

But no-one dies without severe pain do they?

There are very few studies that address the question: what proportion of all cases of terminal suffering (most commonly thought of as pain) does good palliative care fail to control? Andrew Denton made a bold statement in his submission to the Health Select Committee in New Zealand this year. Allegedly quoting from the University of Wollongong's Health Service Unit (actually the Australian Health Services Research Institute) that co-ordinates information from most of the palliative care units in Australia, he wrote: "(The data) show that one fifth of those in the last 24 hours of life died in moderate to severe pain despite the best efforts of palliation."^[i] This is exactly the story that advocates for legalisation from Belgium, the Netherlands, Oregon and Washington States and Canada. And it is not true in New Zealand or Australia.

There are two problems with Denton's statement. One is that the data collected and presented by the Health Services Research Institute is, for epidemiological purposes, based on 'phases' in a patient's clinical course rather than days or hours of survival. A patient may pass through several 'phases' during their time in palliative care. The patient is designated "terminal" when they are considered to be close to death. The second problem lies in his vastly inflated estimate of the number of people who die in pain. The Australian data actually show that 3.6% of patients in this category – which typically has a duration of two days - have moderate to severe pain at the beginning of the phase. But the benchmark for managing pain of this intensity is that in 60% of cases the patient's pain should have been reduced to mild or absent during the terminal phase. Most palliative care units meet or are very close to meeting that standard. Thus at most 2 patients in 100 would be experiencing difficult pain symptoms at the *end* of their terminal phase. This is empirical data not guesswork or hearsay.^[ii] Moreover the figure is consistent with another recent publication which supports this much less dramatic conclusion.^[iii] This study of approximately 24 000 palliative care patients was, according to its authors "designed to analyse routine assessments recorded when a patient was documented as likely to die in hours to days, to determine the prevalence, intensity and associations of physical symptoms." It has the advantage of being a prospective rather than retrospective study. Its research team concluded that: "it is possible to conclude (from our study) that the majority (of those diagnosed as dying) were either not highly symptomatic at the time they were assessed as dying or were well palliated or both. Only 4.2% were documented as experiencing severe pain that *urgently required attention*^[iv]" ...NOT 'that could not be controlled'. They went on to say that the "data provide clinicians with sufficient confidence to honestly reassure people that for the majority the final stages of life are not likely to be complicated by unbearable or unmanageable pain."^[v]

^[i] Denton A. 2017. *Voices from the front line. A submission to New Zealand Parliament's Select Committee inquiry into ending one's life in New Zealand. In support of the petition by Maryan Street and 8974 others.* P.6.

^[ii] Connolly A, Bird S, Allingham S et al.(2016) *Patient outcomes in palliative care in Australia. National Compendium Report January – June 2016.* Palliative Care Outcomes Collaboration. Australian Health Services Research Unit, University of Wollongong, NSW Australia. Web Site: www.pcoc.org.au.

^[iii] Clark K, Connolly A, Clapham S et al. *Physical symptoms at the time of dying was diagnosed: a consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care.* J. Pall. Med. 2016;19 (12): 1288 – 1295. doi:10.1089/jpm.2016.0219.

^[iv] The emphasis is on needing urgent evaluation and attention, not on the failure of medication to ameliorate the symptoms.

^[v] Clark K et al 2016. *Op cit*

