



Dying to Understand



PALLIATIVE CARE

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INTRODUCTION

One of the things that freak people out the most is the concept of palliative care. People tend to believe that a referral to palliative care means the end is here – it's game over. This is simply not true. A palliative care referral is the best thing you can offer someone with an incurable illness. Let me try to explain why.

As a Radiation Oncologist, I use radiation to treat cancer. I cure a number of patients but not everyone will be cured. I was once confronted by a hostile member of the public about the dangers of radiation and was able to explain that, as doctors, it is not our first role to cure - our first role is to care for people.

Ultimately as doctors we all fail, because everyone eventually dies. People die for a number of non-medical and medical reasons; cancer, heart failure, kidney failure, strokes, the list can go on and on. Dying is a normal part of life.

Everyone will eventually face death and the palliative care doctors know this. They are the specialists in medicine who are able to firstly care, always comfort, and make this bumpy journey at the end of life as smooth as possible. The debate is not *whether* palliative care is necessary, it is more about *when* palliative care is necessary.

THE EXAMPLE OF PREGNANCY

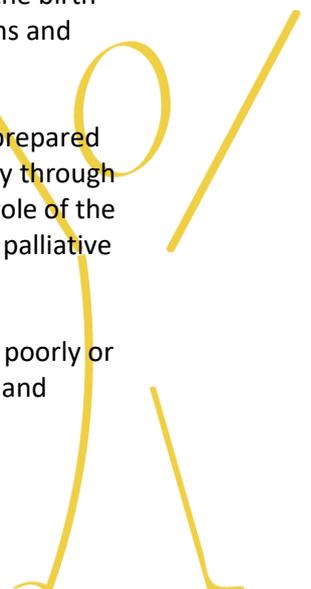
When a young lady becomes pregnant, we would consider it foolish if she met her obstetrician or midwife for the first time when she goes into labour. There is simply too much at stake to leave this big event unattended.

In preparation for the storm of birth, the young lady will see her obstetric team regularly. For the first few months, visits are infrequent and really no more than a "Hi, how are you doing," and perhaps some tests. As the pregnancy develops, more time and attention are given to the health of the mum and the baby. Plans are put in place for the birth and the same goes for after the birth.

By the time labour arrives, everyone knows their roles and they are prepared for the birth and the arrival of the child. Booties have been knitted by grandparents, cots, prams and other baby things are eagerly awaiting the new arrival.

While dying is never a happy occasion, it still requires the same attitude of being prepared for the changes in the body due to illness, the comfort and the support of the body through the process of dying, and the preparation for the changes after death. This is the role of the palliative care team. Just as the obstetrician and midwife prepare for birth, so the palliative care team are skilled in preparing for death.

Having palliative care is a privilege. In many countries palliative care is carried out poorly or not at all, and if you have access to a palliative care team, grab it with both hands and consider everything they offer.



THE BENEFITS OF PALLIATIVE CARE

1. They are specialists

Palliative care doctors in Australia are medical specialists or specialised medical practitioners. They have completed advanced training as physicians and have broad medical knowledge. They have a unique skill set when it comes to caring for the failing body and eventually, the dying body.

2. Teamwork

Good palliative care requires teamwork. This includes involving the general practitioner, palliative care nurses, social workers, spiritual carers and the family. Palliative care is never managed as a 'one-man-band'. The strength of palliative care is in the whole team working together for better outcomes.

Palliative care doctors also have access to a network of other specialists, so if there is a need for a surgeon or physician's opinion, the pathway is clear for a speedy referral.

3. Access to resources

Palliative care requires specialised resources such as palliative care beds with soft air mattresses to reduce the risk of pressure sores developing. Care is mostly provided at home but there are also specialised medical facilities known as a 'Hospice' where exceptional appropriate medical care is provided in a more comfortable environment.

4. Expert symptom control

Palliative care doctors know about symptom control and are able to manage a range of symptoms that occur as the body fails and weakens.

5. Pain management

Good pain management is essential for good quality of life and palliative care doctors do not only know about pain control, they also have access to specialised pain drugs and are skilled at managing complicated pain. Good pain management requires the level of specialised knowledge that palliative care specialists bring.

6. Preparation for bereavement and loss

When it comes to dying, there are losses and sadness along the way. The palliative care team work with the dying every day so they understand the emotional rollercoaster and are able to provide comfort, support, education and guidance in this storm of emotion and loss.



7. Help with medico legal matters

There are many legal matters to consider and the palliative care team will be able to point patients and their families in the right direction when it comes to things like advanced directives, enduring power of attorney, wills and testaments.

8. The right mix of care and compassion.

Most palliative care professionals *do care*. They see enough death to appreciate that egos don't get you far in life. They have a balanced view to life and death and will often help get patients across the line with a good sense of humour.

9. Greater freedom and choice

In palliative care, one size does not fit all, and the palliative care team work together with you to ensure that, as far as practically possible, your needs will be met. They understand that things are often fluid, that thoughts and ideas change and by the nature of palliative care, health needs change and eventually are no longer required. There can be no better team steering the palliative care ship through the uncertain waters of deteriorating health.

10. The bigger picture

Palliative care teams know that illness and dying does not only affect one person, it affects a community. They are able to provide care and support to all involved including care of the caregivers.

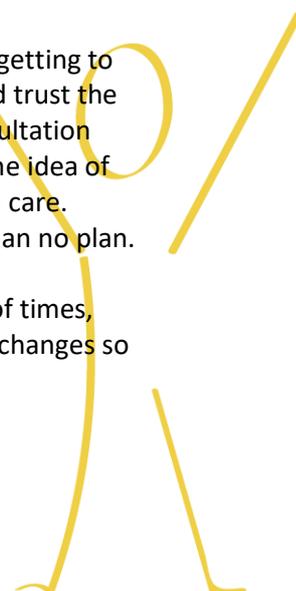
THE PALLIATIVE CARE PROCESS

Relax! When you first see the palliative care team, they should not be measuring you up for the coffin!

Early palliative care referrals are better because there is a whole lot that can be done to improve both the quality and quantity of life with good palliative care.

If you require a palliative care appointment, the first meeting will really be about getting to know each other. You get to know them and decide if you can get along with, and trust the palliative care doctor, who will also get to know your background. The initial consultation may be quite long as there are many aspects of your health they have to cover. The idea of the consultation is to get a good baseline of how things are and to identify gaps in care. Most importantly you need to go away with a plan - a good plan is much better than no plan.

As health deteriorates, the plan will need to be modified and changed a number of times, but that is why palliative care is important. The scenery will be changing and as it changes so too does the level of care.



As illness progresses, the body will become increasingly weak and frail to the point of starting to fail. More care will be required and there may be episodes where admission to care will be necessary. This may sometimes be simply to give everyone else a break. Caregivers also get exhausted, depressed and overwhelmed by the journey of illness. The palliative care team takes care of the caregivers as well.

At the end of life, when the dying process starts, the palliative care team have the skills and knowledge to make this as easy as possible. They may have the option of caring for you at home, in a hospice or hospital. The main thing is to ensure that there is *controlled* and *deliberate* care rather than the chaos that occurs without good palliative care.

By this time, when life is ending, everyone on the team knows and trusts each other. There is a good understanding about what is happening to the body, and the stress and distress of dying are managed so much better with earlier palliative care input. There is no need to freak out.

CHANGED THINKING

Some people do not access palliative care and they are worse off for missing this opportunity as life ends. Dying is difficult enough, so why do it alone? There is no way any of us can avoid death and pretending it won't happen does not make it better, it makes it worse.

Of course, no one wants to die!

But if dying is a reality, and life and the quality of life are deteriorating, why not get help? One of the most difficult things to manage about dying is denial. Denial happens when someone refuses to accept that they are dying or when a family member refuses to accept that their loved one is dying. This denial is a good coping strategy initially, but it is a disaster for the patient, the caregivers, family and the medical team when it continues.

To die is not wrong or evil or selfish, it is simply a fact of life. It may not be fair, but that is a different debate. When it comes to dying, there can be no better team on your side than the palliative care team.

To see the palliative care team does not mean that you are dying yet, but it does mean that we have to face the reality of being mortal. Yes, the truth is that we are mortal, no one gets to live forever. We all get to die once and when we do, we need the palliative care team at our side.



THE NEXT STEPS

If you or someone you know is facing an incurable illness, why not contribute to the debate. At *Dying To Understand* we give people permission to die, it is okay and not wrong to die. This is not an endorsement of euthanasia, but rather a 'letting go' of the struggle for life, when life is ending. There comes a time when the fight has been fought, the battle is over and it is time to rest, to be at peace and to be allowed to die gently with grace and dignity.

But before then, there is the opportunity to live, to make the most of what life offers and to make life count. Good palliative care allows both to happen - good living and good dying.

When it comes to palliative care and dying, are you freaked out? Why not tell us why? Help us to understand. Please share your thoughts at www.dyingtounderstand.com

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