"The most important thing about Advance is it helps us to start these conversations early."

A conversation with Karen Booth, President of the Australian Primary Health Care Nurses Association (APNA)

My background is that I have been a registered nurse since 1981.

I did my initial training at St George Hospital, but the last 18 years I've been working in general practice. I've been the president of the APNA for the last 2 years – and on the board since 2009. My main role in APNA has been advocacy, which involves work on various committees, as well as lobbying on particular health issues, and issues affecting nurses in primary health care. I still work clinically in a GP practice in Sydney, one day a week, because it helps to have that clinical contact, and I am also managing the practice at the moment, so it's busy! But it's very enjoyable, and very rewarding.

I have been working to bring a fresh perspective to a number of areas.

One of those areas is unnecessary hospital admissions, and patients being unprepared for last stages of life - and the introduction of advance care planning. It could be so much better for those patients who would be better managed with a well-planned palliative approach to care, rather than coming in through an emergency system, which is more suited to acute patients. It's about promoting a gentler pathway to care. Patients often don't like to talk about death – often the view is, "it's just something that happens, and then you just cope after someone dies". Getting health professionals to introduce that topic early, and to feel comfortable about doing so, and to make it a routine part of their care - I think that's very important. The benefits are wonderful for the patient, because they can plan while they are still able to make considered decisions, and can plan what they want. In my view, getting this to happen is about comfort levels, both for the patient, and the health professional. So it should be done in my view, at every 75 year old health assessment. It should be introduced, just as one of the normal things that we discuss, perhaps just with a simple handout, as something then to be discussed together regularly. Then also, if there is someone who is younger who becomes unwell with a terminal condition, we should introduce that conversation early, not to cause panic or distress, but to help with planning in the early stages.

I recently had a patient who was only in her 60s, who came in, in respiratory distress.

She had a diagnosis of respiratory cancer. But she and her husband did not want to discuss palliative care. What she probably needed was an admission to a palliative care service, some medication to help with her pain, and an introduction to palliative care. But she came to our clinic in distress, because they had not had a really good conversation about where they were going. As a consequence, they ended up in the emergency department, in hospital. They just didn't want to talk about it. In fact, a lot of people will have a funeral plan, but will not want to actually discuss the details of their end of life care needs.

To me the most important thing about Advance is it helps us to start these conversations early.

So people can talk about it a few times, and that way they can become more comfortable about the subject – that's really important. Having a script also helps, where people are a bit uncomfortable. Even little flash cards, with questions written on them - patients see that it's just a routine part of normal care. It's so helpful for the professional to have these as a guide to start the conversation and ease both parties into it. I think a key person in all this is the health professional. It is better for a patient to have the introductory conversation with health professionals, because they are often not quite as emotionally involved with the family, and are in a position to talk frankly, without the same upset that the family might experience. It also helps the family to approach the issue. The health professional can reassure the family that the person has given their intentions to a professional who is there to guide their care, someone who is separate from the family. So then, with the subject opened in a professional way, the family can become involved in the conversation – and it takes pressure off everybody. The health professional can deliver the information in a non-emotional and non-threatening way. And the information can be provided when it is needed and as often as needed.

I know one thing that makes it difficult, is that health professionals don't like to give bad news.

It's not always easy to say – "if you have a big stroke what do you want us to do?" So, often they will talk about intervention, even when sometimes it's obvious that interventions won't help, but they feel they are still giving a person some hope, when what they really need to do is give the patient some reality, so they can then actually begin to plan what they do over the coming days. And that comes back to your comfort level, and normalising the behaviour about conversations about death. In terms of the broader health reform issues that are being discussed nationally, we have been aware that the for the highest risk tier of people with advanced and multimorbid health conditions, up to 20% of these patients will have high likelihood of mortality in the next twelve months[1]. It's well recognised that these people could be much better supported in a palliative care pathway, rather than continuing to present to an emergency department in some sort of crisis. I really think that even people who register for a nursing home should have an advance care plan. And we need to change the behaviour and thought process of health professionals, so that we actually do advance care plans, and where needed can be moving people into a palliative care pathway. At APNA, we have members scattered all over the country - half of the nurses that are members of APNA identify as being from regional areas, and they often have problems accessing face-to-face education. So the Advance online approach, supported by the opportunity also to attend face-to-face workshops is great. I also really like the idea of train the trainer - the model where peers teach other colleagues to use your program I think works best - from experience in GP network training and Medicare locals, that is a strong driver in change.

Advance is definitely something we would recommend, and would be happy to promote.

1. http://www.health.gov.au/internet/main/publishing.nsf/Content/76B2BDC12AE54540CA257F72001102B9/$File/Primary-Health-Care-Advisory-Group_Final-Report.pdf

HammondCare CareSearch The University of Sydney The University of Queensland UTS University of Wollongong Australia Austin Health