

Palliative Care

Frequently Asked Questions

Introduction:

Some time in the late 1990s, the famous psycho-oncologist Buckman said that there was one missing chapter in Harrison's Textbook of Internal Medicine. The missing chapter was, "What do you do when all the treatment advised in all the other chapters fail?"

Palliative care is that missing chapter. It is about treating the illness rather than the disease (the term illness includes the disease but also encompasses the symptoms as well as psycho-social and spiritual problems that adversely affects the person and his family). But that is an oversimplified statement. Here are a few frequently asked questions on the subject.

1. What is palliative care? Is it just tender loving care?

In life-threatening (and generally prolonged) illness like cancer, AIDS etc, quality of life is decreased by

- Physical problems like pain, nausea and vomiting, breathlessness, fungating ulcers and so on.
- Psychological problems like depression, anger or denial in response to the illness, emotional isolation etc
- Social problems like financial burden induced by loss of employment, cost of treatment, social isolation etc
- Spiritual pain (*Why me? Why did God do this to me? Or What is the point of my being alive?*)

Palliative care is the **active total care** of the person with such problems. The aim of treatment is improvement of quality of life. The disease process is actively addressed. For example, if it is amenable to surgery, chemotherapy or radiotherapy, these measures are pursued provided they can improve quality of life. Pain and other symptoms are

actively treated. At the same time, the emotional, social and spiritual problems are attended to.

2. Is this terminal care?

Not necessarily. The word *terminal* is usually used to mean limitation of life to a matter of days or weeks. While palliative care certainly includes terminal care, it also includes the care of patients who may have a long time to live. For example both in AIDS and in slow growing cancers, the patient may have long survival, and nevertheless palliative care is certainly needed.

It is important to make this clear to all palliative care workers and patients. Because palliative care is often associated with terminal care, patients are often brought for treatment only towards the end of life, unnecessarily suffering pain and other problems till the last week of life. We need to emphasize that (though we will try to make death comfortable when the time comes), the essence of palliative care is about providing a **good quality of life.**

3. When does palliative care start? When the disease is declared incurable?

In one word, **no.**

In answer to question 1, we saw the various problems that adversely affect quality of life. We can easily see that all these problems would exist at the time of diagnosis as well as all through the phase of treatment, whether it is radiotherapy, chemotherapy or surgery. Hence ideally, **all principles of palliative care must be applied from the time of diagnosis.** The patients' need for emotional support may be most when the diagnosis is broken to him. Emotional support will also significantly increase the patient's compliance to definitive treatment. So it will be best for the patient if modalities of palliative care are applied concurrent with definitive treatment. However, the need for palliative care does become more when the disease is declared incurable.

Some people continue to follow the old WHO definition and say that the term palliative care applies only to the incurable. They may then follow a different terminology and use the term **supportive care** to describe the **active total care** that is given during definitive treatment. The terminology matters little. What really matters is that you consider the

patient as a whole and address all domains of the patients' problems, whether or not the disease is curable.

Palliative care is not only for the patient; it is also for the family. Therefore it does not end even if the patient dies. It includes bereavement support for the family.

4. And all this applies only to cancer and AIDS?

No. It applies to any long-standing disease that causes poor quality of life. Cardiac or renal disease, chronic pain states, quadriplegia or paraplegia, all may need appropriate application of the same principles. Some people use the term **long term care (LTC)** to describe this.

And it includes rehabilitation of the patient and the family.

5. Is not morphine what is used for pain relief?

Morphine is only one of the drugs that are used to relieve pain. Morphine does not work in all pains. Only about two-thirds of all pains can be adequately treated with morphine. It is important that the type of pain is identified and the appropriate drugs are used. And morphine is seldom used alone. It is combined with other appropriate painkillers depending on the type of pain. If morphine is used in pains that are not morphine-responsive, it will only make the patient sedated and cause side effects.

6. Will the patient on morphine be sedated for the rest of life?

No, certainly not. If morphine is used in morphine-responsive pain in the right dose, it does not cause sedation in the majority of cases. In fact the patient can often pursue a profession and lead a normal life while on morphine.

7. Will morphine not cause addiction?

No, not if used properly. Medical science has clearly understood in the last few decades, that if morphine is used in doses adequate for pain relief, it does not cause addiction. The fear is totally unfounded.

8. So there will be no withdrawal symptoms if morphine is stopped abruptly?

That is not correct either. There may be withdrawal symptoms if morphine is withdrawn abruptly from someone who has been on the drug for a long time. But **withdrawal symptoms do not mean addiction**. We have to distinguish between addiction and physical dependence which are two separate entities. In simple terms, addiction can be described as psychological dependence, manifesting as craving for the drug, steadily increasing quantity of consumption unrelated to disease progress and continued use despite harm. If oral morphine is used in doses titrated to the degree of pain in opioid responsive pain, the chance of addiction is infinitesimally small.

9. If morphine is taken for pain now, will it become ineffective later when the pain gets worse?

No, this fear is unfounded too. Morphine can be continued as long as needed and continue to provide pain relief. Of course if the disease process and hence pain worsen, the patient's need for morphine may increase too. But tolerance, manifesting as decreasing pain relief with continued use, is not a clinical problem with opioids. So morphine should not be reserved for the last few weeks of life. The time to start morphine is when pain demands it.

10. How about the risk of respiratory depression with oral morphine?

Used with reasonable caution, it is almost impossible to cause respiratory depression with oral morphine. The right dose of morphine is what is needed to relieve the pain. If this dose is exceeded, there are toxic signs like drowsiness, delirium and myoclonus. These serve as warning signs which prevent further consumption of the drug.

11. What about pains that do not respond to morphine?

About one third of all pains fail to respond to morphine. Most neuropathic pains, for example, are only partially responsive to morphine. Assessment of the type of pain and evaluation of opioid sensitivity is therefore key to proper management of pain. Most of these pains can be adequately treated if we use the right combination of non-opioid analgesics and adjuvant drugs. Of course, to do this some training in evaluation of pain and management is necessary.

12. Can palliative care be delivered by any doctor or nurse, or is it something to be done only by specialists?

Palliative care is multi-disciplinary care. Family members, volunteers and professionals all have their role to play. But for any one to do this optimally, some training is necessary.

Ideally, palliative care is something to be incorporated into routine medical practice. For this, palliative medicine has to become part of medical and nursing curriculum. For the time being, a short period of training would enable any volunteer, doctor or nurse to practice principles of palliative care. And they have the responsibility to train the family member in caring for the patient.

13. What role does a layman have in this? It is a medical problem, is it not?

Palliative care is not only treatment of pain and other symptoms and of disease. It is total care, incorporating emotional, and social and spiritual support. Volunteers have a large role to play in it. Volunteers can help depending on the skills they have and time available. It may be assistance with administrative matters or fund raising, but it can also be active patient care. It can include helping with nursing chores or counseling.

14. What a volunteer then needs is the will to help?

The will, certainly; but it is also essential to have the right training if one is to help people who are suffering. It is necessary to develop listening and counseling skills. It is also necessary to learn to understand needs and do what exactly is required to improve quality of life. Remember, it would be easy to hurt even with the right word at the wrong time. Many palliative care programs now conduct training programs for volunteers.

15. What sort of training programs are available?

Trivandrum Institute of Palliative Sciences (TIPS) undertakes the following training programs:

- a. 3-level training programs for volunteers.
- b. 10 day training program in pain management for doctors.

- c. Six weeks' training program in palliative care for doctors.

16. How are patients to be referred?

TIPS offers the following clinical services:

- a) Pain and Palliative care clinic at TC 4/436, Ambalamukku, Trivandrum 695005. Phone: 0471 325 7400 (Providing free service to those who cannot afford to pay). [Add timing](#)
- b) Pain and Palliative care clinic at SUT Hospital, Pattom, Trivandrum. Phone: 093872 96889. [Add timing](#)
- c) Home visit program – once a week, for patients who are too sick to travel to the clinics, covering Trivandrum city as well as in Venganoor Panchayat. Patients may be referred either to the clinic at Ambalamukku or SUT Hospital.