

PALLIATIVE CARE AND QUALITY OF LIFE

The World Health Organization (WHO) defines health as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. The goal of health care is therefore not just to treat disease and extend quantity of life, but to also promote overall wellbeing and enhance quality of life.

But what exactly *is* quality of life?

According to the WHO, quality of life is “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”. It is affected by their “physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment”.

A bit of a mouthful for sure. But the bottom line here is that while a person’s quality of life is affected by their health, it is about *more* than just their health. A person’s quality of life depends on what is important to them, where they have come from, and where they are going. In other words: what constitutes quality of life for an individual is defined by *who* they are.

What does all of this have to do with palliative care?

Palliative care is all about quality of life. Back to the WHO: “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness”.

For many people, quality of life is just as important as quantity of life. For some, quality is *more* important than quantity – particularly if their quantity of life is limited by incurable and/or life-threatening illnesses.

How does palliative care improve a person’s quality of life? The WHO definition suggests that it does so “through the prevention and relief of *suffering* by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

However, the prevention and relief of suffering is merely the opening gambit of the palliative care approach. Alleviating suffering is a prerequisite to improving quality of life, but it is not sufficient on its own. In order to help patients and families live as well as possible, palliative care must also promote psychological, social and spiritual wellbeing.

This is only possible if palliative care clinicians are more than symptomologists or scientists-technicians. They must also be brave witnesses and loyal companions. “Don’t just do something, stand there.” And *listen*, with our hearts as well as our brains, as fellow human beings, sharing the human condition, travelling together along the journey of life.

To summarise: palliative care starts by seeking to find out *what* is the cause of a person’s suffering, but goes beyond this by striving to know *who* is the person suffering, in order to ultimately discover *how* to improve their quality of life, and help them to live as well as possible.

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CHANGING FOCUS

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My journey into palliative care started after losing both of my parents to cancer. My father died at home from oesophageal ca, whilst I was in my second year of nurse training. My mother died a few years later from MM in hospital which was a challenging experience. I was fortunate enough to be present at both of their deaths. At that time I was working as an orthopaedic nurse in England and as a result of the negative experience of my mum's death I felt that I had more to give.

So I decided to change my nursing focus and secured a job at the local hospice. I was able to care for patients in a beautiful tranquil workplace which gave me great fulfilment and I loved my job. Patients and their families had wonderful facilities to share their last days together in a supportive, relaxing holistic environment.

Education and support for the nurses and staff was deeply interwoven within the hospice culture along with great teamwork amongst the MDT. I felt that I had found my niche but in the meantime I met and married an Aussie and sometime later moved out to Australia. I worked at St Vincent's Public Hospital for a few months in the Palliative Care Unit which was a great experience but I was travelling from Ballarat, felt emotionally drained and felt that I needed a change.

I was fortunate enough to join the Urology Team on 3 North at the Ballarat Base Hospital which I really enjoyed. During this time BBH were supporting the initiative to drive forward the Care of the Dying Management Plan and ensure that Goals of Care Resuscitation forms were completed. Ward champions were required to support this initiative, to which I hastily applied, and reconnected with end of life care. The Grampians Regional Palliative Care Team advertised for a temporary CNC position, working two days a week. Having always been impressed by the timely, knowledgeable service that the GRPCT supported the wards with, I applied and nervously but happily accepted the position.

I am in no doubt how lucky I have been to have this experience, to learn from the doctors and specialist nurses within the team and also the exposure that it has given to me within the hospital and surrounding areas. It has reinvigorated my passion for nursing and the desire to be more effective and I am looking forward to the opportunities that this brings.



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