Personhood and Palliative Care

Professor Erna Haraldsdottir

11th June 2026

Continuing Medical Education Session

Lausanne University Hospital

CHUVcentre hospitalier universitaire vaudois

You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only to die peacefully, but also to live until you die

Dame Cicely Saunders 1918-2005

Personhood in palliative care

Recognising the individual's identity, relationships, values, experiences, and dignity.

Personhood refers to what makes us unique individuals. It encompasses our identity, values, beliefs, relationships, memories, life experiences, culture, and sense of self

Focus on the ethics and philosophy of the patient as a person

The impact of disease and imminent death on personhood

Serious illness and approaching death can profoundly challenge a person's sense of self. Physical decline, loss of independence, altered roles, social isolation, and uncertainty about the future can threaten identity and dignity.

The nature of suffering

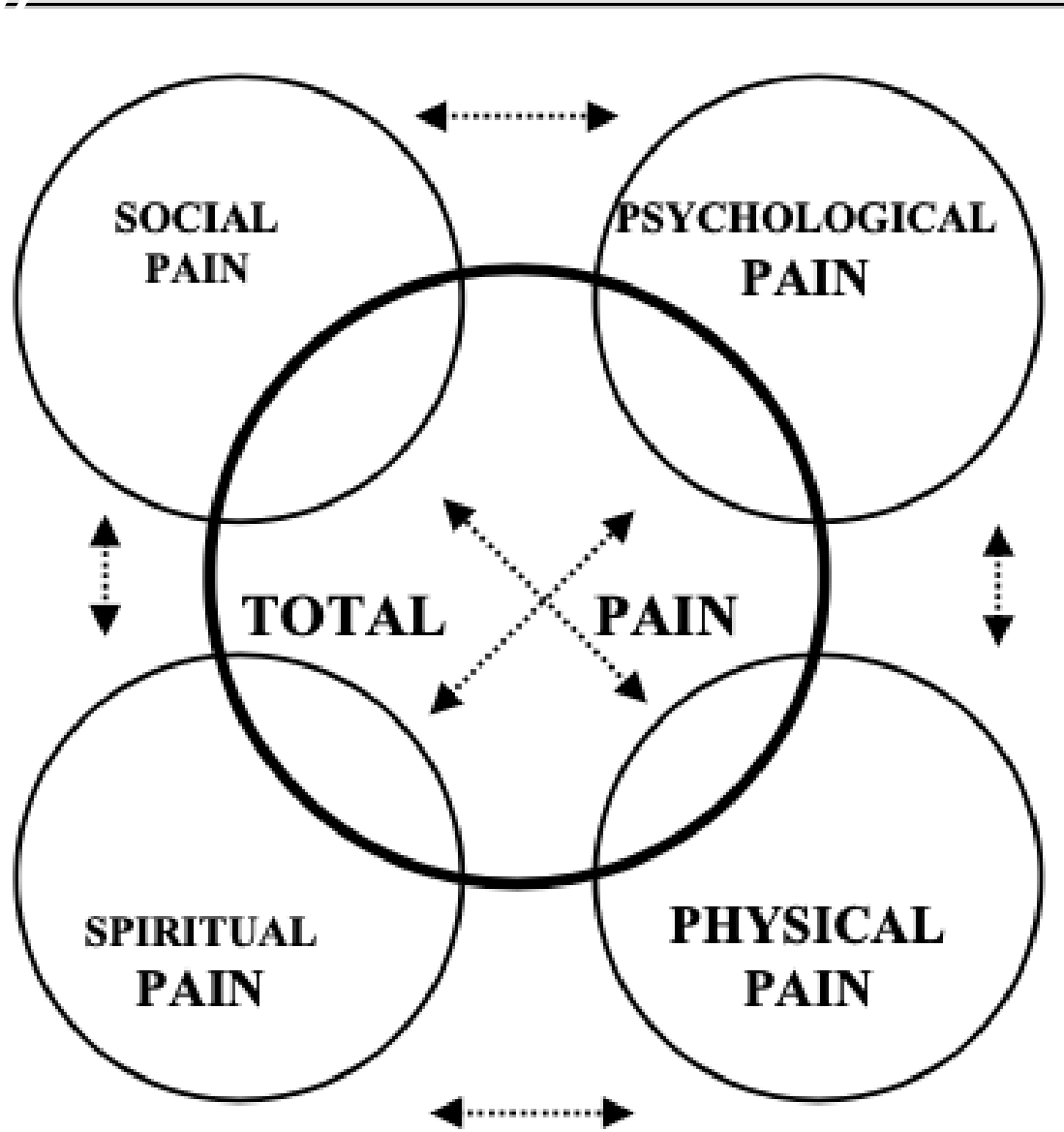
- Michael Kearney argues that suffering extends beyond physical pain. He suggests that illness can disrupt a person's sense of meaning, purpose, and wholeness. When individuals feel reduced to their disease, their personhood can become diminished.

https://www.michaelkearneymd.com/

- The concept of "total pain," introduced by Saunders and expanded upon by others such as Kearney, recognises that suffering encompasses physical, psychological, social, and spiritual dimensions. Threats to personhood often arise across all of these domains.

Total pain Framework for understanding pain

- https://www.mypcnow.org/fast-fact/total-pain/



Michel Kearny

Mortally Wounded: Stories of Soul Pain, Death, and Healing,1996

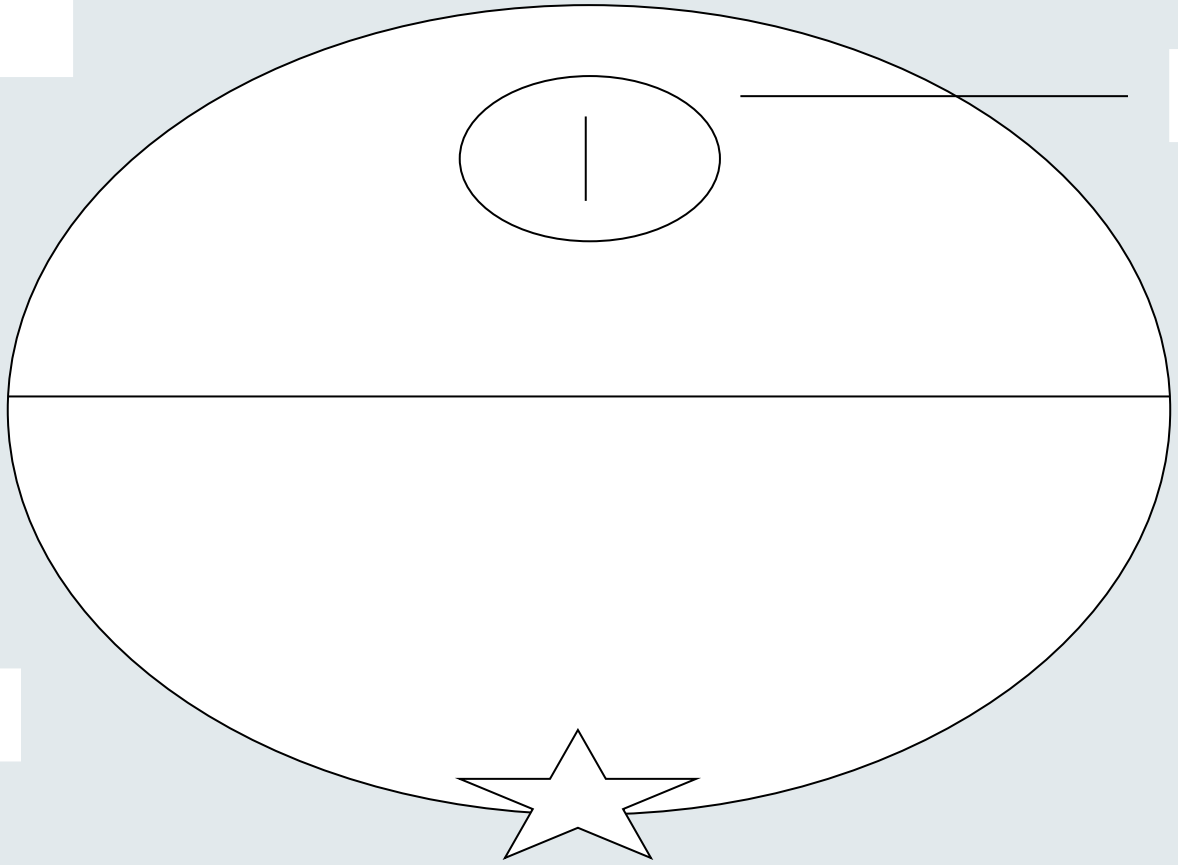
A Place of Healing: Working with Nature and Soul at the End of Life, 2000

The Nest in the Stream, 2012

Becoming Forest- A Story of Deep Belonging, 2023

Michael Kearney

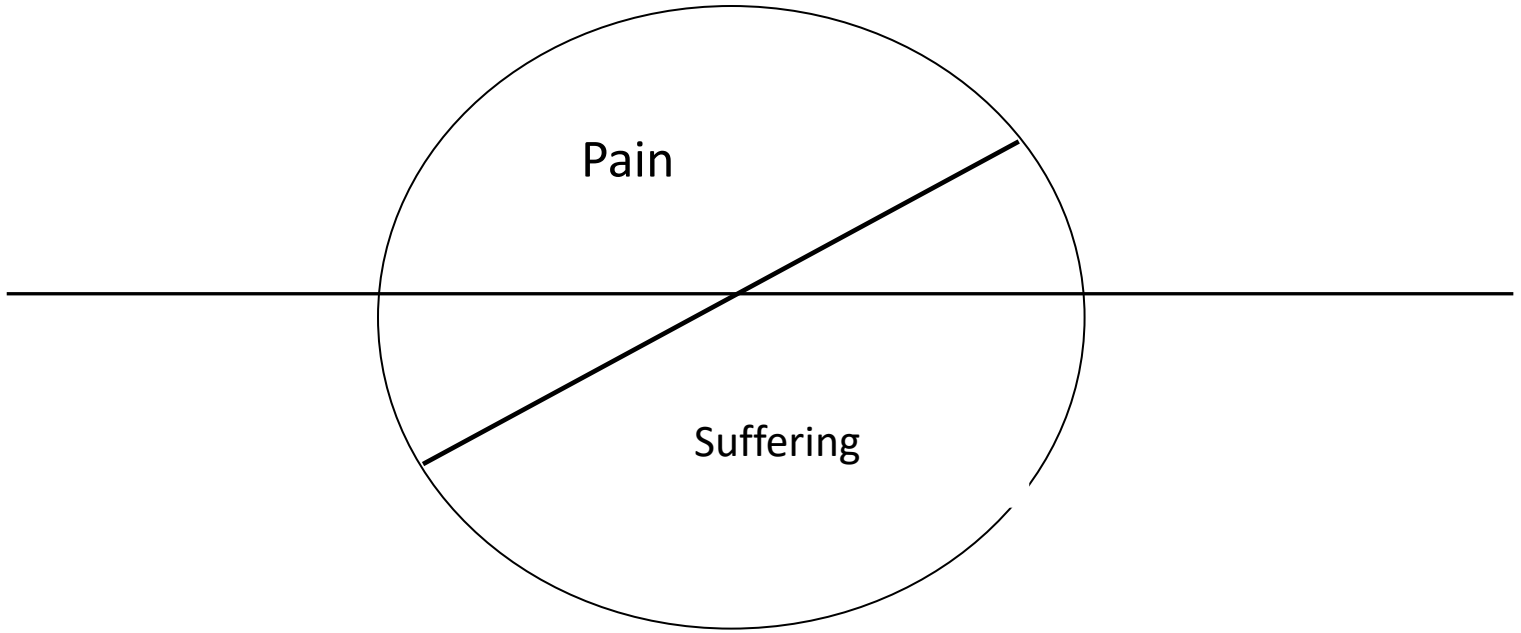
Surface mind



Deep mind

Michael Kearney

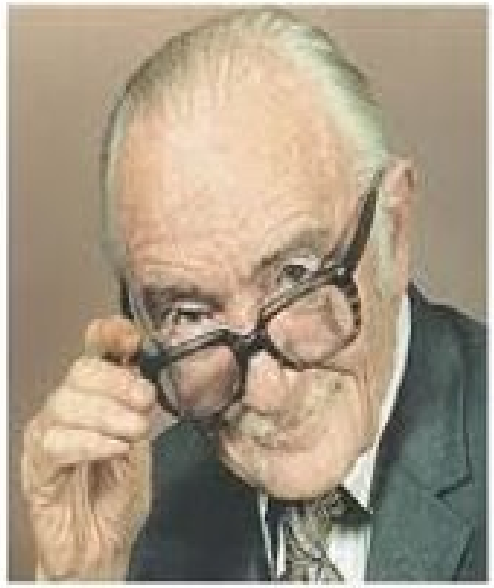
Receptive to the medical and nursing model of physical pain

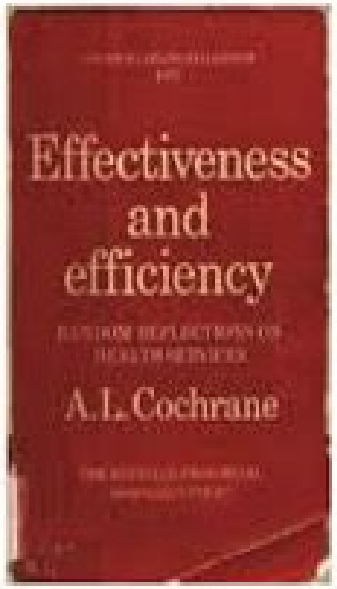


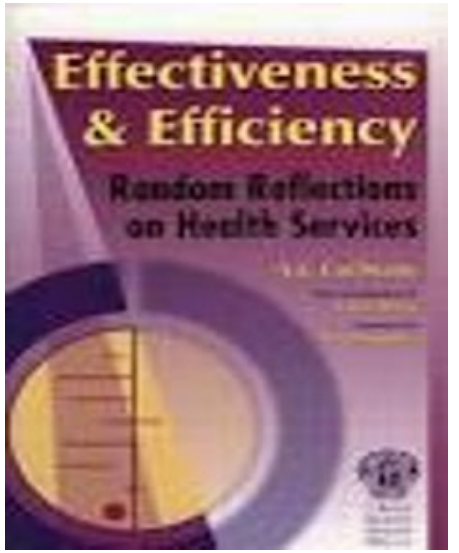
Not receptive to the medical and nursing model of physical pain

ARCHIE COCHRANE

12TH JANUARY 1909 – 18TH JUNE 1988







Cochrane Library

1943 Cochrane prisoner of war and medical officer in German prison camp

The Germans brought a young Soviet prisoner to my ward late one evening. The ward was full, so I put him in my own room, where he lay dying and screaming, because I did not want to wake the rest of the ward.

I examined him. He had obvious extensive bilateral cavitary disease and severe pleural friction rubs. I thought the latter was the cause of his pain and screaming. I had no morphine, only aspirin, which had no effect. I felt desperate. At that time I knew very little Russian, and there was no one on the ward who spoke it.

Finally, almost instinctively, I sat down on the bed and took him in my arms, and the screaming stopped almost immediately. He died peacefully in my arms a few hours later.

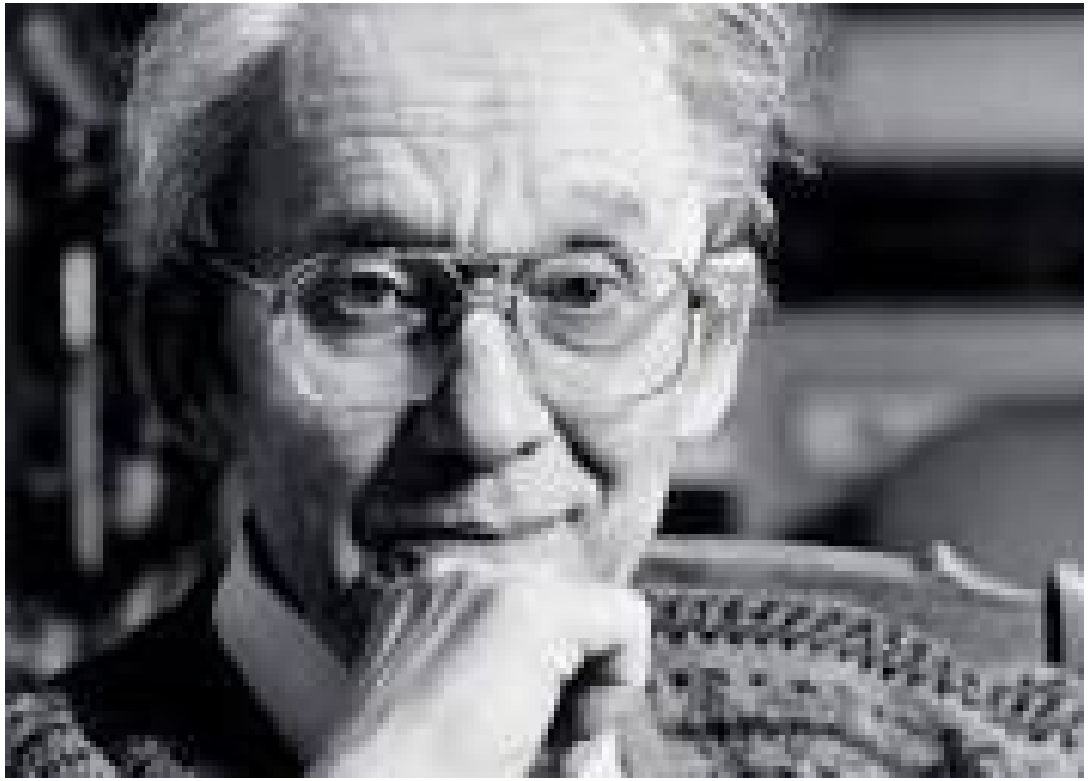
It was not his chest that had caused the screaming, but his loneliness. It was a wonderful lesson in caring for the dying. I was ashamed of my misdiagnosis and kept the story to myself.

Paul Ricoeur 27th February 1913-20th MAY 2005

Person vulnerability should not be considered as a problem but a crucial part of what makes us human

Suffering as part of humanity

Part of self-discovery and growth



Healthcare professionals can protect personhood by:

Listening to patients' stories and experiences.

Supporting autonomy and choice wherever possible.

Recognising the importance of relationships and family.

Acknowledging emotional, social, and spiritual concerns.

Treating individuals with dignity and respect.

Focusing on what matters most to the person rather than solely on clinical outcomes.

Specialist input to protect personhood in Palliative Care

Narrative Therapy

Dignity Therapy

Arts and music

Not a problem but a person

Dignity Therapy Harvey Max Chochinov

Individuals retain a unique life story, values, relationships, and legacy

What are the most important roles you have played in life?

What are your most significant accomplishments?

What life lessons would you like to pass on to others?

What would you want your loved ones to remember about you?

Narrative therapy

People make sense of their lives through the stories they tell about themselves and their experiences.

Narrative Therapy views people as separate from their problems, it encourages exploration of the broader story of their life, values, relationships, achievements, and resilience

Tell and reflect on their life story.

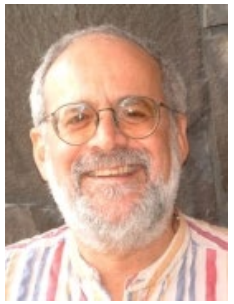
Identify personal strengths and sources of resilience.

Explore what gives their life meaning and purpose.

Challenge problem-saturated narratives that focus only on illness and loss.

Re-author their story in a way that reflects their identity, values, and accomplishments.

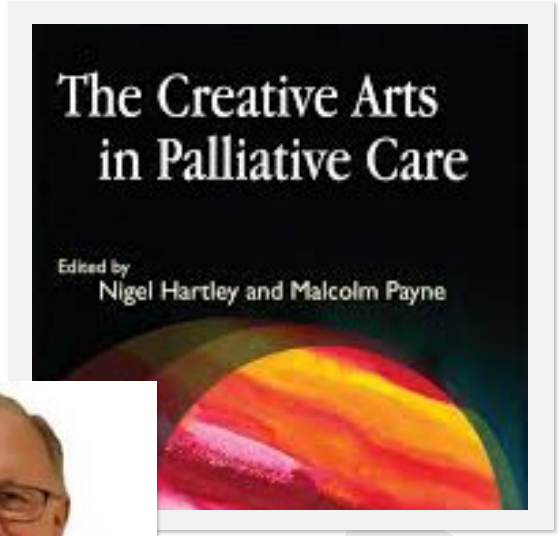
https://narrativetherapycentre.com/about/



Creative Arts Therapy in Palliative Care

Provides patients with alternative ways to express thoughts and feelings that may be difficult to communicate through words alone.

Creativity is a fundamental aspect of being human. Artistic expression can help individuals explore their identity, emotions, relationships, and experiences of illness while maintaining a sense of personhood and meaning.



Personhood and person-centred care

Over the past 40 years, person-centredness has evolved into a global movement shaping health and social care systems.

It has its roots in Carl Rogers' humanistic theory of self-growth and the importance of interpersonal relationships.

Today, it is widely recognised as best practice and is embedded in international policy, including World Health Organization frameworks.

World Health Organization

From policy to practice the ongoing challenge

Person-centred practice is a set of values such as dignity, compassion, respect, and relationship-based care

These are enacted across interactional, relational, and systemic levels


Commitment
Care
Care
Policy
Support
Embedded in Policy
Embedded in Training
Embedded
in Strategy
The right approach
to health and social care
Health
Inclusive
Universally agree
Equity
Standards
as the right thing
is universally agreed
Best Practice
Support
Wellbeing

The constraint of the ordinary

Within health and social care systems, competing pressures continue to push practice towards task-focused care and a dominant biomedical model.

These system pressures are translated into everyday practice, shaping what is enabled, what is valued, and ultimately what is delivered.

We must establish routines that effectively initiate, integrate care approaches that preserve person hood

Inpatient hospice admissions. Who is admitted and why: a mixed-method prospective study

Palliative Care & Social Practice

2023, Vol. 17: 1–15

DOI: 10.1177/26323524231182724

Erna Haraldsdottir, Anna Lloyd, Martyn Bijak, Libby Milton and Anne M. Finucane

Abstract

Background: Over the next two decades, the numbers of people who will need palliative care in the United Kingdom and Ireland is projected to increase. Hospices play a vital role supporting people who require specialist palliative care input through community-based and

Aim of the study

Gain insight into and understanding of:

- Who is admitted (demographics and characteristics)
- The reason for patients being admitted
- The appropriateness of the admission based on patient's families' staffs' perception

Clinical reasons as why patients were admitted based on 6 preset categories

End of life care 27%

Symptom Control 46%

Symptom control/possible end of life care 24%

Assessment of complex needs 1%

Blood transfusion/symptom control 1%

Other 1%

Why admitted ? qualitative data

Symptom control

Anxiety or fear

Social isolation

End of life care, either through the wish of the patient or because the family were struggling to cope.

I think he's very frightened. He lives alone and the symptoms that he is experiencing now though they don't appear to be very severe at present he felt that things couldn't get any worse for him and that he was dying. He was frightened and he didn't appear to be managing anymore (staff member)

So I think for somebody like him I think it is an anxiety type thing and it is comforting for him to be in this situation (at the hospice) (staff member)

I am a lot happier here and quite settled... you know what I mean (patient)

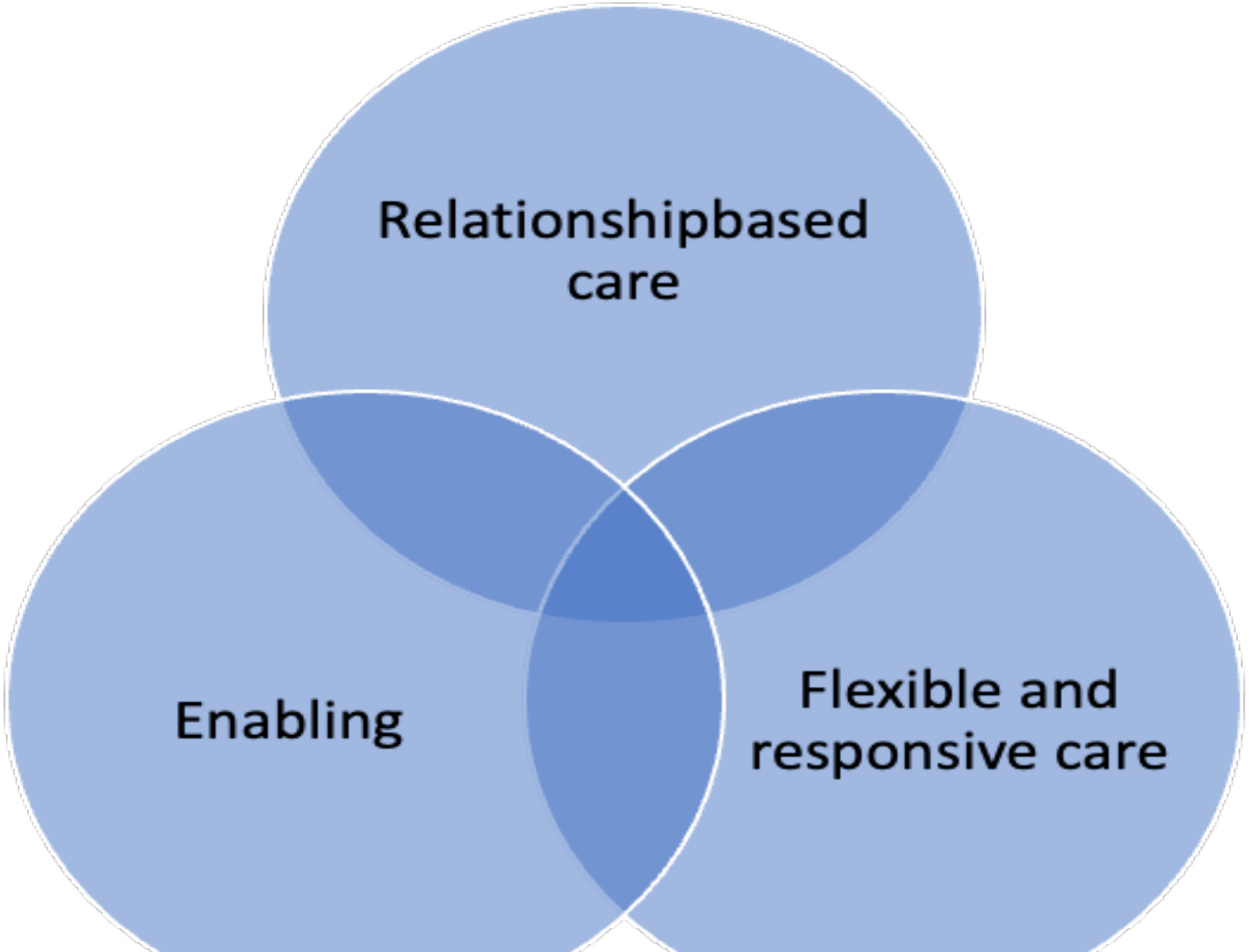
What the patients and staff told us

SC3 staff '*I think he's very frightened. He lives alone and the symptoms that he's experiencing now; though they don't appear to be very severe at present; he felt that things couldn't get any worse for him and that he is dying.' 'He was frightened and didn't appear to be managing anymore.*

Hospice at Home

- To evaluate the new Hospice at Home service with particular reference to the benefits and impact of the service for patients and families
- To identify the factors that have underpinned the outcomes of the Hospice at Home service
- To support the development of a model of care that underpins the Hospice at Home service

FEELING SAFE :A Person-centred End of *LIFE CARE AT HOME*



Why does this matter

- We down-play the importance of the emotional safety created through focusing on what matter to people
- We continue to view care through a medical lens
- We underplay the value of creating emotional safety through a care focusing on what matters to people
- We need to be able to integrate what matters to patients and their families into health care services and make this more visible as the fundamental aspect of care
- We need to truly understand the positive outcomes of a care that focuses on what matter to patients in a holistic way.

Feeling safe, holistically as an outcome of care

Ethical and relational framework for care

Acknowledging the ill person's needs while considering them capable, resourceful with expert knowledge about the daily lives and goals

Preserving personhood in palliative care; complex and essential skill

Does not require highly technical expertise, but complex emotional intelligence, communication skills, and ethical judgment

It requires us to look beyond disease and recognise the individual's story, identity, values, and dignity. In the end, the greatest challenge is not treating the illness, but ensuring the person remain seen, heard, and valued.