Written evidence submitted by East Metropolitan Health Service, Western Australia (ADY0389)

"I am the master of my fate,
I am the captain of my soul"
Invictus – William Ernest Henley

My name is Dr Clare Fellingham, and I am a consultant anaesthestist at Royal Perth Hospital, Perth, WA. In addition to my medical and specialty degrees I hold a Clinical Diploma of Palliative Medicine and am currently studying for a Master of Bioethics.

East Metropolitan Heath Service (EMHS) is 1 of 4 Health Service Providers (HSPs) in Western Australia (WA), employing over 8500 staff and with a catchment population of approximately 750,000 patients, including those residing in both metropolitan and regional areas.

My involvement in VAD began when I took on the role of Clinical Lead for the implementation of VAD across EMHS, 5 months before WA's VAD law was enacted on 1 July 2021. During this time, I designed both our VAD service and a comprehensive staff and patient education and awareness campaign, ensuring that as an organization we were prepared to deliver the highest quality care which honoured individuals whilst upholding the law. Subsequent to 1 July 2021 I have also acted as a trained VAD practitioner; in this role it has been my privilege to walk alongside over 60 people with a life limiting illness as they explore VAD as an end-of-life care option. Over a third of these people have died through the administration of a VAD substance.

Being a VAD practitioner is not easy. Nor should it be, given the significance of the decision-making involved, and the gravity of the outcome. Many of my doctor colleagues on initial thought find the idea of assisting someone to die seemingly incongruent with the practice of modern medicine; are we not taught to heal, to cure, to use all the extraordinary advances of the 21st century to preserve life at all costs? My answer to them is both yes, and no.

Yes, we should offer a patient with a serious and life limiting illness every opportunity to battle that foe, to meet it square-on, armed to the teeth with all that we have available in our glittering medical armoury. Yes, we should be in awe of what we can do, steeped in gratitude for the treatment opportunities these advances have made possible. Yes, we should sink and rise up with our patient's, time and time again, as they navigate the circumstance of their disease process. But we should also know when to stop. We should also be mindful to ask how much is too much? Is this really in their best interest? Will this treatment extend the quantity of their life, at the expense of its quality?

Death in its deeply personal, intimate, and unique way, comes to us all. Rather than embrace this inescapable truth, modern medicine has instead been seduced by its ability to stave it off; but with this medical mastery does not necessarily come the wisdom to astutely wield such power.

Autonomy (along with Beneficence, Non-maleficence, and Justice) is one of the 4 foundational pillars of modern medical ethical theory. Autonomous decision making in healthcare can only occur through the provision of genuine informed consent. Notably, a decision by a competent individual to refuse treatment may be made despite the opinion or recommendation of a doctor to the contrary, despite that doctor feeling uncomfortable, despite others viewing the decision as unreasonable, or even if that refusal leads to death. Critics argue that VAD runs counter to the philosophy that human life is sacred. In reality the principle of autonomous self-determination already prevails over the sanctity of human life.

If an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which life might be prolonged, doctors responsible for that patient's care must abide by their wishes, even if they do not consider it to be in the patients' best interests. This doesn't make it any less confronting, yet we know we must support our patients in this no matter what our internal conflict,

lest we force upon them a continued existence that is incompatible with their fundamental views as to how their life should be led.

VAD differs from other healthcare decisions only in that the patient is not consenting to treatment, but to their own death; an understandably challenging concept given the magnitude and irreversibility of the outcome, but one which a competent patient nonetheless has a right to determine for themselves. When viewed in the context of an inevitable death (as per the law in WA), one where the only other option is a protracted death not guaranteed free from suffering, it can be seen the challenge of acceptance rests on anyone other than the patient; for the patient, the outcome of any decision they make will be the same.

Relief of suffering is at the core of medical practice. Suffering is not ours to judge, it is ours to explore delicately yet deliberately; only then can we hope to treat it adequately. Hard as it is to acknowledge, there are some life-limiting conditions that cause profound suffering that cannot be completely palliated.

Palliative care and VAD are branches growing from the same tree; both seek to relieve the suffering caused by an inevitable death in a pragmatic, humane and holistic manner. Palliative Care services the world over are seen to grow and gain better understanding through the legalisation of VAD. Almost 95% of the patients I have cared for have also been receiving excellent quality Palliative Care; their reasons for seeking VAD as their preferred way to die are not due to lack of access to services. Time and again it is existential distress: a loss of the sense of self, dignity, autonomy, meaning, or purpose in life, that causes a kind of hopelessness particularly resistant to palliative interventions. These concerns are particularly prevalent in those seeking access to VAD.

The power of suffering laid bare, though, is often to promote healing; it can act as an incredible release. People have at times shared with me fears and anxieties they've never told another soul, things that they would otherwise have taken with them. VAD then presents the most powerful opportunity; for knowing for certain the time and the place of your own death can dramatically affect what occurs between this day and that. VAD offers up a sacred space in which to be vulnerable, and an unparalleled opportunity to leave no stone unturned and no word unsaid.

Death by VAD is a planned, intentional process that definitively addresses suffering and involves the patient's family intimately, allowing them to lean into their grief often before death has even occurred. It is a collaborative, respectful and compassionate process which brings a deep sense of relief, spiritual peace and at times, joy to the dying process.

For me personally, my experiences in offering VAD only strengthen my resolve to continue in this important work. My belief in its righteousness is strong, and my conscience is clear. Our laws in WA are amongst the most conservative in the world; a person can only access them if they are already terminally ill. VAD then does not offer a choice between living and dying, only between dying and dying. Giving a person the ability to take charge of that process, to regain ultimate control of a disease that has all but consumed them, is the most extraordinary gift. It is an immense privilege to be able to allay fear at the end of life and bring peace and comfort to those who surely deserve it most. Such is the significance of this work that it has changed the trajectory of my career and my life, and I am proud to be so involved.

No two people seeking access to VAD are the same; there is no obvious unifying feature, no single determinant that seemingly prompts a kind of person to choose this path. There is, however, one universal characteristic that binds and unites them all as they travel: bravery. To be able to look to the place most of us would dare not go; to project forward into the future and truly acknowledge the inescapable reality of your own death is astonishing enough. To then have the pragmatic determination and presence of mind to look that fate in the eye and say I see you, I feel you, I know

you're coming but you know what? I'm going to take charge and die my way, on my terms; that, surely, is the very definition of courage.

In allowing VAD we not only offer patients the choice in end-of-life care they have requested, moreover we acknowledge that through deep and meaningful conversation between doctors, patients and their loved ones we can dispel fear, reduce iatrogenic suffering, bring death and dying out of the shadows, and so allow patients and their families a better quality of life *and* quality of death, however that might occur, because everyone is on the same page and actually talking about what matters most.

At the start of this document, I quoted from one of my favourite poems, by William Ernest Henley. Titled Invictus, from the Latin meaning unconquered, I read it often as it reminds me of all the dauntless warriors I've cared for over the last year, to whom I owe an immense debt of gratitude for all they've taught me about living, loving, and being.

I would be extremely grateful for the opportunity to present further evidence and testimony to this inquiry on the positive nature of VAD.

Jan 2023