

40 STORIES IN 40 YEARS

Barbara Hayes



Barbara Hayes's passion for palliative care is a deeply personal one. As a teenager, she watched her 16-year-old brother die at home, without any palliative care services.

"There was no one back then to support and teach my parents how to care for him. We had a GP and the local minister attend our home at the end, but for the most part my parents had to figure it out for themselves."

"Palliative care means providing good care – good medical care, good emotional support, good social support and good spiritual support for people."

This experience formed Barbara's drive to help people. She trained as a doctor before starting a Registrar position in Aged Care in the late 1980s. This included working within nursing homes. After a short time, Barbara identified a need to gain specific experience around caring for people at end of life.

"At this time there were very limited positions available in Melbourne where you could gain experience in palliative care. I was lucky to secure a Registrar position at Peter MacCallum Cancer Centre. At that time, the Peter Mac role was more a pain and continuing care service, so it gave me the opportunity to learn about managing symptoms."

In the early 1990s, after six months in the role at Peter Mac, Barbara went to New South Wales. Here she worked in a number of other positions that helped to improve her knowledge of palliative care, before eventually coming back to Melbourne where she continued working in palliative medicine, mainly in in-patient palliative care units, along with consultancy roles and some community work.

"Palliative medicine was an area I loved working in, because I enjoyed the whole person care. Often there were times where other doctors felt like they had run out of things to do, but we knew there was lots more we could do to help the patient and support them. It was an incredibly satisfying time."

“One of the best things about palliative care is that you really do get to know your patients and families, and you build a connection with them. I have memories of so many patients and families that I will take to my own grave. I’ve met some amazing people, and heard some incredible yet tragic stories. I’ve also learned a lot from my patients.”

Now, Barbara works more heavily in the education space, as well as being current Board Chair for Palliative Care Victoria – a position she has held since 2017.

“My interest now particularly lies in aged care. There is a lot of work to be done to improve end of life care for those in residential aged care. I want to advocate for people who perhaps fall between the cracks. Through Palliative Care Victoria, and our connection with Palliative Care Australia, I now have the opportunity to be an advocate for these people.”

Changes in palliative care

For Barbara, one of the biggest changes she has noted across the last 40 years has been the growth, particularly around specialist palliative care services.

“There has been a lot of changes over my career. Now, there are many more in-patient beds and units. Hospitals all have palliative care consult services and there are also community palliative care services, with doctors as part of the services – something that was less common in the earlier days.”

“As humans, it is so easy to turn your head away from death until you are forced to see it, so when the time comes we’re not prepared. This can be hard when it is your time, or you’re trying to care for a loved one.”

“Clinicians also recognise more now that palliative care is not just for people with cancer, that we can be involved with people across a range of illness areas.”

“We’ve also seen a change in the way we practice palliative care. It used to be a model where people would have life prolonging treatment then a point would be reached where they would be referred to palliative care, and that life prolonging treatment would be largely ceased. Now we see the benefits of overlapping palliative care with treatment that is aimed at modifying the underlying disease and extending life.”

“We’ve also seen changes in the training for palliative care. Younger doctors are now choosing palliative care as their career. Even more interesting is that we’re seeing dual trainees, that being, doctors who are doing palliative care alongside another specialty like geriatrics or oncology, so you actually get doctors who have such a fantastic set of skills and knowledge.”

The future of palliative care

When it comes to the next 40 years of palliative care in Victoria, Barbara would like to see specialist palliative care easily accessible for anyone who needs it, while also ensuring all clinicians have skills in palliative care. She would also like to see greater support for people in residential aged care when it comes to palliative care, for both generalist and specialist palliative care services.

“This focus would mean that you get the same support no matter where you are, be it at hospital, in residential aged care or at home.”

“A lot of people have a very outdated understanding of palliative care, so there is a lot of work needed to grow people’s knowledge about what palliative care is. A big part of the work Palliative Care Victoria has done across the past 40 years is to help educate both health professionals and the community, but this needs to continue into the future.’

“It is important that we create greater community awareness about health and the limits of medicine when it comes to curing everything. No matter how much money you put into health systems, people will still die because we are mortal, so we need to be more accepting of that as a society.”

While Barbara’s experience caring for her brother had a significant impact on her future career, it is her experience caring for her mum 45 years later that showed her how important the sector is to people.

“45 years after my brother died, my mum died in the same house, however her death was different. We had a local palliative care service with a doctor who assessed my mum and prescribed the medication needed for symptoms and comfort. There were also nurses who visited, and bereavement support available. This difference in end of life care showcases the importance of palliative care in Victoria.”