Grampians Regional
Palliative Care Team

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WHERE WILL WE DIE?

How much have *you* thought about *you* dying? *Your* death will probably be something you'll have time to ponder. It will likely be much more predictable than in previous eras (Swerissen & Duckett, 2014). So what do *you* want *your* death to be? How and where should it be? Never mind that it's all a bit abstract without an actual diagnosis, I'll bet you have firm ideas about what *your* good death should look like.

Maybe *you*r good death is aged ninety-nine while watching a sunset at your favorite holiday spot, with a Guinness in hand or puffing a joint? How about in your sleep (you pick a suitably old age)? *Your* good death probably includes having good control of symptoms and being surrounded by your family and friends. If the literature is correct you will probably also say you want to die at home.

What does the literature actually say in respect to dying at home versus other sites of care? The Grattan Institute published a report called Dying Well (Swerissen & Duckett, 2014) which addresses these issues and is a pretty good place to start. Some interesting international data are shown.

Compared to other countries Australia has a low rate of home death with only 14% of Australians dying at home, compared with about 30% in the US, South Korea, UK, Ireland, France and New Zealand. At either end of the spectrum is Iceland, with 9% and Cyprus with 42% (Broad et al, 2011). Obviously national characteristics including cultural and service delivery differences must be important factors (Broad et al, 2014) but there isn't space here to discuss the various service delivery models in Australia, Victoria or the Grampians region. Suffice to say that the model of care in the community (including both professional and informal care) will be critical to how many people can realistically achieve a home death.

So what actually happens in total is that 14% of Australians die at home, 54% die in hospital/institutional settings and 32% die in residential care (Broad et al, 2014), but what does the literature say about where people want to die?

When people are asked about their preferred site of death the response varies depending on how the question is asked (Higginson et al 2013), at what point during an illness it is asked and, importantly, whether the question is asked of real patients, their carers or the wider general population. However, the generally accepted figure is that about 60-70% of people would prefer to die at home (Brazil et a, 2005; Foreman et al, 2006; Swerissen & Duckett, 2014).

There are some predictors of these preferences. They are associated with demographic circumstances, availability and type of carers, gender and the course of someone's illness as death approaches (Swerissen & Duckett, (2014). Foreman et al (2006) recorded some of these for South Australians at least, which included being in a younger demographic, being male, and being born in the UK, Ireland, Italy or Greece. Interestingly, having poorer mental health and having an overall better health status (despite their life limiting illness) were also independent predictors of wanting to die at home.

In contrast Gott et al (2004) report that older patients had quite specific practical concerns about their physical care and how burdensome to carers that may become. They also worried that their home environment may not be conducive to their care needs and unsurprisingly, potentially needing to have intimate care provided by their children also affected their choice.

Some people also thought that the need for profession carer input *at home* compromised their feeling of *being at home* while some even characterised the idea of professional input into their care at home as intrusive (Foreman et al, 2006), rather than helpful as we would intuitively assume. These factors may incline patients to opt for dying in hospital or a palliative care unit if they don't expect to feel the benefits of being *at home*.

A preference for dying in a palliative care unit rather than a hospital can also be unpicked to some extent. For example, being older, being female, being single, living in a metropolitan area, being in paid employment and having higher levels of education are all predictors of choosing a palliative care unit rather than hospital as their site of death (Foreman et al, 2006).

Of great interest is the result of Brazil et al's (2005) paper which reported on over 200 interviews with bereaved informal carers. Overall about 68% of patients and their carers had stated a preference for dying at home, while only 14% of carers and about 5% of patients preferred it to *not* be at home. About 30% of patients in this study did not die at their preferred site, and yet 92% of carers, in retrospect, considered that the actual site of death was the *appropriate place* under the circumstances.

I don't have the numbers for deaths at home in our region but GRPCT sees many dying people at home who want to stay there and many dying people in hospital who want to go home. A number do come to the conclusion that dying at home is not practical or due to the complexity of their care, not in their best interests. Of course, any discussion with the patients we see about their care involves much more than just their preferred site of death. The care people receive, including where it is delivered, is the product of a distillation process, where complex problems and difficult choices are weighed and discussed to find the most acceptable practical outcomes for the patient.

On a slight tangent, I do know that very few palliative care patients have an Advance Care Plan (ACP) through which their preferences could be clearly communicated. In fact, we recently audited all referrals from BHS to a community palliative care service. This covered a full year and included 110 patients. We found only 4 ACPs in place.

Perhaps most relevant to this discussion, only 1 ACP mentioned a wish to die at home, while the other 3 specifically said they *did not want to die at home*.

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