



So, this blog today investigates the thoughts and feelings we may have around pain.

**Let's start with some definitions.**

The word pain comes from the Latin '*Poena*' meaning punishment and the Greek word '*Poine*' meaning penalty. In ancient times Homer believed pain was delivered from arrows shot by the Gods. Aristotle described pain as being '*passion of the soul*' where the heart is the source, whereas Plato believed pain was the result of an emotional experience coming from the soul. The Bible references pain not only as a consequence of injury and illness but also acknowledges pain of the soul.

Another – more official - definition of pain is:

*an unpleasant sensory and emotional experience associated with actual or potential tissue damage described in terms of such damage*

International Association for the Study of Pain (ISAP)

Or a commonly used definition which has been helpful for doctors is:

*Pain is whatever the experiencing person says it is, existing wherever he/she says it is*

Margo McCaffery (1968)

There is a theory that because we enter the world in pain, birth is where our relationship with pain begins. From this early age, we manage and mitigate pain - from scraped knees to broken bones – and we endure. In the course of our life we learn to live with pain in all its forms. We have broken hearts, toothaches, migraines, back pain. We give birth. We know pain. We talk about it. We empathise. We advise. Pain is our common ground.

How often have we regaled people with tales of our falls, the pain of childbirth, a broken bone, a severe headache, back pain, our near-death experiences? We can recall every detail; we revel in peoples' squirms. We perhaps take some enjoyment out of the retelling, even if it happened decades ago. We are hardwired to remember these experiences.

The threat of pain also changes our behaviours. Take me for instance. I don't like going down steep stairs. I hold onto the railing and slowly edge my way downwards out of a fear of falling and hurting myself. This is a direct consequence of many broken bones as a child. Friends of mine no longer run, for fear of reviving previous back problems. We cannot bear the thought of the pain. As we grow older, we become more aware perhaps, or are we more fearful? We adapt, we avoid, we resist. We pull back our hand from the fire.

Pain inflicted upon us is often viewed as a punishment. From an early age, we are taught that if our behaviour is not appropriate, there are consequences. These consequences could be minor – a shove from a disgruntled commuter – or medium - a long-remembered punch from the school bully, or as serious as the methods of torture still used throughout the world today.

We are threatened by pain and its use as a tool to force or coax us to change our ways, or persuade us to part with information is still effective. Pain is our weakness and even the very strong eventually succumb.

Being afraid of pain is a rational response that has given us substantial evolutionary benefits. Pain tells us there is something that needs attention. But the problem with pain is that even when localised pain it affects the whole person. I remember burning my hand with boiling water. Only my hand was damaged, but I was miserable for days. The experience of this fairly benign hurt invaded my whole being.

Perhaps we have become a 'pill for every ill' generation. We instinctively reach for the painkillers. We don't like this invasion. Our aim is for immediate removal of our discomfort. For people who live with chronic and debilitating pain, this may be a long battle and an elusive goal.

In our survey what people told us they often associated with pain was fear.

*"I'm afraid I will die in pain."*

Fear compounds pain. It affects us physically by contracting our muscles, quickening our heart, raising our temperature. Fear can perpetuate pain. Quite often the fear itself is the most 'painful' part of the pain experience.

Fear triggers the fight or flight part of our brain, and fear makes us want to run. What researchers have found is there is a distinct correlation between fear and pain, and on many occasions, the degree to how we manage our pain is related to the amount of fear, anxiety, tension and pressure we put on ourselves.

The Buddha's teachings are when we fear we tend to cling to or resist the 'actual' experience. And as some have aptly put it: "Pain is inevitable, but suffering is optional."

Judging from the 'Have Your Say' survey people have a fear that at the end of their life their pain will not be managed. There still is a view, if they are medicated to the point of 'no pain' they will not be conscious and unable to understand what is happening for them.

Conversely, they fear they will be under medicated and have to feel the 'shame' of needing more.

When time is precious people don't want to worry about pain. Are we afraid to complain? I don't know about you but when I meet doctors I turn into a strange version of myself, a being who apologises and thanks in equal measures. The last thing I would want to be known as is as a complainer, or – horror - a whinger or whiner.

I want to be a warrior – but I fear I am not.

But doesn't it raise a good question? At what point are we allowed to ask for the 'heavy stuff' and without judgement. Do we understand what comfort care is when all methods of curative therapy have been exhausted?

Do we know what to ask?

I'm not sure. The fears of the people who took our survey are real.

Their deepest fears were:

*"That I am not in dreadful pain."*

*"Terrifying to imagine the pain..."*

*"I often think about how awful it would be to be in a lot of pain, especially if there are no people around who care"*

Where does this fear of dying in pain come from? Does it perhaps come from the experience of seeing a loved one in pain at end of life?

Of feeling – or fearing - *their* pain?

I acutely remember when my mother was dying, she was having problems sleeping. We asked the GP for some stronger medication to help her. He replied they were very addictive, and he was unsure if he should prescribe. We were incredulous. How can it be that somebody with a severe terminal illness could not be prescribed drugs to keep her comfortable? I think the answer is that she was not officially receiving palliative care.

Palliative care has transformed the way we are cared for. Palliative care allows us to no longer be a passive recipient of treatment and care but to be an active collaborator. It is with good palliative care that we will conquer our fears of pain and hopefully - in a few years' time if we ask the question again – the word pain won't be as prevalent.

What do you think? Is pain a significant fear for you when you think about living with advanced illness or approaching the end of life?

Let us know: [info@hospicefoundation.ie](mailto:info@hospicefoundation.ie)

Find out more about palliative care [here](#)

Read about the [Have Your Say survey report and the People's Charter on Dying, Death and Bereavement](#)

More information about the [IHF's healthcare programmes](#)

*The IHF is a national charity, set up in 1986 to fund and develop hospice services. Since then, we have expanded our scope to encompass the key issues affecting the end of life. Our programme and services now seek to address the needs of people dying at home, in hospitals and in other care settings, as well as the needs of the bereaved. We also promote discussion of a broad range of issues related to dying, death and bereavement, in order to identify what matters most to Irish people at the end of life*