



PALLIATIVE CARE TAMING THE TIGER

by Matthew Monberg

Yann Martel's "Life of Pi" tells the story of Pi Patel, a boy who finds himself sharing a lifeboat with a Bengal tiger following the sinking of the ship they were both traveling on. It is a story about the strength of the human spirit in the face of what seems like insurmountable odds. Pi must change in order to survive.

Does any of that sound familiar?

Perhaps you feel as though you're riding in a lifeboat with a tiger. Maybe it's called diabetes, cancer or Alzheimer's. And, like Pi, you may feel alone and afraid.

"I HAVE WHAT?"

For most people, being diagnosed with a chronic or serious illness comes at the end of a long road. Countless tests followed by doctor visits followed by more tests. Scanned and poked, biopsied and scoped, at long last your doctor confirms what you never wanted to hear.

One minute you're sitting in the doctor's office, or in your kitchen with the phone to your ear; the next, you're in a lifeboat with a tiger. Now you know the animal you're dealing with, but you can't get out of the boat. And you can't ignore it. That means it's time for a plan.

WHAT'S THE FIRST THING THAT COMES TO MIND WHEN YOU HEAR "PALLIATIVE CARE?"

People often think palliative care is another term for hospice. Unfortunately, these two words are often used interchangeably, which is a bit like equating "biopsy" with "transplant."

Hospice provides specialized care and support during the last phase of life for individuals with a likely prognosis of six months or less. This care focuses on decreasing pain and distressing symptoms while ensuring a person's dignity and comfort. Hospice caregivers provide support to patient and family, including ongoing bereavement support.

A PLAN IS POWER

While hospice promotes quality at the end of life, palliative care is a medical specialty that benefits those with a chronic or serious illness, helping them live life to the fullest in the midst of treatment, or if they've decided to forego treatment. And it starts with a plan.

Palliative care helps you live a better life in spite of your diagnosis, medical treatments or symptoms. It doesn't matter when you received your diagnosis, but studies show that palliative care reduces depression and increases quality of life. So the earlier you begin palliative care, the sooner

you begin to see benefits.

Dr. Diane Meier, Director of the Center to Advance Palliative Care, sums up the key goal of palliative care as, *"helping people to live as well as possible for as long as possible."*

The key concept in palliative care is improved quality of life. Your diagnosis forms the starting line. Together with your healthcare providers you develop a comprehensive plan that fits your life, your needs, and your priorities—a plan for taming the tiger through symptom management, emotional and spiritual support, and family support.

1. SYMPTOM MANAGEMENT

The first step is addressing your symptoms such as anxiety, sleeplessness, nausea and pain. A palliative care professional can help you develop a symptom management plan that reduces the negative impacts of your symptoms, including the side effects of required medications.

The most important aspect of symptom management is controlling pain. On the role of pain, Meier observes, "...if a person is in pain, nothing else can really be accomplished. That is, they can't interact effectively with their families. They can't accomplish important goals to them. Very often they can't even get out of bed in the morning, because the pain is draining all their strength and energy."

Palliative care takes seriously the impact of pain upon a patient's well-being. Some believe that in living with pain—soldiering up—we are somehow fighting its underlying causes. This approach casts pain in the role of purifying moral force, and

a patient's endurance of pain signals superior physical and mental strength.

But if you could sedate the tiger in your lifeboat, wouldn't you? Why let him roam around causing problems? Pain, especially when it's ongoing, creates an uncomfortable distraction from the business of living your life.

Clearly you are entitled to deal with the pain that may be accompanying a chronic or serious illness however you see fit. But leading palliative care professionals, like Dr. Meier, point to research that pain is the number one cause of a reduced quality of life. Pain, above all other symptoms, can result in depression, isolation, and family strife.

Methods of pain management vary across diagnoses and patients, but in general your palliative care professional will:

1. Take your pain management seriously.
2. Help you rate your levels of pain accurately.
3. Prescribe a medication plan to bring pain under control quickly.

Listening to patients and helping them with practical ways to improve their lives is a key aspect of palliative care.

2. EMOTIONAL AND SPIRITUAL SUPPORT

Next, it's time to decide where you want to take this boat. We all need to be able to get things off our chests and someone who will listen without judgment. Sometimes it's awkward to know how to talk to your friends or family members about your illness, leading to feelings of separation from those you love the most.

Palliative care connects you with professionals who can help you talk

honestly about where you are with your illness and how you are feeling. Their job is to listen to your questions and provide you with the tools to better integrate your illness with your life. Because of their experience and training, they know what it's like to navigate the waters ahead. They know how to keep the tiger as quiet as possible. They will help you steer your boat to the calmest waters possible, if that is what you desire.

This aspect of palliative care helps you answer questions like:

- What comes next?
- How do I cope with treatment?
- What are other people with the same illness facing?
- How do I talk to my family, friends and coworkers?

In the words of one palliative care patient, Rita: *The first time I spoke to my chaplain I had no clue what we were going to talk about. We talked for two hours—she got me to pour myself out about where I was with my disease and lack of control vs. where I was before: working, managing people, running my family, having my own home. ...It really helps quite a bit.*

3. FAMILY SUPPORT

One of the most valuable byproducts of palliative care is the impact it can have on your loved ones. In fact, most patients say that one of their top concerns is how their disease or illness will negatively impact the people closest to them.

Your family is worried about you, whether you're being honest about your level of pain or anxiety. They wonder how you are really feeling.

Often, caregivers and family members feel that they have to do it all. They



want to get in the lifeboat. But in reality, they can't. Not being able to help a loved one creates a unique stress, often leading to tension and conflict. Family simply can't offer the wisdom of a trained and experienced professional. They can't adequately manage medications or prepare you for the side effects of a new one. But that doesn't stop them from wanting to.

Palliative care helps you understand and talk about your illness better, and it provides your loved ones with support, tools and information. They see you feeling better, and they feel better. It won't stop all the worry, but it does help create a more positive environment for all of you.

THE LIFE OF YOU

That tiger, whatever his name, is along for the ride. But that doesn't mean he's in charge. No matter what

your diagnosis, you're still you with many opportunities for a meaningful, full and rewarding life.

Palliative care puts you in charge, helping you control pain, develop a system of emotional support and improve each day of your life—the life of You. ❖

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