

# Breakfast at Parliament

## *Dr Norman Swan*

*During National Palliative Care Week, Dr Norman Swan, Host of The Health Report on ABC Radio National presented the keynote speech at the PCA Breakfast at Parliament on 27 May 2009. This is an edited version of this speech.*

Thank you very much for asking me to speak on what is something that will affect us all one day – those of us who are egoists and like to think we are going to live forever will get a little shiver down the spine and a bit cold and sweaty when we talk about this – but we all know we are all going to face death.

When I trained in medicine, either there was no such thing as palliative care or it was some people around in the corner in a thing called a hospice. You didn't really want to know about it.

One reason you didn't want to know about it is a mass delusion in the medical profession which I'll come to in a moment.

A few years ago, I broadcast a series of stories from an eminent palliative care physician and for months afterwards listeners were requesting copies of these simple stories: stories of experiences at the end of life, of the dilemmas faced by people.

The community gets palliative care, but somehow a lot of us in the medical profession don't.

So what's this mass delusion?

Well the mass delusion is that modern health care is about cure.

But what medicine ever cures anybody of anything? Occasionally you may have a sore throat caused by a bacterium and your doctor will give you antibiotics and it will get better.

There's the occasional surgeon who goes in and removes something and you're cured. But most of the time we ain't cured.

And so from the moment we are born, we are on that downward slope toward that brick wall at the end of the hill and sometimes our progress speeds up.

The issue is we don't recognise this – because the other thing about health care is that we are trained not to fail. Failure is unacceptable. That's actually an Australian thing.

I was involved with a group undertaking research in workplaces around the world in the banking and telecommunications industries. The study asked people what meaning they took from certain words. In particular, they asked people what they meant by 'success'.

If you ask an American worker what they mean by success, they usually say 'I've achieved the target set for me'. And you know the American thing is to just get there, they don't care so much how you get there, just get there.

When you ask Australians how they define success, it's that they haven't failed. We are very intolerant of failure.

In health care we see the lack of cure as failure. We see death as failure. We see illness and suffering as failure. Sometimes indeed it is – there are thousands of people who die prematurely because of the injuries inflicted upon them from the health care system.

But nonetheless we're actually very rarely curing, and one of the things healthcare reform in this country has to do is actually recognise this fact at a deep and emotional level.

One area where there is delusion to the  $n^{\text{th}}$  degree is in cancer care, although to be fair, it's



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not just confined to cancer, but if we take cancer as a case study, there is delusion in cancer care.

Cancer specialists like to think they cure – even though if you actually ask them they will say ‘no, we’re not’. The reality is most cancer treatment in this country is not curative cancer treatment. It’s palliative – just with a longer timeframe than most people would attach to the label.

Cancer treatment happens in the part of the hospital, or the clinics where they have this delusion that what they are about is curative medicine. But what they are actually doing is extending life, and hopefully extending it with a reasonable quality.

In fact, end-of-life care in cancer medicine should happen years before somebody dies. While the cancer community is getting better, it is still not good at recognising this fact and there is still a perception that the dreaded words ‘palliative care’ mean that in ten minutes you’re going to die.

When we come to a breakfast talking about end-of-life care, palliative care and recognising end-of-life issues, everybody thinks cancer, that this is what it is all about – people dying of cancer.

But that’s not what it’s all about. If you look at how Australians live and how Australians die,

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yes they die of cancer, but probably more of us are going to die of coronary heart disease, and we are going to die of coronary heart disease in situations where we’ll need palliative care.

There is an epidemic of congestive heart failure in this country and if any of you have elderly relatives, parents, or know others who have that condition, you will know that it is a condition that needs palliative care.

Anyone who has an elderly relative who is demented or knows someone who is demented will know that people with serious mental illness like dementia often need end-of-life care and palliative care.

What happens in this country is we don’t introduce end-of-life care early enough. We don’t recognise when it’s needed, and the result of this is that people suffer unnecessarily.



The Hon. Alan Griffin, MP, Minister for Veterans’ Affairs; Ms Donna Daniell, CEO Palliative Care Australia; Dr Norman Swan

If you look at the statistics, while there are around 140,000 deaths in Australia each year, 100,000 of these are no surprise.

An academic in the UK talks about the 'no surprises' approach to policy in this area. In other words, if somebody you know dies and you say to yourself, well that was no surprise, that's someone who probably needed end-of-life care.

If you say to yourself it'll be no surprise if this person dies in the next twelve months, then there are a whole series of things that should fall into place for that person. You don't necessarily need palliative care specialists, but you need an attitude of mind which is focused on care rather than cure.

This mentality is upstream of where we are at the moment.

You see, another thing we are obsessed with is prognosis. You get a diagnosis from the doctor, then you ask how long have you got.

Prognosis is a dark and inaccurate art and doctors are optimists. Even though they may look miserable, doctors actually are optimists and they usually overestimate prognosis. People are obsessed with prognosis – but this is not the real issue.

The real issue is timing, and it's about timing upstream.

So let's talk a moment about advance care planning. This is bandied around a lot.

When you talk to policy makers, and when you talk to legislators, such people like you here in the room, often you think about advance care directives – pieces of paper that you write out

telling doctors and nurses what you might or might not want done to you if you get into a situation that might be dire.

In fact, this is the least of it.

Advance care planning is about having conversations with your family and loved ones, it's about the people around you, all knowing what each other would want in a given set of circumstances.

This is so the family actually does know how you want to be cared for, and they know when you're fit and well, not when you're sick.

It's even more important when you start to become sick or develop dementia. It's having a community that thinks about life in its continuity, thinking about the end of life, long before it happens.

People love pieces of paper, some of you in this room are lawyers, that's the black and white of paper, you just love it. But you also know that once you put something down in black and white, problems arise – usually that's business for lawyers.

Advance care directives have a different status in different jurisdictions in Australia, sometimes they can be overturned because of loose wording. They may not be something to be relied upon. But this is not necessarily a problem.

What is crucial is family and friends who actually know what a person wants. If you've got it down in writing, all the better.

I had an extraordinary experience on air the other day where I was talking about religiosity and doctors, and what difference it might make



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to the care people receive. I was talking with an American doctor who was a Christian, a committed Christian, who made a study of this area.

I noted that as an ethicist, he must set a lot of value by autonomy. But his response was – autonomy was generally put right out on the side as a very secondary issue.

That's when you start to realise the cultural difference between us and our American friends. The gulf is quite considerable.

In Australia, whether you're religious or not, autonomy and choice is an important issue. We all want freedom – freedom to choose how we live and how we die, obviously within the constraints of a modern civilised society.

However, the system isn't very good at giving us those choices. It's not because the medical profession conspires against us, it's because the structures don't often exist.

So when people in the palliative care community talk about end-of-life care versus palliative care, it's code for 'end-of-life care is everyone's business'.

Palliative care is the business of specialists, to provide that specialised support which is quite extraordinary when you see it.

I've had the experience over the last couple of years of seeing this practice in action. You get this person who comes in, it may be a nurse or it may be a doctor and they just know how it works. They know how drugs work in this area,

they know the side effects, they know the cocktails.

Pain management is a huge issue, not just in cancer but in other areas as well.

You see people who are referred for this specialist care a month before they die, and you think they should have had it two years before they died.

We don't refer early, partly because of knowledge about the area and what is available, but also because of structures and training.

We haven't invested enough in training people to understand this area so there is a broad base of knowledge: the technology, the techniques, the evidence in this area.

If what we rely on in Australia to help us though the end of life is specialist palliative care, we'll never get there.

We need a broad base of people across the community who understand the issues so it's consumer driven with consumer pressure. We need nurses, general practitioners, psychologists and others who have a broad understanding in this area.

We will never have enough pain control specialists in the community, we will never have enough specialist palliative care nurses and physicians to meet the needs.

Instead, we must have a broad community of health professionals who are knowledgeable in this area. Training of the workforce is crucial.



Dr Norman Swan

There are also issues where legislators can help. You go to the doctor, you need a drug, the doctor writes out a script. Most of the time when a doctor writes out a script you know it's been through the regulatory hoops and the doctor's giving you a reliable drug.

In the palliative care area, much of the prescribing is what's called off-label.

Most of the prescribing is beyond what the drugs have actually been tested for. It's not that they don't work, it's that we have communities of doctors who are out on a legal limb prescribing drugs for purposes for which they have not been designed or formally approved, but for which they know work.

Off-label prescribing is not a criticism, it's a fact, it's a world-wide fact in palliative care. You go anywhere in the world and it's the same situation, most drugs are being used for purposes other than the ones for which they have been tested.

There is legal exposure in this area, there's evidence exposure. So we need investment in evidence, even though palliative care has been pretty good at finding ways around the blocks and getting access to drugs.

But the off-label issue goes further. There's a whole group of drugs in pain management which are not subsidised by the PBS and therefore people don't have easy access to them.

Weird things work in pain. There are drugs that might work in epilepsy and for some reason they work in pain. But they're expensive and they're not subsidised for use in pain management.

We have to find ways through this to give people access to care.

We also have to find a way of getting the private sector more involved in end-of-life care and palliative care. Health insurance companies are very patchy about how they support this area. We have to be able to find ways of encouraging the private sector to get more involved in this area.

And carers, there are half a million primary carers in Australia. There are 2.6 million people

who are in one shape or form caring for others, many of whom are at the end of their life. Maybe not next week, maybe not next month, but they're on that progression and they're looking after people in that state.

We need the infrastructure to help those people. Again, we're not going to get there just with palliative care physicians and nurses – it's everybody's business.

We're a community and it's got to be at a community level. If communities understand and share, and in many country towns it can work quite well, where you have general practitioners who know it's their business, and communities who do pull together, and are much closer to each other.

So, what I am saying is, this is not abnormal, this is normal.

We've got to get away from the delusion, we've got to get to the fact that this is going to happen to us all, it's going to happen to our parents, and don't pretend it's not going to happen. At every level in the community we have to understand it.

Some people are lucky and have strong spiritual beliefs, and there is some evidence that can help you through. But many people don't, and you cannot rely on religion or spirituality to get through this. This is a broad-based community activity.

I haven't even begun to talk about indigenous communities where this happens twenty years sooner than it happens in the non-indigenous community. We have an indigenous palliative care policy.

Choosing the place you die is important for every single person in this room but it's even more important for indigenous people. The last thing many indigenous people want is to die in a hospital. They want to be close to their community, and we often don't have the infrastructure to allow that to happen.

So my message is advance care planning, pain management, getting the training out there, it's everybody's business, but most of all, it's normal.

Thank you very much.