issue of concern. Certainly, reports by those involved with VSED while the individual remains conscious include details of a range of discomforts experienced. As for those placed into an induced coma, conventional but untested thinking has been that unconscious individuals will not experience discomfort, but this may be an aspiration rather than a tested and proven claim.

Another question raised is why it would be any less subject to malfeasance i.e. coercion and targeting of vulnerable individuals that opponents of assisted dying claim would be part and parcel of state-supported processes to assist individuals to end their lives. It is, after all state-supported and has been accessible for some time, and without the extensive protections advanced by the McArthur Bill. It can be noted that opponents of AD do not appear to have committed similar time, attention and resources to the protection of individuals pursuing VSED.

VSED merits an examination both as a counterpoint to assisted dying and in its own right.

VSED has been available, legal and accessed by Scots for decades. It is supported by the national health service and in private care homes. However, there are in fact several problems with VSED:

1. The problem of VSED’s similarity to Assisted Dying.
2. The problem of lack of data.
3. The problem of a lack of standardised national guidance, and inequality of provision.
4. The problem of no standardised protections against malfeasance.
5. The problem of suffering.

³² Quill, Timothy E.; Menzel, Paul T.; Pope, Thaddeus; Schwarz, Judith K.. *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death*. Kindle Edition. Oxford University Press 2021: 34

³³ Quill, Timothy E.; Menzel, Paul T.; Pope, Thaddeus; Schwarz, Judith K.. *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death*. Kindle Edition. Oxford University Press 2021: 67

1. The problem of VSED's similarity to Assisted Dying

AD is intended as a process to curtail unnecessary suffering and to instigate a painless end of life. VSED has been regarded by supporters of that process as a close analog as both processes involve medical support, and for both processes death is the expected and intended outcome. It can be noted that after failed legal cases to access AD in the UK, both Debbie Purdy and Tony Nicklinson ended their lives via VSED. Purdy described the time taken to die as “agonising”.³⁴

Pope & Anderson argue that in VSED medics simply respect the wishes of the patient, and that

VSED is not assisted suicide as it “entails a passive refusal. The patient’s natural state is to dehydrate unless fluids are affirmatively introduced. VSED does not entail the acceleration of this process, but rather the mere absence of action to slow or stop it.”³⁵

VSED has existed on the edge of double effect, where any death occurring as a result of overdose is argued to have been “foreseen but not intended”. As a person undergoing VSED weakens and organs fail, and particularly in the cases where an induced coma is involved, death primarily by overdose cannot be discounted.

The process of VSED itself is specifically intended to end a life, and no medical staff providing support will be in any doubt about that. The scenario where a medical practitioner, again particularly in cases involving an induced coma, administer drugs to facilitate the ending of a life would appear to be closely aligned in understanding of outcome with a scenario where a medical practitioner supplies a pill (but in some AD states will not administer) to assist an individual to end their life. The perceived difference may come down to notions of causality in Scotland. In the case of AD, Lord Carloway has stated:

the voluntary ingestion of a drug will normally break the causal chain. When an adult with full capacity freely and voluntarily consumes a drug with the intention of ending his life, it is this act which is the immediate and direct cause of death. It breaks the causal link between any act of supply and the death.³⁶

As such, the provision of a lethal dose to be self-administered may be regarded as similar to the provision of any other element of the environment and support for AD or VSED. The line between facilitation and assistance can be argued to be rather thin. A great deal has been taken on faith in the absence of research, in relation to VSED, simply because it has allowed the medical community to maintain a veneer of passivity within that process.

³⁴ Wikipedia. Debby Purdy. https://en.wikipedia.org/wiki/Debbie_Purdy#:~:text=Purdy entered the Marie Curie,23 December 2014, aged 51.

³⁵ Pope, Thaddeus & Anderson, Lindsey. Voluntarily Stopping Eating and Drinking: A Legal Treatment Option at the End of Life. *Widener Law Review*, Vol 17. 2011: 420-21. https://www.researchgate.net/publication/47354408_Voluntarily_Stopping_Eating_and_Drinking_A_Legal_Treatment_Option_at_the_End_of_Life

³⁶ Gordon Ross (reclaimer) v Lord Advocate 2016: [30]

Medical practitioners themselves experience ambiguity in terms of difference between VSED and AD³⁷. Jox et al argue that there is inconsistency in the support of palliative care societies, professional bodies of physicians, legal scholars, and ethicists:

Most Western jurisdictions seem to permit medical support for VSED, even in jurisdictions where assisted dying is prohibited by law... the widely held position by palliative care societies, professional bodies of physicians, legal scholars, and ethicists to disapprove of assisted suicide but approve of and even promote medically supported VSED appears inconsistent.³⁸

Liu et al³⁹ contend that there are three types of ‘Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration’. Type 1 is palliative sedation that will not hasten the patient’s death. Type 2 might, but is not certain to, hasten death, as in the doctrine of double-effect. Type 3 is certain to hasten death. They note that all three types are practiced in Australia, Colombia, the Netherlands, Switzerland, the United States of America. The first two exist within palliative care provision in Scotland as, arguably, does the third.

Liu et al⁴⁰ note that Type 3 is perceived as a form of euthanasia or assisted dying a number of states. Liu et al acknowledge the risk that “there could be a situation where Type 3 Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration is allowed in the absence of the safeguards usually associated with euthanasia.”⁴¹ Jox et al are more forthright in arguing that:

VSED falls within the concept of suicide, albeit with certain unique features (non-invasiveness, initial reversibility, resemblance to the natural dying process). Second, we demonstrate, on the basis of paradigmatic clinical cases, that medically supported VSED is, at least in some instances, tantamount to assisted suicide. This is especially the case if a patient’s choice of VSED depends on the physician’s assurance to provide medical support.⁴²

While the primary purpose of medical support in VSED may be symptom relief, as in AD the commonly understood outcome is death. They go on to argue that:

Two elements of assistance in suicide are critical for our argumentation. First, the assistance is instrumental for death to occur, meaning that, without the

³⁷ Gerson, S.M., Bingley, A., Preston, N. et al. When is hastened death considered suicide? A systematically conducted literature review about palliative care professionals’ experiences where assisted dying is legal. *BMC Palliat Care* 18, 75 (2019). <https://doi.org/10.1186/s12904-019-0451-4> <https://doi.org/10.1186/s12904-019-0451-4>

³⁸ Jox et al. When is hastened death considered suicide? 2019, as above.

³⁹ Liu, Richard, Pope, Thaddeus Mason and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 *Indiana International & Comparative Law Review* XXX (forthcoming 2025)., 35(1) *Indiana International & Comparative Law Review* 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

⁴⁰ Liu et al. Deep and Continuous Palliative Sedation, 2024, as above.

⁴¹ Liu et al. Deep and Continuous Palliative Sedation, 2024, as above.

⁴² Jox et al. When is hastened death considered suicide? 2019, as above.

assistance, the suicide would not (or could not) occur. Second, the assisting person knows and at least partially shares the patient's intention to induce death.⁴³

2. The problem of lack of data

While VSED has always been legal in Scotland, there is a definite lacuna in general in research into VSED. There is an absence of published research specifically in relation to the support of VSED in palliative care in Scotland.

The number of VSED cases per year in Scotland is unavailable, although research elsewhere suggests a common occurrence - Bolt et al found in that in their survey of over 700 physicians between October 2011 and June 2012 in the Netherlands, "46% had cared for a patient who hastened death by VSED".⁴⁴ In their literature review, Mensger et al found that "surveys from different countries have shown that 32%–62% of participating healthcare professionals had already accompanied a person during VSED".⁴⁵ Lowers et al suggest that "VSED may be more common than physician-assisted forms of dying simply because it falls beneath the level of legal scrutiny except in some cases involving institutional settings."⁴⁶ The Scottish Partnership for Palliative Care however note that "there are no systematic mechanisms in place to measure and understand the experiences and outcomes of people dying in Scotland".⁴⁷

There is no formal regulatory body for VSED, monitoring and reviewing data and reporting upon uptake numbers, practice and compliance. In general "such deaths are not even usually recorded as suicides".⁴⁸ ⁴⁹ Quill et al note that "[l]ittle information is available in the published literature on the experience of patients wishing to VSED in

⁴³ Jox et al. When is hastened death considered suicide? 2019, as above.

⁴⁴ Bolt EE, Hagens M, Willems D, Onwuteaka-Philipsen BD. Primary care patients hastening death by voluntarily stopping eating and drinking. *Ann Fam Med*. 2015 Sep;13(5):421-8. doi: 10.1370/afm.1814. PMID: 26371262; PMCID: PMC4569449.

⁴⁵ Christina Mensger, Yang Jiao, Maximiliane Jansky, Christian Banse, Friedemann Nauck, Monika Nothacker, Henrikje Stanze. Voluntarily stopping eating and drinking (VSED): A systematic mixed-methods review focusing on the carers' experiences. *Health Policy* Volume 150, December 2024, 105174. <https://www.sciencedirect.com/science/article/pii/S0168851024001842> 27/04/25

⁴⁶ Lowers et al. Overview of voluntarily stopping eating and drinking to hasten death. *Annals of Palliative Medicine*. Vol 10, No 3 (March 31, 2021) <https://apm.amegroups.org/article/view/44492/html#B24>

⁴⁷ Scottish Partnership for Palliative Care (SPPC). Response to Proposals for an Assisted Dying for Terminally Ill Adults (Scotland) Bill. <https://www.palliativecarescotland.org.uk/content/publications/SPPC-Response-to-Proposals-for-an-Assisted-Dying-Bill.pdf>

⁴⁸ Nancy Preston, Sheila Payne, and Suzanne Ost. Breaching the stalemate on assisted dying: it's time to move beyond a medicalised approach *BMJ* 2023; 382 doi: <https://doi.org/10.1136/bmj.p1968> (Published 29 August 2023)
Cite this as: *BMJ* 2023;382:p1968
27/04/25

⁴⁹ Uemura T, et al. Challenges in Completing a Death Certificate After Voluntary Stopping of Eating and Drinking [published online: July 27, 2023]. *J Am Med Dir Assoc*. DOI: <https://doi.org/10.1016/j.jamda.2023.06.022>.

institutional LTC [long-term care] settings”⁵⁰ and it is reasonable to assume that significantly less (if any) significant data exists in relation to non-institutional settings. VSED has none of the standardised recording processes or indeed protections⁵¹ that the McArthur Bill proposed. This is problematic. As Ivanović et al conclude, “VSED has hardly been examined in the past 20 years.”⁵² The authors note that “[t]he available articles can indeed be described as heterogeneous and inconclusive. They represent a patchwork rather than a picture”,⁵³ and offer “marginal insight into VSED for hastening death”.⁵⁴ The authors also conclude that “[n]o study was found that explicitly examined physiological processes during VSED in adults at the end of life”⁵⁵ and “[t]o date no qualitative study has comprehensively investigated patients’ experiences with VSED at the end of life.”⁵⁶ Pope & West confirm that VSED has been under-examined compared to other end-of-life options.⁵⁷

Fringer and Staengle describe VSED as “a critical but poorly understood issue”.⁵⁸ Without sufficient research it remains impossible to confirm that VSED deaths are as peaceful as some would claim, or for example whether coercion has been a genuine issue. Bolt et al note that

“[t]he literature mostly comprises commentaries and case reports rather than original research....They mention possible serious complications, such as a prolonged dying phase, thirst or hunger, agitation, delirium, and overburdened family members”.⁵⁹

⁵⁰ Quill, Timothy E.; Menzel, Paul T.; Pope, Thaddeus; Schwarz, Judith K.. *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death*. Kindle Edition. Oxford University Press 2021: 111

⁵¹ Robertson, J. *Legal Rulings* 2026: 12-15, as above.

⁵² N. Ivanovic, D. Bueche, and A. Fringer, “Voluntary Stopping of Eating and Drinking at the End of Life—A ‘Systematic Search and Review’ Giving Insight into an Option of Hastening Death in Capacitated Adults at the End of Life,” *BMC Palliative Care* 13, no. 1 (2014).

⁵³ Ivanovic et al. *Voluntary Stopping of Eating* 2014, as above.

⁵⁴ Ivanovic et al. *Voluntary Stopping of Eating* 2014, as above.

⁵⁵ Ivanovic et al. *Voluntary Stopping of Eating* 2014, as above.

⁵⁶ Ivanovic et al. *Voluntary Stopping of Eating* 2014, as above.

⁵⁷ Pope, TM & West, A. *Legal Briefing: Voluntarily Stopping Eating and Drinking*. *The Journal of Clinical Ethics* 25, no. 1 (Spring 2014): 68-80. https://www.researchgate.net/publication/261996427_Legal_briefing_Voluntarily_stopping_eating_and_drinking

⁵⁸ Fringer, André and Stängle, Sabrina. *Scientia*, Nov 11, 2020 *Editor's Pick, Medical & Health Sciences* <https://digitalcollection.zhaw.ch/server/api/core/bitstreams/0c46ed58-fe59-4e8c-a073-f5736cb68321/content> 28/04/25

⁵⁹ Bolt EE, Hagens M, Willems D, Onwuteaka-Philipsen BD. Primary care patients hastening death by voluntarily stopping eating and drinking. *Ann Fam Med*. 2015 Sep;13(5):421-8. doi: 10.1370/afm.1814. PMID: 26371262; PMCID: PMC4569449.

Lowers et al found that “[f]ew studies have looked specifically at the incidence of VSED.”⁶⁰ Pope et al confirm that “deep and continuous palliative sedation combined with withholding or withdrawal of artificial nutrition and hydration...has gone largely unexamined.”⁶¹

General articles discussing VSED go back before 2000 - in 1993, Bernat et al called for systematic research on VSED⁶², but Mensger et al in 2024 found available research dealt less with practice, and “mostly dealing with the ethical and legal issues”⁶³, and in their literature review Ivanović et al describe existing research as a: continuous interweaving of published articles. In this respect, we conclude that the evidence was artificially reproduced over time through repeated citations of narrative reviews without new insights based on original studies.⁶⁴

They note that:

articles provide marginal insight into VSED for hastening death. Research is needed intensive examination of the literature shows that the subject under study has been marginally researched and that there is no scientific basis on which VSED could be explained in all of its dimensions.⁶⁵

3. The problem of a lack of standardised national guidance, and inequality of provision.

Dykes et al observe that “no nationalised information or guidance exists”.⁶⁶ There appears to be no standardisation nationally of procedural guidance or support services for patients, patients’ families or for medical staff. Jox et al concluded that “[p]hysicians, lawmakers, and societies should discuss specific ways of regulating

⁶⁰ Jane Lowers, Sean Hughes, Nancy J. Preston. Overview of voluntarily stopping eating and drinking to hasten death. *Annals of Palliative Medicine*, Vol 10, No 3 (March 31, 2021) <https://apm.amegroups.org/article/view/44492/html> 27/04/25

⁶¹ Pope, Thaddeus Mason and Liu, Richard and Xu, April Xiaoyi, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 *Indiana International & Comparative Law Review* XXX (forthcoming 2025)., 35(1) *Indiana International & Comparative Law Review*. 2025: 70. <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660>

⁶² Bernat JL, Gert B, Mogielnicki RP. Patient refusal of hydration and nutrition. An alternative to physician-assisted suicide or voluntary active euthanasia. *Arch Intern Med*. 1993;153(24):2723–2728.

⁶³ Christina Mensger, Yang Jiao, Maximiliane Jansky, Christian Banse, Friedemann Nauck, Monika Nothacker, Henrikje Stanze. Voluntarily stopping eating and drinking (VSED): A systematic mixed-methods review focusing on the carers’ experiences. *Health Policy* Volume 150, December 2024, 105174. <https://www.sciencedirect.com/science/article/pii/S0168851024001842> 27/04/25

⁶⁴ Ivanović, Nata & Bueche, Daniel & Fringer, André. (2014). Voluntary stopping of eating and drinking at the end of life - A 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life. *BMC palliative care*. 13. 1. 10.1186/1472-684X-13-1. <http://www.biomedcentral.com/1472-684X/13/1> 27/04/25

⁶⁵ Ivanović, Nata & Bueche, Daniel & Fringer, André. (2014). Voluntary stopping of eating and drinking at the end of life - A 'systematic search and review' giving insight into an option of hastening death in capacitated adults at the end of life. *BMC palliative care*. 13. 1. 10.1186/1472-684X-13-1. <http://www.biomedcentral.com/1472-684X/13/1> 27/04/25

⁶⁶ Dykes et al. Voluntarily stopping eating and drinking—lack of guidance is failing patients and clinicians. *BMJ* 379:o2621, 2022 <https://www.bmj.com/content/379/bmj.o2621>

medical support for VSED in order to provide clear guidance for both patients and healthcare professionals.”⁶⁷ Quill et al propose a set of stages for VSED after any (US) individual has been fully informed of their available options and has chosen VSED:

- Formal Psychiatric Evaluation.
- Formal Advance Care Planning.
- Health Care Proxy - power of attorney.
- Advance Instructional Directive - specific on treatment preferences during VSED.
- Practitioner Orders for Life Sustaining Therapy (POLST) forms - both current care and advance care directives.
- Hospice referral - if required.⁶⁸

Batzler et al detail a similar level of checks and supports within the German health system.⁶⁹ It is unclear if such a process has been formalised and implemented consistently throughout Scotland.

There are references to VSED in advisory documents by disparate medical organisations such as the GMC in 2015⁷⁰, the BMA in 2019⁷¹ and the Royal College of Physicians in 2021⁷². However, Compassion in Dying note that “[t]he lack of guidance on VSED leads to significant inconsistencies in how it is managed by clinicians.”⁷³ Liu et al note that “[Deep and Continuous Palliative Sedation Without

⁶⁷ Jox, Ralf J, Black, Isra orcid.org/0000-0001-5324-7988, Borasio, Gian Domenico et al. (1 more author) (2017) Voluntary stopping of eating and drinking: is medical support ethically justified? *BMC Medicine*. 186. ISSN 1741-7015 <https://doi.org/10.1186/s12916-017-0950-1>

⁶⁸ Quill, Timothy E.; Menzel, Paul T.; Pope, Thaddeus; Schwarz, Judith K.. *Voluntarily Stopping Eating and Drinking: A Compassionate, Widely-Available Option for Hastening Death*. Kindle Edition. Oxford University Press 2021: 41-45

⁶⁹ Batzler et al. Caring for patients during voluntarily stopping of eating and drinking (VSED): experiences of a palliative care team in Germany. *BMC Palliative Care* 22:185, 2023. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01308-z>

⁷⁰ General Medical Council, Patients seeking advice or information about assistance to die, June 2015, https://www.gmc-uk.org/-/media/documents/gmc-guidance—when-a-patient-seeks-advice-or-information-about-assistance-to-die_pdf-61449907.pdf

⁷¹ British Medical Association, Responding to patient requests for assisted dying: guidance for doctors, June 2019, <https://www.bma.org.uk/media/1424/bma-guidance-on-responding-to-patient-requests-for-assisted-dying-for-doctors.pdf>

⁷² Royal College of Physicians, Supporting people who have eating and drinking difficulties, March 2021, <https://www.rcplondon.ac.uk/projects/outputs/supporting-people-who-have-eating-and-drinking-difficulties>

⁷³ Compassion in Dying. Voluntarily stopping eating and drinking (VSED): A call for guidance. Nov 2022. <https://cdn.compassionindying.org.uk/wp-content/uploads/vsed-call-for-guidance-november-2022.pdf>

Artificial Nutrition and Hydration] is often not governed by a clear legal framework”.⁷⁴

In the absence of standardised national guidelines and protections, compliance to any agreed standards is impossible. As things stand, even the level and detail of information available to both the public and to medical staff can often be lacking and inconsistent.

A Yougov survey in July 2022 commissioned by Compassion In Dying of over 500 UK professionals found that

50% of the respondents did not have correct information about the legal status of VSED” and “94% of the respondents said it would be helpful for health and care professionals to have guidance on the legal and clinical aspects of VSED.”⁷⁵

Dignity in Dying observe that “[u]nlike other end-of-life practices, there are also no standardised guidelines in the UK for how healthcare professionals should support people who decide to hasten their death via VSED.”⁷⁶ They note that inadequate pain relief can result from a lack of clear guidance.

Support by medical staff is also by no means guaranteed. Compassion in Dying cite recent examples of patients experiencing difficulty in accessing information, being stonewalled, being referred to psychiatric services and in one case a patient requesting VSED being sectioned seven days before his death.⁷⁷ They note that “[p]eople have also reported that their healthcare team refused to provide pain relief and symptom management when stopping eating and drinking.”⁷⁸

In terms of public awareness, although euthanasia has a page on the NHS Scotland public website, there was still no mention anywhere relating to VSED or VRRF, in acronym or full-form (on April 30 2025).

⁷⁴ Liu, Richard, Pope, Thaddeus Mason and Xu, April, Deep and Continuous Palliative Sedation without Artificial Nutrition and Hydration: An International Review (September 14, 2024). 35 *Indiana International & Comparative Law Review* XXX (forthcoming 2025)., 35(1) *Indiana International & Comparative Law Review* 67-151 (2025), Available at SSRN: <https://ssrn.com/abstract=4956660> or <http://dx.doi.org/10.2139/ssrn.4956660> <https://open.mitchellhamline.edu/cgi/viewcontent.cgi?article=1622&context=facsch> 27/04/25

⁷⁵ Compassion in Dying. Voluntarily stopping eating and drinking (VSED): A call for guidance. Nov 2022: 12. <https://cdn.compassionindying.org.uk/wp-content/uploads/vsed-call-for-guidance-november-2022.pdf>

⁷⁶ Dignity In Dying: The Inescapable Truth About Dying in Scotland (2019): study commissioned by the campaign group Dignity in Dying and conducted by the Office of Health Economics, a research company. <https://features.dignityindying.org.uk/inescapable-truth/>

⁷⁷ Compassion in Dying. Voluntarily stopping eating and drinking (VSED): A call for guidance. Nov 2022 8. <https://cdn.compassionindying.org.uk/wp-content/uploads/vsed-call-for-guidance-november-2022.pdf>

⁷⁸ Compassion in Dying. Voluntarily stopping eating and drinking (VSED): A call for guidance. Nov 2022: 9. <https://cdn.compassionindying.org.uk/wp-content/uploads/vsed-call-for-guidance-november-2022.pdf>

4. The problem of no standardised protections against malfeasance

Quill et al note that “[a]mong other ‘last resort’ decisions, VSED raises the fewest concerns that the choice is voluntary⁷⁹. An argument can be made however that VSED merits the same safeguards for any individual as are regarded as necessary for AD.

There is no evidence that availability of VSED as a choice has been abused by individuals targeting the vulnerable or that coercion has played a part in Scotland. However, it is also fair to say that without similar extensive safeguards proposed by Liam McArthur in his Bill for AD, and the concomitant centralised record-keeping and analysis, there remains little collated data upon which to mount an analysis. As things stand, it remains an assumption that most if not all individuals initiating VSED will be asked if it is their autonomous choice to sign an advance directive form and proceed. However, questions can be asked as to whether an appropriate degree of scrutiny is applied, or whether coercion is a significant risk. The lack of public scrutiny or indeed data collection and analysis on issues such as potential coercion leaves an uncomfortable lack of clarity. It would appear to make sense to offer checks within the ambit of a similar monitoring and protection system to that proposed in the McArthur Bill. Without an agreed national multi-stage process of checks, safeguards and data collection such questions will persist.

5. The problem with suffering: it may well be a longer and more unpleasant process than its supporters believe

Evidence suggests that discomfort and delirium are experienced in VSED causing unnecessary suffering could occur over a longer period. Pope and West⁸⁰ note that while some undergoing VSED may experience euphoria and tranquility, others have been observed to experience pain, delirium and anxiety. Professor Stephen Duckworth describes VSED as “a long, slow, cruel death.⁸¹ That patients can experience such delirium from both a refusal of food and water and from the drugs used to induce a coma raises doubt as to a peaceful and dignified experience. Loewy refers to the current practice of Voluntary Stopping of Eating and Drinking as “physician stimulated starvation”.⁸²

⁷⁹ Quill TE, Ganzini L, Truog RD, et al. Voluntarily Stopping Eating and Drinking Among Patients With Serious Advanced Illness-Clinical, Ethical, and Legal Aspects. *JAMA Intern Med* 2018;178:123-7. 125

⁸⁰ Thaddeus Mason Pope and Amanda West, “Legal Briefing: Voluntarily Stopping Eating and Drinking,” *The Journal of Clinical Ethics* 25, no. 1 (Spring 2014): 68-80.

⁸¹ Duckworth, Prof Stephen (2022) *Written evidence submitted by Professor Stephen Duckworth OBE, DSc, PhD, FKC, MSc LRCP MRCS (ADY0002)* UK Parliament. <https://committees.parliament.uk/writtenevidence/114065/pdf/>

⁸² Loewy, E. “Euthanasia, Physician Assisted Suicide and Other Methods of Helping Along Death.” *Health Care Analysis*, Springer Nature, 2004: 181. https://www.academia.edu/113873484/Euthanasia_Physician_Assisted_Suicide_and_Other_Methods_of_Helping_Along_Death?email_work_card=view-paper

Starvation and dehydration is a slow and unpleasant process. Bolt et al found that “in 8% of cases, dying was a prolonged process of more than 14 days”⁸³, while Quill et al found that “[t]he process of VSED until death may take up to 21 days”⁸⁴. Wax et al state that “VSED is an intense process fraught with new sources of somatic and emotional suffering for individuals and their caregivers”⁸⁵. Jean Davis, while undergoing VSED without an induced coma, described the experience as: “It is hell. I can’t tell you how hard it is. You wouldn’t decide this unless you thought your life was going to be so bad. It is intolerable.”⁸⁶ The Patients Rights Council describes the process as follows:

As a person dies from dehydration, his or her mouth dries out and becomes caked or coated with thick material; lips become parched and cracked; the tongue swells and could crack; eyes recede back into their orbits; cheeks become hollow; lining of the nose might crack and cause the nose to bleed; skin begins to hang loose on the body and becomes dry and scaly; urine would become highly concentrated, leading to burning of the bladder; lining of the stomach dries out, likely causing the person to experience dry heaves and vomiting; body temperature can become very high; brain cells dry out, causing convulsions; respiratory tract also dries out causing thick secretions that could plug the lungs and cause death. At some point the person’s major organs, including the lungs, heart, and brain give out and death occurs.⁸⁷

Proper palliative care can reduce the suffering of the patient as they starve and dehydrate. Wechkin et al note that for those who remain awake experiencing VSED, “end-of-life dreams and visions....may be eased with antipsychotic medications”⁸⁸. However the Patients Rights Council cite a case where despite a patient being “administered small doses of morphine to combat cramps and a sedative to relieve ‘emotional anxiety’” after more than a fortnight she was “howling with anguish.”⁸⁹

⁸³ Bolt EE, Hagens M, Willems D, Onwuteaka-Philipsen BD. Primary care patients hastening death by voluntarily stopping eating and drinking. *Ann Fam Med*. 2015 Sep;13(5):421-8. doi: 10.1370/afm.1814. PMID: 26371262; PMCID: PMC4569449.

⁸⁴ Quill TE, Lo B, Brock DW. Palliative options of Last Resort: a comparison of voluntarily stopping eating and drinking, terminal sedation, physician-assisted Suicide, and Voluntary active euthanasia. Springer Science + Business Media B.V.; 2008.

⁸⁵ Wax JW, An AW, Kosier N, Quill TE. Voluntary Stopping Eating and Drinking. *J Am Geriatr Soc*. 2018 Mar;66(3):441-445. doi: 10.1111/jgs.15200. PMID: 29532465.

⁸⁶ Guardian. Sun 19 Oct 2014 14.19 BST <https://www.theguardian.com/society/2014/oct/19/right-to-die-campaigner-starved-herself-jean-davies> 28/04/25

⁸⁷ The Patients Rights Council. Voluntarily Stopping Eating & Drinking: Important Questions & Answers https://www.patientsrightscouncil.org/site/wp-content/uploads/2013/03/VSED_Questions.pdf 28/04/25

⁸⁸ Hope Wechkin, Robert Macauley, Paul T. Menzel, Peter L. Reagan, Nancy Simmers, Timothy E. Quill. Clinical Guidelines for Voluntarily Stopping Eating and Drinking (VSED). *Journal of Pain and Symptom Management*. Volume 66, Issue 5E625-E631 November 2023 [https://www.jpmsjournal.com/article/S0885-3924\(23\)00565-1/fulltext](https://www.jpmsjournal.com/article/S0885-3924(23)00565-1/fulltext) 27/04/25

⁸⁹ The Patients Rights Council. As above.

It is also reasonable to note the same option to offer medication in response to visible suffering is not available to those in an induced coma whose peaceful stillness may belie a far from peaceful experience. Those who look on may feel reassured by the apparent peace of their loved one in a comatose state. The patient however may experience traumatic delirium and physical discomfort.

Where a coma has been induced, any mental or physical suffering is generally not apparent. As noted by Sheen & Oates: “The absence of physical responses should not be misinterpreted to mean that cognitive processes are not occurring.”⁹⁰ In such cases of an induced coma the sufferer is unconscious for the entire period, paralysed and non-responsive, and can no longer communicate or interact or wake up and change their mind. This persists until death.

Nilsen et al note that “states presumed to be unconscious are not always devoid of reported experience”, and that

[c]areful studies have provided evidence that dreaming occurs surprisingly often in deep non-REM slow-wave sleep stages (Suzuki et al., 2004; McNamara et al., 2010; Windt et al., 2016; Siclari et al., 2017, 2018), as well as during general anesthesia (Käsmacher et al., 1996; Brandner et al., 1997; Leslie et al., 2007, 2009; Eeret al., 2009; Noreika et al., 2011; Leslie, 2017).⁹¹

In addition to the possibility of delirium whilst unconscious, there is a possibility that pain is experienced.

Owen et al note that “37% to 43% of patients who receive the diagnosis of a persistent vegetative state can be demonstrated by careful, standardized clinical examination on the basis of the Coma Recovery Scale (CRS-R) to have at least minimally preserved consciousness.”⁹² O’Connor et al note that in dying patients as “conscious level deteriorates so too does their ability to reason, to process information and instructions, and articulate their needs or a response to stimuli”⁹³, recommending that based on available evidence of continued cognition that patients should be regarded as unresponsive rather than unconscious. Formisano et al note the need for more in-depth research and better application of personalised and “more

⁹⁰ Sheen, L & Oates, J. A phenomenological study of medically induced unconsciousness in intensive care. *Australian Critical Care* Volume 18, Issue 1, February 2005, Pages 25-32. <https://www.sciencedirect.com/science/article/abs/pii/S1036731405800219#preview-section-abstract>

⁹¹ Sevenius Nilsen A, Juel BE, Thürer B, Aamodt A and Storm JF (2022) Are we really unconscious in “unconscious” states? Common assumptions revisited. *Front. Hum. Neurosci.* 16:987051. doi: 10.3389/fnhum.2022.987051

⁹² Owen AM, Coleman MR, Boly M, Davis MH, Laureys S, Pickard JD. Detecting awareness in the vegetative state. *Science.* 2006 Sep 8;313(5792):1402. doi: 10.1126/science.1130197. PMID: 16959998.

⁹³ O’CONNOR, T., PATERSON, C., GIBSON, J. and STRICKLAND, K. 2022. The conscious state of the dying patient: an integrative review. *Palliative supportive care* [online], 20(5), pages 731-743. 4 <https://doi.org/10.1017/S1478951521001541>

aggressive and appropriate pain management”⁹⁴ for patients with a disorder of consciousness. This has clear implication for both existing assumptions of VSED as a ‘peaceful experience’ and to palliative care requirements.

Patients in a minimally conscious state appear to register and experience pain. Herr et al observe that “[i]ndividuals who are unable to communicate their pain are at greater risk for under recognition and under-treatment of pain.”⁹⁵ This observation is supported by Formisano et al, who recommend a revised Nociception Coma Scale (NCS-R), but acknowledge that “Functional communication impairments in patients with Vegetative State (VS)/Unresponsive Wakefulness Syndrome (UWS) and Minimally Conscious State (MCS) makes assessment of pain a challenging task”⁹⁶, dealing with different forms of pain and a variety of sensory perception abnormalities. Boly et al found:

In patients in MCS and in controls, noxious stimulation activated the thalamus, S1, and the secondary somatosensory or insular, frontoparietal, and anterior cingulate cortices (known as the pain matrix). No area was less activated in the patients in MCS than in the controls. All areas of the cortical pain matrix showed greater activation in patients in MCS than in those in PVS. Finally, in contrast with patients in PVS, those in MCS had preserved functional connectivity between S1 and a widespread cortical network that includes the frontoparietal associative cortices.⁹⁷

Correctly assessing care needs for patients experiencing an ‘altered conscious state’ has always been challenging. Providing appropriate relief for VSED patients who have chosen to remain conscious during the process may therefore be problematic as the patient approached death and may become less coherent. Similar difficulties may exist where VSED patients have chosen to be rendered unresponsive by drugs. A key question, based on the drug regimen applied to render the patient

⁹⁴ Formisano R, Aloisi M, Ferri G, Schiattone S, Estraneo A, Magliacano A, Noé E, Pérez MDN, Hakiki B, Romoli AM, Bertoletti E, Leonardi G, Thibaut A, Martial C, Gosseries O, Brisbois M, Lejeune N, O’Valle M, Ferri J, Frédéric A, Zasler N, Schnakers C, Iosa M. Nociception Coma Scale-Revised with Personalized Painful Stimulus Versus Standard Stimulation in Persons with Disorders of Consciousness: An International Multicenter Study. *J Clin Med.* 2024 Sep 18;13(18):5528. doi: 10.3390/jcm13185528. PMID: 39337015; PMCID: PMC11432094. <https://pmc.ncbi.nlm.nih.gov/articles/PMC11432094/>

⁹⁵ Keela Herr, Patrick J. Coyne, Margo McCaffery, Renee Manworren, & Sandra Merkel. Pain Assessment in the Patient Unable to Self-Report: Position Statement with Clinical Practice Recommendations. *Pain Management Nursing* Volume 12, Issue 4, December 2011, Pages 230-250 <https://www.sciencedirect.com/science/article/abs/pii/S1524904211001883>

⁹⁶ Formisano R, Aloisi M, Ferri G, Schiattone S, Estraneo A, Magliacano A, Noé E, Pérez MDN, Hakiki B, Romoli AM, Bertoletti E, Leonardi G, Thibaut A, Martial C, Gosseries O, Brisbois M, Lejeune N, O’Valle M, Ferri J, Frédéric A, Zasler N, Schnakers C, Iosa M. Nociception Coma Scale-Revised with Personalized Painful Stimulus Versus Standard Stimulation in Persons with Disorders of Consciousness: An International Multicenter Study. *J Clin Med.* 2024 Sep 18;13(18):5528. doi: 10.3390/jcm13185528. PMID: 39337015; PMCID: PMC11432094. <https://pmc.ncbi.nlm.nih.gov/articles/PMC11432094/>

⁹⁷ Boly M, Faymonville ME, Schnakers C, Peigneux P, Lambermont B, Phillips C, Lancellotti P, Luxen A, Lamy M, Moonen G, Maquet P, Laureys S. Perception of pain in the minimally conscious state with PET activation: an observational study. *Lancet Neurol.* 2008 Nov;7(11):1013-20. doi: 10.1016/S1474-4422(08)70219-9. Epub 2008 Oct 3. PMID: 18835749.

unresponsive during VSED and until death, is whether the patient is rendered closer to an unconscious vegetative state or to an unresponsive minimally conscious state. If the latter, then there is a definite possibility that the patient could experience both pain and delirium, but be unable to indicate the experienced discomfort. Demertzi et al noted from their European survey of 2059 medical and paramedical professionals that

“To the question “Do you think that patients in a minimally conscious state can feel pain?” nearly all interviewed caregivers answered “yes” (96% of the medical doctors and 97% of the paramedical caregivers).”⁹⁸

This appears to be supported by neuroimaging for vegetative state (VS) patients and minimally conscious state (MCS) patients, where Demertzi et al observe that [i]n striking contrast to what we observed in VS, MCS patients showed activation in not only midbrain, thalamus, and primary somatosensory cortex but also in secondary somatosensory, insular, posterior parietal, and anterior cingulate cortices. The spatial extent of the activation in MCS patients was comparable to controls and no brain region showed less activation in MCS as compared to healthy individuals. A functional connectivity assessment of insular cortex demonstrated its preserved connections with a large set of associative areas encompassing posterior parietal, motor and supplementary motor, striatum, and dorsolateral prefrontal and temporal associative cortices as observed in controls (Boly et al., 2005). These neuroimaging data show large differences in brain activation between VS and MCS patients, despite a similar bedside behavioral evaluation.⁹⁹

Schnakers & Zasler¹⁰⁰, Boly et al¹⁰¹, and Wade & Hanrahan¹⁰² suggest that while patients in a vegetative state may remain inured to any pain stimulation. However Wade and Hanrahan also observe that patients with “a prolonged disorder of consciousness...may have episodes of transitive occurrent (‘in the moment’)

⁹⁸ A. Demertzi, C. Schnakers, D. Ledoux, C. Chatelle, M.-A. Bruno, A. Vanhauzenhuysse, M. Boly, G. Moonen and S. Laureys. Different beliefs about pain perception in the vegetative and minimally conscious states: a European survey of medical and paramedical professionals. CHAPTER 22, S.Laureys et al. (Eds.) Progress in Brain Research, Vol. 177 ISSN 0079-6123 <https://www.academia.edu/8996148/>
Different beliefs about pain perception in the vegetative and minimally conscious states a European survey of medical and paramedical professionals

⁹⁹ Demertzi et al. Different beliefs about pain. 2009: , as above.

¹⁰⁰ Caroline Schnakers & Nathan Zasler. Assessment and Management of Pain in Patients With Disorders of Consciousness. *PM&R Volume 7, Issue 11, Supplement*, November 2015, Pages S270-S277 <https://www.sciencedirect.com/science/article/abs/pii/S1934148215010242#preview-section-references>

¹⁰¹ Mélanie Boly, Marie-Elisabeth Faymonville, Caroline Schnakers, Philippe Peigneux, Bernard Lambermont, Christophe Phillips, Patrizio Lancellotti, Andre Luxen, Maurice Lamy, Gustave Moonen, Pierre Maquet, Steven Laureys. Perception of pain in the minimally conscious state with PET activation: an observational study. *The Lancet Neurology*, Volume 7, Issue 11, 2008, Pages 1013-1020, ISSN 1474-4422, <https://www.sciencedirect.com/science/article/abs/pii/S1474442208702199>

¹⁰² Wade, Derick T & Hanrahan, Andrew. Do some people with a prolonged disorder of consciousness experience pain? A clinically focused narrative review and synthesis. *Clinical Rehabilitation* 2025, Vol. 39(6) 796–807. DOI: 10.1177/02692155251333540. <https://journals.sagepub.com/doi/pdf/10.1177/02692155251333540>

consciousness of mental states when awake. This state is likely to be an unpleasant one with a negative experience of pain.”¹⁰³

Schnakers et al note that:

while vegetative patients only show reflexive activity, patients in a minimally conscious state demonstrate inconsistent, elementary but reproducible signs of consciousness, and can sometimes verbalize, but they do not show functional communication that could be used for pain assessment. Recent studies suggest that minimally conscious patients can experience pain to some extent.¹⁰⁴

Fratino et al note that “[d]etection of inadequate pain control might vary according to the method used to assess nociception in ICU patients.”¹⁰⁵ Schnakers et al also note that:

[e]ven if they present some level of consciousness, MCS patients are unable to consistently or reliably communicate their feelings and possible conscious pain perception. Hence, it is of utmost importance to develop sensitive tools to assess the level of pain perception in these patients.¹⁰⁶

Nazari et al note:

most patients in ICU cannot report their pain due to altered consciousness, mechanical ventilation, or sedation. Despite great efforts to accurately assess pain in patients in the ICU, their pain is still underestimated or remains undiagnosed and unmanaged.¹⁰⁷ O’Connor et al also note a “lack of suitable assessment tools to determine and assess care needs when the dying patient’s conscious state changes”.¹⁰⁸

Schnakers et al recommend that

future research will need to address the relationship between pain perception and the experience of suffering in patients in a MCS. Pain perception must be differentiated from suffering, as the latter involves a complex cognitive–affective phenomenon, involving not only a negative emotional response to the

¹⁰³ Wade, Derick T & Hanrahan, Andrew. Do some people with a prolonged disorder of consciousness experience pain? A clinically focused narrative review and synthesis. *Clinical Rehabilitation* 2025, Vol. 39(6) 796–807. DOI: 10.1177/02692155251333540. <https://journals.sagepub.com/doi/pdf/10.1177/02692155251333540>

¹⁰⁴ Schnakers, Caroline; Chatelle, Camille; Majerus, Steve; Gosseries, Olivia; De Val, Marie & Laureys, Steven. Assessment and detection of pain in noncommunicative severely brain-injured patients *Expert Rev. Neurother.* 10(11), 1725–1731 (2010).

¹⁰⁵ Fratino, S.; Peluso, L.; Talamonti, M.; Menozzi, M.; Costa Hirai, L.A.; Lobo, F.A.; Prezioso, C.; Creteur, J.; Payen, J.-F.; Taccone, F.S. Evaluation of Nociception Using Quantitative Pupillometry and Skin Conductance in Critically Ill Unconscious Patients: A Pilot Study. *Brain Sci.* **2021**, *11*, 109. <https://doi.org/10.3390/brainsci11010109>

¹⁰⁶ Schnakers et al. Assessment and detection of pain 2010:

¹⁰⁷ Nazari R, Froelicher ES, Nia HS, Hajihosseini F, Mousazadeh N. Diagnostic Values of the Critical Care Pain Observation Tool and the Behavioral Pain Scale for Pain Assessment among Unconscious Patients: A Comparative Study. *Indian J Crit Care Med.* 2022 Summer;26(4):472-476. doi: 10.5005/jp-journals-10071-24154. PMID: 35656052; PMCID: PMC9067504.

¹⁰⁸ O’CONNOR, T., PATERSON, C., GIBSON, J. and STRICKLAND, K. 2022. The conscious state of the dying patient: an integrative review. *Palliative supportive care* [online], 20(5), pages 731-743. 4 <https://doi.org/10.1017/S1478951521001541>

pain experience, but also the ability to remember that particular experience or set of experiences.¹⁰⁹

There is sufficient evidence in the studies cited that those who are in a drug-induced coma can experience both delirium and pain, despite the non-response and apparent peacefulness of the individual. In reality, the comatose individual is unable to express suffering and seek relief. The overall process may move from MCS to something more akin to VS as the body's organs fail. However, lack of research specifically on this process in relation to VSED leaves cause for concern as to how unpleasant the experience may be. No nociception measurement tools appear to have been applied during VSED, but as noted earlier, those who choose to remain conscious during VSED can become agitated, confused, distressed and in a great deal of discomfort up until the end. Of course, even if suffering may be experienced, whether conscious or unconscious, it must be considered within the context of the comparably greater suffering anticipated (or indeed already being experienced) that the individual is seeking to circumvent. It may well be an experience for some of a lesser harm over a worse one. For some it may be a choice instead of a more immediate form of assisted dying, but for most it is likely a choice made because the former is not legally available.

In addition to doubts that may remain about the peaceful and humane nature of the process for the dying patient, the process can also be a prolonged and traumatic deathwatch for their loved ones, where days can extend into weeks. There is also a sense of abandoning their loved one experienced by those who cannot stay 24 hours a day over such an extended death, due to the many other life commitments they may have. They may well be robbed of the catharsis from being with their loved one at the end, an outcome allowed by AD.

As the outcome of VSED is both foreseeable and intended, a common question is why deaths need to be dragged out for the sufferer and their loved ones when supply and/or administration of a more immediately lethal dosage could allow a more compassionate and shared goodbye, as is available in other countries.

Summary

Citations and web addresses checked and confirmed Xth May 2026.

No AI.

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¹⁰⁹ Schnakers, Caroline; Chatelle, Camille; Majerus, Steve; Gosseries, Olivia; De Val, Marie & Laureys, Steven. Assessment and detection of pain in noncommunicative severely brain-injured patients *Expert Rev. Neurother.* 10(11), 1725–1731 (2010).