

“Now it seems all of me is wrong...” - Total pain and palliative care

This is the eleventh blog by Rebecca Lloyd of the Irish Hospice Foundation (IHF) in the series on The People’s Charter on Dying, Death and Bereavement in Ireland. This month, the theme is around this line of the People’s Charter:

“I can get relief from pain, no matter where I am being cared for or what condition I have.”

In our [first blog about pain](#), we investigated our life relationships with pain and our fears around pain and death. We also looked briefly at the value and benefit of palliative care in the management of pain and other distressing symptoms – not just at the end of life, but throughout a life-limiting condition.

We’ll explore that in a bit more detail later in this blog.

But first, let’s go back to the words of one of the people who responded to the Irish Hospice Foundation’s “Have Your Say” survey. They said:

If terminally ill people are afraid of diseases and death, and if they are not given the right support and encouragement, they can feel emotionally pressured and even undervalue their lives, because they feel overwhelmed and a burden on those around them. It's essential to ensure that they are peaceful and pain-free, not just on a physical level but also emotionally, mentally, spiritually and socially.

That person may be describing what was defined in 1964 by Cecily Saunders, who is credited as one of the greatest advocates for palliative care and the founder of the modern hospice movement, as “total pain”.

As Cecily Saunders was working in St. Joseph’s Hospice in England she asked her patient, Mrs Hinton, to tell her about her pain, and ‘without any more prompting’ Mrs Hinton went on to say;

Well, Doctor, it began in my back, but now it seems that all of me is wrong..... I could have cried for the pills and the injections, but I knew that I mustn't. Nobody

seemed to understand how I felt, and it seemed as if the world was against me, and my husband and son were marvellous but they were having to stay off work and lose their money, and it's wonderful to just feel safe again."

Wonderfully put, but still a bit scary ..?

The pain began in one place but soon *"all of me is wrong....and the world was against me"*. Do you think she meant that her whole body was in pain – or is she describing how all of life becomes a pain when pain takes over? The *"total pain"* that starts in one place and then goes everywhere – invading and altering our lives more than physical pain alone can ever do?

What Mrs Hinson described is how her illness had thrown her whole world into disarray. She felt damaged, isolated, hopeless. Not only had her illness affected her but it had bled into her family as well. This description shows us how finely balanced our lives really are. Like a house of cards, when one shifts, the whole lot can fall.

Mrs Hinson needed - and we will all need - more than relief from physical pain. Being able to manage and alleviate any suffering, be it physical, spiritual or social often helps with management in other areas. It's heartening that Mrs Hinson ends her description with *"and it's wonderful just to feel safe again."* She is still ill, still approaching death, but now she feels safe. She feels safe because she is receiving palliative care.

And as the years have gone on the teams that look after us in palliative care have grown. There is considerable value made by interdisciplinary teams as they support families and patients. Their goal? To offer a combination of tailor-made therapeutic interventions which will not only manage a patient's illness but will help to relieve suffering and improve the quality of their life.

It is this holistic approach that affects the overall outcome for both the person/patient and their family. Through good palliative care the hope is that the experience of illness and grief will be different from traditional care, and the future may be closer to what we imagine. That is to have a 'good death' and to experience 'healthy grieving'.

It may come as a surprise that people receiving palliative care may not be actively dying, or in the final stages of an illness. Palliative care is about you living until you die, as the late Cecily Saunders who was caring for Mrs Hinson puts it;

“You matter because you are you, and you matter to the end of your life.

We will do all we can not only to help you die peacefully but also to live until you die.”

It is this emphasis on living that is driving a definite energy worldwide towards the introduction of a palliative care approach at the early stages of an illness and throughout its course. It is therefore really important that we understand the changing landscape of the palliative care philosophy.

Palliative care encompasses end of life care, but a lot more as well. The HSE describes palliative care as:

“...an approach that improves the quality of life of people facing the problems associated with life-limiting illness and supports their families.

... focuses on the prevention and relief of suffering by means of assessing and treating pain and other physical, psychosocial or spiritual problems.

...to enhance quality of life and, wherever possible to positively influence the course of illness.

...extends support to families to help them cope with their family member’s illness and their own experience of grief and loss. ”

Thankfully with the growth and investment in good palliative care in Ireland, there is considerable research and resources put into easing suffering, with more and more resources being put into social work, counselling, mindfulness and other disciplines. And it is our job in the IHF to continue to advocate for increased investment in palliative and hospice care and deliver cutting-edge educational programmes for the thousands of medical staff we see through the years in hospitals, hospices and nursing homes. We also believe that through continued public engagement we can help every person understand the many benefits of

palliative care and the small things every one of us can do to alleviate suffering for those for whom we love and care.

We know that in the last years and months of their lives, the majority of people spend most time being cared for in their homes and their communities.

It makes sense that we should have some ideas what to do and what to say to help the person who may be suffering. This help can range from knowing what the healthcare staff need when they visit, to monitoring the time of visitors, and allowing for the opportunity for the person in the bed to be able to talk and, perhaps more importantly, to be listened to.

So back to our mantra.

We need to get more used to talking about death, no matter how awkward or uncomfortable we find it. One day it will be vital to us, and we will be glad that we overcame our fears. We need to be able to give ourselves and our loved ones the opportunities, space and the openness to be able to say what is on our minds and in our hearts at the end of life. We now recognise that there are great benefits in conversations, especially at the end of life. These conversations are centred around love and forgiveness. The result can be relief of stress, an increase in peaceful interactions, and a greater preparedness at end of life.

What do you think? Tell us your experiences.

You can 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