Impact case study (REF3)



Institution: University of Oxford		
Unit of Assessment: 30 - Philosophy		
Title of case study: Change in Assisted Dying Legislation		
Period when the underpinning research was undertaken: 2014-2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by
Professor Julian Savulescu	Uehiro Chair in Practical	submitting HEI:
	Ethics	July 2002-present

Period when the claimed impact occurred:

2015 - December 2020

Is this case study continued from a case study submitted in 2014? N

1. Summary of the impact (indicative maximum 100 words)

Julian Savulescu's research concludes that it is both lawful and ethical to respect lethal refusals to eat and drink, and therefore that it can be both lawful and ethical to provide palliative care to reduce the suffering associated with such self-induced dying. The research formed a core motivation to legalise assisted deaths in the Australian states of Victoria and Western Australia. The changed legislation has been implemented in over 220 cases, leading to reported benefits to patients, family members, and carers.

2. Underpinning research (indicative maximum 500 words)

Savulescu has researched and published extensively in the field of euthanasia and assisted dying. The research that is the focus of this case study was work undertaken in Australia in 2014.

Changed the debate about self-determination at the end of life

The desire for self-determination at the end of life is one of the drivers for the ever-increasing number of jurisdictions overseas that are legalising voluntary euthanasia and/or assisted suicide, and for the continuous attempts to reform State and Territory law in this area in Australia (which has no national euthanasia policy). This area of reform has been in development in Australia for a number of years and is a topic of lively public debate. "Voluntary palliated starvation" refers to the process which occurs when a competent individual chooses to stop eating and drinking, and receives palliative care to address pain, suffering and symptoms that may be experienced by the individual as he or she approaches death. Savulescu carried out research in collaboration with two legal researchers from Queensland University of Technology, Lindy Willmott and Ben White, which examined the evidence provided in recent rulings on cases involving palliative care. Willmott and White provided the legal expertise and Savulescu, the ethical perspective. Savulescu contributed approximately 50% to the resultant article [1].

The researchers examined three recent cases: Brightwater Care Group (Inc) [2009] 40 WAR 84; The Queen on the Application of Mrs Jane Nicklinson (in her own right and as administrator of the Estate of Mr Tony Nicklinson Deceased) [2013] 961; and v Sydney Children's Hospitals Network (Randwick and Westmead) (incorporating The Royal Alexandra Hospital for Children) [2013] NSWCA 320. In each case, the rights of the individuals concerned, the responsibilities and options of their medical advisers/carers, and the legal framework were examined. The legal and ethical rights of the individuals to refuse treatments were examined on a case-by-case basis, and then followed by a consideration of whether a person who refuses to eat and drink should be able to receive palliative care. Specifically, the researchers considered whether the addition of palliative care, so-called 'voluntary palliated starvation' or VPS, alters the legal and ethical analysis of the individual's decision to refuse sustenance. The researchers reached two major conclusions, both of which have been elaborated in Savulescu's additional publications:

- 1) That it is both lawful and ethical to respect lethal refusals to eat and drink [2, 5];
- 2) That it can be both lawful and ethical to provide palliative care to reduce the suffering associated with such self-induced dying [3, 4].



This second argument is more controversial, yet an important one to have in light of the ongoing debate about whether competent adults should be entitled to assistance to die, and the ongoing resistance of Australian Parliaments to enact laws that allow assistance to be given.

3. References to the research (indicative maximum of six references)

- 1. [Journal Article] White, Benjamin P, Willmott, Lindy, & <u>Savulescu, Julian</u> "Voluntary palliated starvation: A lawful and ethical way to die?" Journal of Law and Medicine, 2014, 22(2), 376-386 (available on request).
- [Journal Article] <u>Savulescu J</u>, Schuklenk U. "Doctors Have No Right to Refuse Medical Assistance in Dying, Abortion or Contraception." Bioethics, 2017, 31(3),162-170. DOI: 10.1111/bioe.12288
- 3. [Journal Article] <u>Savulescu, J,</u> 'A simple solution to the puzzles of end of life? Voluntary palliated starvation', Journal of Medical Ethics, 2014, 40(2), 110-113. DOI: <u>10.1136/medethics-2013-101379</u>
- [Chapter] <u>Savulescu, J.</u> (2015) 'Autonomy Interests, Justice and Active Medical Euthanasia' In *New Directions in the Ethics of Assisted Suicide and Euthanasia* eds M. Cholbi and J. Varelius. International Academy of Law, Ethics, and the New Medicine Series, (Cham: Springer) pp.14-58. ISBN: 3319220497 DOI: <u>10.1007/978-3-319-22050-</u> 5 4
- 5. [Journal Article] <u>Savulescu, J.</u> "The Structure of Ethics Review: Expert Ethics Committees and the Challenge of Voluntary Research Euthanasia." Journal of Medical Ethics, 2018, 44(7), 491-493. <u>10.1136/medethics-2015-103183</u>.

4. Details of the impact (indicative maximum 750 words)

The research influenced policy in the Australian States of Western Australia and Victoria. In those states, Savulescu was invited to participate in the Joint Select Committee (in both parliaments) on End of Life Choices' investigation into assisted dying. His research (especially 1 and 3 above) was cited and used by the committees to form eventual Governmental assisted dying legislation.

Changing euthanasia legislation in the State of Victoria

In Victoria, Savulescu made a written submission to the Victorian Legislative Council Standing Committee on Legal and Social Issues: Inquiry into End of Life Choices, with Ben White and Lindy Willmott on 3 August 2015 [A]. He also made an oral submission to the Council at Parliament House, Melbourne, Victoria on 19 August 2015 [A]. In addition, his work (3 above) was heavily cited throughout the Parliament of Victoria's final report produced in 2016 [B]. Overall, the state government agreed with Savulescu's findings and recommendations that there should be appropriate guidelines for the administration of continuous palliative sedation.

Savulescu also presented his work to Victorian Coroners in 2015 [C]. As a result of his presentation, the Coroners concluded that the elderly were committing suicide in circumstances where they would be eligible for assisted dying if the new law was brought in. The Coroners agreed on the basis of this presentation that the data they carry on suicide in the elderly would be useful for the Committee in considering the decisions. This data was repeatedly referred to in the transcript of the discussion around the new law [A], and played a major role in deciding to enact the new law [C].

Introduction of 'gentle deaths' in the State of Victoria

In 2017, Victoria legalised assisted dying, and the law came into force in June 2019. [D] The first assisted dying permit was issued in July 2019, and 580 requests had been received by 31st December 2020 [E], with over 220 assisted deaths recorded. The first person to end their

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life under the new law passed away in August 2019 supported by her family. Her family, in an interview with BBC Australia, said that the new laws enabled her to have "the empowered death that she wanted". [F, pages 2,3]

A retired nurse is another of the early applicants for a permit, who welcomed the option to end her own life. Having provided palliative care throughout her career, she was acutely aware of the suffering experienced by terminal patients. In an interview with The Age, she said "I have such very vivid memories of how terrible a process it was and of people just suffering so greatly"... When she realised landmark voluntary assisted dying laws had passed and would come into effect this year, she said "Emotionally I just feel so much better, It's incredible the comfort it has given me." Cases such as these demonstrate the significant effect that this law change has had on end-of-life care and the autonomy given to terminally ill patients [F, pages 2,3].

The main beneficiaries of the research are Victorian palliative care patients, their families and carers. This enables individuals to take responsibility and plan for their own deaths, and provides much greater clarity and guidance for the physicians involved in their care. As described in the two cases mentioned above, the new law has provided comfort through autonomous decision-making, and the knowledge that individual suffering can be averted.

Changing euthanasia legislation in the State of Western Australia

In Western Australia, Savulescu's work also changed the recommendations of the Joint Select Committee on End of Life Choices [G]. The parliamentary committee referred to Savulescu's research 11 times in their report 'MY LIFE, MY CHOICE' in August 2018 [G], specifically the paper [5], above. The main conclusion of the report was that "Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying." [G, page 7] As a result of the report, the West Australian Government initiated a bill to legalise voluntary assisted dying for patients suffering from a terminal illness after a cross-party parliamentary committee recommended the move, saying the law would limit "unnecessary suffering at end of life" [H].

Changing public perception of 'gentle death' and facilitating ethical assisted dying

The main beneficiaries of the research are the Western Australian palliative care patients and their families, and those campaigning for assisted dying legislation. One breast cancer patient had campaigned for the legislation, taking the view that watching the slow degeneration of loved ones is unbearably hard for families, as well as for the patient themselves. Speaking to the news channel ABC after the legislation was passed, she said of the opportunity for voluntary assisted dying "And you can make that time a special time rather than them remembering you as somebody that was maybe struggling to breathe, in pain and they can't do anything about it" [F, pages 2,3].

Besides the individual cases of gentle deaths that have gone forward as a result of the new legislation (which, in turn, was explicitly informed by Savulescu's research), Savulescu's research has prompted extensive coverage in the mainstream press. This includes articles that cite Savulescu in The Age, The Guardian, and The Conversation (combined monthly readership of over 35,000,000 people), as well as on Twitter and other social media outlets [F, pages 5,6].

5. Sources to corroborate the impact (indicative maximum of 10 references)

The State of Victoria

- A. Transcript: Standing Committee on Legal and Social Issues: Inquiry into end-of-life choices, Melbourne, 19 August 2015. This transcript documents Savulescu's contribution to the debate (Savulescu was the sole witness for this meeting).
- B. Selection of pages from *The Inquiry Report: Inquiry into end of life choices: Final Report.* Parliament of Victoria, Legal and Social Issues Committee. June 2016 PP No 174, Session 2014-16 (Document 1 of 2) ISBN: 978 1 925458 39 8. Full report available here:

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- https://www.parliament.vic.gov.au/lsic/inquiries/article/2611 (Accessed 1 February 2021). Savulescu's contribution is documented on page 3.
- C. Letter from the Deputy State Coroner of Victoria. The letter details how the coroner's decision was informed by conversations with Savulescu.
- D. The subsequent legislation: *Voluntary Assisted Dying Act, 2017*. Legislation has since been introduced and has been in force since 2019. Accessible via https://www.legislation.vic.gov.au/inforce/acts/voluntary-assisted-dying-act-2017/004 (Captured 26 January 2021).
- E. i) Web archive of the Victoria Government Response: The Government response to this report was tabled in Parliament on 8 December 2016. Accessible via <a href="https://web.archive.org/web/20200925110312/https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL Report/Government response End of Life Choices In quiry 081216 9bfdVt5Y 2.pdf (captured 25 September 2020). ii) Voluntary Assisted Dying Review Board, Report of Operations July-December 2020, which contains statistics for requests received under the legislation Jun 2019 December 2020, available at https://www.bettersafercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-july-to-december-2020
- F. Report by University of Oxford REF Impact Evaluator December 2020, analysing coverage in the press of the new assisted dying legislation.

The State of Western Australia

- G. The Report of the Joint Select Committee on End of Life Choices: 'MY LIFE, MY CHOICE: The Report of the Joint Select Committee on End of Life Choices', Ms A. Sanderson, MLA & Hon C.J. Holt, MLC August 2018. ISBN: 978-1-925724-20-2 (Series: Western Australia. Parliament. Legislative Assembly. Committees. Joint Select Committee on End of Life Choices Report 1). Available here: https://apo.org.au/sites/default/files/resource-files/2018-08/apo-nid188761.pdf. Savulescu's work is cited 11 times between pages 158 and 323 of the report.
- H. The Western Australia Government Response to the Joint Select Committee on End-of-Life Choices Report. The report confirms acceptance of the recommendations from the Report. Available here: https://ww2.health.wa.gov.au/-/media/Files/Corporate/general-documents/Voluntary-assisted-dying/PDF/WA-Gov-Response-My-Life-My-Choice-JSC-report.pdf.