

RESPONDING TO REQUEST TO DIE – IT’S NOT JUST ABOUT VAD

Since the implementation of Voluntary Assisted Dying (VAD) there has been an increased emphasis on patients’ requests to die. However, even prior to the legislation it was not uncommon for patients with advanced diseases to request to hasten their deaths or assist them to die. This is a confronting conversation for any health professional. The evidence would tell us that health professionals often avoid or deflect such questions and find it challenging to know how to respond. Previously it was easy to dismiss this with “unfortunately we cannot legally...” and now we can refer them to the care navigators. Either way we miss a valuable opportunity to engage with our patients on what is most important to them. How do you respond to these conversations? In the next few paragraphs I hope to challenge you to think of a request to die as an opening to an important conversation and to review some of the tools to help open up this dialogue.

It is not unusual for clinicians involved in the care of patients with advanced illness to be confronted by a patient’s request to die. The literature tells us that health professionals often feel unprepared for these conversations or fear saying the wrong thing. Under the umbrella of the current legislation there is also a concern about whether you can bring up VAD and or knowing how to help them with that.

For me a request to die is a spotlight on what is most distressing for the patient or what they fear most. This is vital and useful information to assist us in caring for our patients. It could be pain, it could be becoming dependent or being incontinent. For each person this is different. If we can understand this then we can begin to acknowledge and plan to address these issues. We cannot always solve them but we can support them and work with them. Clinicians may fear engaging in this conversation in case they uncover something they cannot fix or cannot answer. We know that patients value being supported and heard over having all the answers. I have been reflecting on how we respond to these requests and what skills we have to offer our patients.

So how do you respond? Can I share a story? Bob was a 62 year old retired engineer. He lived with his wife in a rural town. Bob was diagnosed with metastatic lung cancer earlier this year. Unfortunately, his disease was refractory to treatment including radiotherapy, immunotherapy and chemotherapy. Each treatment would stabilise things for a period but it would break through again. Bob had a number of hiccups over his cancer journey. He had pain which required radiotherapy and multiple medications to control, his breathing deteriorated. The most important thing you need to know about Bob is that he was a physical person. He needed to be doing. He was always fixing something or playing golf. He was never one for sitting and watching TV. He was a very private man and fiercely independent. Have you met a patient like Bob?

One day he came for review with his wife, his pain was fairly stable although he was anxious about his upcoming restaging scans. He asked me “I want to know about this euthanasia thing”. How would you respond? This is explicit enough that I could launch into my VAD spiel and whip out the contact details for the care navigators. However, I said “tell me more”. Bob talked about his views on this, including the usual comparison to veterinary medicine. He talked about his fears for what the scan might show. Was it worth pushing through this next treatment, would it help, would it improve his quality of life? What was, to quote Atul Gwande “a life worth living” for Bob. To him it came down to not wanting to be bed bound and cared for or have “people fussing over him”. He did not want to die today. He still enjoyed parts of his life and he was worried about the future. So what do we do now?

We then spent time considering what this information meant in terms of his advanced care wishes. We worked out a clear advance care plan that helped in future treatment decisions i.e. he would have X treatment if it would help him to remain active and independent and if it was unlikely to do that then he would choose to withdraw life prolonging treatment. Fast forward a few months and Bob had deteriorated, he was becoming more fatigued and not able to do all the things he wanted. When the next hiccup came he decided not to go for active treatment. He was managed in his community with the support of his family and GP. He was able to spend a weekend at home with his family then was admitted to the local hospital and died within two days of becoming bed bound (after ceasing life-prolonging treatment). He told me on our last meeting that it gave him peace to know that we understood him and what was important.

What does Bob's story tell us? He reminds me of the importance of engaging in this conversation as part of his treating team. Yes I could have referred him on to access VAD. He would have been eligible. But I would have missed this opportunity and the insight which gave me a framework to continue to care for him and assist in decision making. It was also a powerful connecting and aligning conversation. He felt heard and trusted that we understood him. Bob had not been open to exploring what he called "fluffy stuff" before and told me exactly what he thought about any mention of social work or psychology. It was through exploring his thinking about what "would make you want to end it" and what "makes you not want to" he could start to verbalise these fears which he otherwise struggled to find the language for (you can probably picture a similar non-psychologically minded person).

We have considered why it is important to engage in conversations and use the request to die as a spotlight on what is important or distressing, but how do you do it? There was an article written in Australia in 2006 by Hudson et al (see reference). A few years old now but it is still relevant in terms of providing a framework for responding to requests to die (and even some suggested lines to use). If I summarise their framework it can be broken down into a few key principles:

- Be alert to your own responses – adopt an open posture and be mindful that your responses can shape a conversation
- Be open to hearing concerns – ask questions to explore emotional concerns, be alert to verbal and non-verbal cues to emotional responses, acknowledge feelings without needing to fix, use silence, sit through tears, express empathy
- Assess contributing factors – what makes them feel that way, what past experiences have they had, what supports do they have, assess for psychological distress (anxiety/depression), assess for uncontrolled physical symptoms, explore interpersonal stressor (family conflict, unresolved issues etc)
- Respond to specific issues – develop a management plan for reversible issues and consider support options, review advance care planning
- Concluding the conversation – summarise and confirm your perceptions with the patient's, ask what other questions or things they would like to discuss, offer follow-up and ongoing support to continue the conversation.
- After the discussion – self care, document and communicate to other members of the treating team as needed.

There are many different approaches to this conversation. The key points are; remaining open to the topic (avoiding the reflex referral), exploring the patient's key concerns, respond to their emotions. How do I do it? My hot tips are to use "tell me more" i.e. "tell me more about what you're thinking" and silence is golden, this gives the patient time to think and gives the perception that you have all the time in the world (when we all know you don't). I ask them about if they had the medication for VAD what would make them take it, if they wouldn't take it today why not? This is a hard conversation. The greatest tool you have is yourself. Be open and available to the conversation and most people will share their thoughts.

In summary when you next encounter a request to die, remember this is an opening to an important conversation. If you would like to practise your communication skills in a safe environment keep an eye out for the next Grampians Regional Palliative Care Team communication skills workshop. For information on VAD please refer to the DHHS website at <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>.

Reference:

Hudson et al. Responding to desire to die statements from patients with advanced disease: recommendations for health professionals. Palliative Medicine 2006;20:703-710

Dr Penny Cotton

Palliative Care Physician, Grampians Regional Palliative Care Team

CONTACTS

	Phone	Fax
Grampians Regional Palliative Care Team	5320 3553	5320 6493
Ballarat Hospice Care Inc	5333 1118	5333 1119
Central Grampians Palliative Care	5352 9465	5352 9425
Djerriwarrh Palliative Care	5367 9137	5367 4274
Gandarra Palliative Care Unit	5320 3895	5320 3763
Wimmera Palliative Care	5381 9363	5362 3480
Grampians Region Palliative Care Consortium	0428 737 330	

OCTOBER 2019



www.grpct.com.au

