

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

This document specifically includes Scottish data. The more general observations may however apply more widely.

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 deprivation^{3 4 5}), and an ageing population⁶, 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 and 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

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/>

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 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/>

more prevalent among disadvantaged groups”¹¹, 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 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 Bill 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 insufficient to ameliorate 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;

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

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.

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 of 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. The process is not restricted to terminal patients. 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 drinking directly causes death.”¹⁸ 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.¹⁹

According to Wax et al,

Voluntary stopping of eating and drinking (VSED) is a deliberate, self-initiated attempt to hasten death in the setting of suffering refractory to optimal palliative interventions or prolonged dying that a person finds intolerable.

¹⁸ 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>

¹⁹ 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)

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.²⁰

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. However as death is intended from the process as a whole, and in view of the lack of available research, the contribution of the dosage to overall cause of death remains open to debate.

As for double-effect, the purpose of VSED, as supported by Scottish medical staff, is for the individual to end their life, an outcome both foreseen and intended. As 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.²¹

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 with non-fatal conditions.

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. VSED merits

²⁰ 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

²¹ 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

an examination as a counterpoint to assisted dying - as the closest legally practiced analog to assisted dying for those seeking to end their life, and as most likely alternative option if assisted dying is legalised. It can be noted that opponents of AD do not appear to have committed similar time, effort and resources to the protection of individuals pursuing VSED.

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 similarities with Assisted Dying
2. The problem of no standardised regulated approach or equality of provision.
3. The problem of no standardised protections (eg against coercion).
4. The problem of lack of data: no standardised record-keeping, data-sharing or analysis.
5. The problem of suffering: it may well be a longer and more unpleasant process than its supporters believe.

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., but this somewhat discounts evidence of additional suffering (see later). Evidence suggests that discomfort and delirium are experienced in VSED causing unnecessary suffering could occur over a longer period.

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 particularly in the cases where an induced coma is involved, death primarily by overdose cannot be discounted. The process of VSED itself however 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 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.

Medical practitioners themselves experience ambiguity in terms of difference between VSED and AD²². Jox et al argue that there is inconsistency in the support of palliative care societies, professional bodies of physicians, legal scholars, and ethicists:

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.²³

Jox et al note that:

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.²⁴

Liu et al²⁵ 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 al²⁶ 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."²⁷ 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,

²² 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>

²³ Jox, R.J., Black, I., Borasio, G.D. et al. Voluntary stopping of eating and drinking: is medical support ethically justified?. *BMC Med* 15, 186 (2017). <https://doi.org/10.1186/s12916-017-0950-1> <https://doi.org/10.1186/s12916-017-0950-1>

²⁴ Jox et al. When is hastened death considered suicide? 2019, as above.

²⁵ 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

²⁶ Liu et al. Deep and Continuous Palliative Sedation, 2024, as above.

²⁷ Liu et al. Deep and Continuous Palliative Sedation, 2024, as above.

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.²⁸

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 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.²⁹

Loewy refers to the current practice of Voluntary Stopping of Eating and Drinking as "physician stimulated starvation".³⁰

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. A degree of facilitation can be argued, but this is not analogous to causality. Pope³¹ argues that there are key 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 regarded very specifically as 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.

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. 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.

²⁸ Jox et al. When is hastened death considered suicide? 2019, as above.

²⁹ Jox et al. When is hastened death considered suicide? 2019, as above.

³⁰ 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

³¹ 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>

2. The problem of lack of data

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”.^{32 33} VSED has none of the standardised recording processes or indeed protections that the McArthur Assisted Dying For Terminally Ill Adults (Scotland) Bill (2024)³⁴ proposed. This is problematic. As Pope and West note: One recent meta-review³⁵ concluded that “VSED has hardly been examined in the past 20 years.” The authors describe the available research as ‘heterogenous and inconclusive,’ representing a ‘patchwork rather than a picture.’ Indeed, VSED has been under-examined compared to other end-of-life options.³⁶ Fringer and Staengle describe VSED as “a critical but poorly understood issue”.³⁷ 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”.³⁸

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 VRFF, in acronym or full-form (on April 30 2025).

There is also an absence of published research specifically in relation to the support of VSED in palliative care in Scotland.

While VSED has always been legal in Scotland, there is a definite lacuna in general in research into VSED. Lowers et al found that: “[f]ew studies have looked

³² 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

³³ 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>.

³⁴ Robertson, J. Legal Rulings 2026: 12-15, as above.

³⁵ 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).

³⁶ 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

³⁷ 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

³⁸ 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.

specifically at the incidence of VSED.”³⁹ Pope et al confirm that “deep and continuous palliative sedation combined with withholding or withdrawal of artificial nutrition and hydration...has gone largely unexamined.”⁴⁰ 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”.⁴¹ 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”.⁴² 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”.⁴³

General articles discussing VSED go back before 2000 - in 1993, Bernat et al called for systematic research on VSED⁴⁴, but Mensger et al in 2024 found available research dealt less with practice, and “mostly dealing with the ethical and legal issues”⁴⁵, and in their literature review Ivanović et al describe existing research as a:

³⁹ 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

⁴⁰ 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

⁴¹ 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.

⁴² 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

⁴³ 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>

⁴⁴ 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.

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

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.⁴⁶

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.⁴⁷

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

There is 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 medical support for VSED in order to provide clear guidance for both patients and healthcare professionals.”⁴⁸

There are references to VSED in advisory documents by disparate medical organisations such as the GMC in 2015⁴⁹, the BMA in 2019⁵⁰ and the Royal College of Physicians in 2021⁵¹. However, Compassion in Dying note: “The lack of guidance on VSED leads to significant inconsistencies in how it is managed by clinicians.”⁵²

⁴⁶ 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

⁴⁷ 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

⁴⁸ 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>

⁴⁹ 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

⁵⁰ 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>

⁵¹ 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>

⁵² 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>

Liu et al note that "[Deep and Continuous Palliative Sedation Without Artificial Nutrition and Hydration] is often not governed by a clear legal framework"⁵³

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."⁵⁴ They note that inadequate pain relief can result from a lack of clear guidance.

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."⁵⁵

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.⁵⁶ 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."⁵⁷

4. The problem of no standardised protections against malfeasance

Quill et al note that

VSED requires a sustained determination of the patient's own will despite substantial discomforts such as thirst and hunger. Furthermore, decisions to undertake VSED can be reversed by the patient, at least in the early phases. Among other 'last resort' decisions, VSED raises the fewest concerns that the choice is voluntary⁵⁸.

However, as many of those choosing VSED in Scotland can do so facilitated by an induced coma, the very 'protections' that Quill et al cite above are unlikely to be

⁵³ 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

⁵⁴ 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/>

⁵⁵ 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>

⁵⁶ 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>

⁵⁷ 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>

⁵⁸ 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

available. An argument can be made 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. However, it is also fair to say that without the more extensive safeguards proposed by Liam McArthur in his AD Bill, 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 scandals and prosecutions arising from instances of coercion remains an anomaly. Inconsistent reporting and record keeping may be a partial reason, but there appears to be no evidence of coercion related to VSED. 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 and safeguards, such questions will always persist.

5. The problem with suffering

Pope and West⁵⁹ 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.”⁶⁰ 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.

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”⁶¹, while Quill et al found that “The process of VSED until death may take up to 21 days”⁶². Wax et al state that “VSED is an intense process fraught with new sources of somatic and emotional suffering for individuals and their caregivers”⁶³. 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

⁵⁹ 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.

⁶⁰ 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/>

⁶¹ 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.

⁶² 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.

⁶³ 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.

was going to be so bad. It is intolerable.”⁶⁴ 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.⁶⁵

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”⁶⁶. 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.”⁶⁷

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, although apparently comatose and inactive, may experience traumatic delirium and physical discomfort.

In addition, a traumatic deathwatch is forced upon 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.

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

⁶⁴ 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

⁶⁵ 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

⁶⁶ 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

⁶⁷ The Patients Rights Council. As above.

be misinterpreted to mean that cognitive processes are not occurring.”⁶⁸ In such cases of 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).⁶⁹

In addition to the possibility of delirium whilst unconscious, there is a possibility that pain is experienced. 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.⁷⁰

Fratino et al note that “[d]etection of inadequate pain control might vary according to the method used to assess nociception in ICU patients.”⁷¹

Schnakers & Zasler⁷², Boly et al⁷³, and Wade & Hanrahan⁷⁴ 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

⁶⁸ 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>

⁶⁹ 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

⁷⁰ 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.

⁷¹ 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>

⁷² 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>

⁷³ 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>

⁷⁴ 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...may have episodes of transitive occurrent ('in the moment') consciousness of mental states when awake. This state is likely to be an unpleasant one with a negative experience of pain."⁷⁵

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."⁷⁶ 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"⁷⁷, 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.⁷⁸

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."⁷⁹ O'Connor et al note that in dying patients as "conscious level deteriorates so too does their ability to reason, to process

⁷⁵ 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>

⁷⁶ 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>

⁷⁷ 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/>

⁷⁸ 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.

⁷⁹ 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.

information and instructions, and articulate their needs or a response to stimuli”⁸⁰, 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 aggressive and appropriate pain management”⁸¹ 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.

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 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).”⁸²

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

⁸⁰ 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>

⁸¹ 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/>

⁸² A. Demertzi, C. Schnakers, D. Ledoux, C. Chatelle, M.-A. Bruno, A. Vanhauzenhuyse, 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](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)

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.⁸³

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.⁸⁴

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.⁸⁵

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”.⁸⁶ 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 pain experience, but also the ability to remember that particular experience or set of experiences.⁸⁷

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 measurement tools have been applied during VSED, but as

⁸³ Demertzi et al. Different beliefs about pain. 2009: , as above.

⁸⁴ 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).

⁸⁵ Schnakers et al. Assessment and detection of pain 2010:

⁸⁶ 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>

⁸⁷ 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).

noted earlier, those who choose to remain conscious during VSED can become agitated, confused, distressed and in a great deal of pain up until the end.