LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),
Mr Ed Cocks MLA, Dr Marisa Paterson MLA

Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

Submission Number: 013

Date Authorised for Publication: 04 December 2023

From: [redacted]
To: LA Committee - VAD
Subject: Submission to Select Committee on Voluntary Assisted Dying legislation
Date: Tuesday, 28 November 2023 2:15:00 PM

[redacted]

Thank you for inviting submissions on this important health and ethical issue.

My submission is mainly about the eligibility requirements for adults (Part 2, Section 11). Specifically, I support the provision that the person has "one or more of the relevant conditions" or "the combination of the relevant conditions". It is important that the person has documented decision-making capacity, at some stage in their illness, in relation to VAD.

I will briefly outline my personal experience which has caused me to reflect on VAD. This account is about my sister's experience in another Australian jurisdiction.

My older sister (who for this purpose I will call Jan) had bi-polar disorder from her late twenties to her death in 2021 at the age of 71. Periodically, Jan had recurrences of her illness, but recovered with electro-convulsive therapy, medication, and 'talking therapies'. Nevertheless, at the time of her death, she had attempted suicide by the overdose of medication between 8 and 10 times over a period of about thirty years, and each time had been revived in emergency. On at least two occasions in recovery, Jan said to me, "I hoped not to be here." By attempting suicide on many occasions, Jan showed her practical wish for VAD.

In her late sixties, after treatment over about two years for psychiatric illness without improvement, Jan was diagnosed with frontotemporal dementia. This made life very distressing for her and her husband Jeff. They lived an increasingly isolated life, with Jeff very stressed by living with the effects of Jan's overwhelming anxiety and paranoia. After several stints in respite care, Jan was finally admitted to permanent residential aged care in November 2020. She was extremely unhappy. For three months, Jan stayed in her room, and had no visitors (party due to CovID). As described in Section 11, subsection (3) (a) (B) Jan was experiencing persistent suffering (whether physical mental or both) being caused to them by (B) the combination of the relevant conditions and any other condition or conditions they have been diagnosed with (the other conditions).

Finally, Jeff took Jan home for the weekend in April 2021, and they took their own lives with the use of ether. Jeff left a suicide note for the Coroner, which read in part, "… As she has attempted several times to end her life without success, I feel that it is now my job to help her achieve this. The alternative is for her to rot away in an institution for years, unhappy and assailed by anxiety. As we both have incurable conditions [Jeff had chronic fatigue syndrome], and are unhappy with our lives which have no prospect of improvement, it seems stupid to "soldier on". By going now, we can avoid the pain and indignities likely to further besiege us as we grow older."

VAD laws may have enabled Jan and Jeff to plan her legal exit from “intolerable suffering”, as it clearly was. I learned afterwards from the psychiatrist specializing in older persons mental health, that Jan was very distressed due to the combination of her particular mental health diagnosis and frontotemporal dementia. Jeff felt obliged to help Jan to achieve her goal, but also had to take his own life to avoid being charged with murder.

This experience has led me to these suggestions relating to decision-making capacity and eligibility be “person-centred”.

1. Advanced Care Plans should enable people to elect to have VAD if they develop dementia and their quality of life is much diminished, and they are distressed. If dementia overlays an existing mental health problem, the person can suffer extraordinary distress and pain. This might continue for years. If they have *already elected* to have VAD, their misery should end.
2. If the health conditions are complex and don’t fit the standard requirements, eligibility should be reviewed on an individual basis.

I hope that in future in the ACT it will be possible for people with intractable mental illness and neurodegenerative conditions to elect for a humane and timely end-of-life. Dementia has many variants, and the law should enable eligibility to be assessed on an individual basis.

Yours sincerely,

Susan Rockliff

[redacted]

Virus-free.www.avg.com