

Care of the Spirit in Palliative Care

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What is spirit?

- Essence

- Energy / life force

“The force that through the green fuse drives
the flower...” Dylan Thomas

- Spark of the Divine

- Ground of Being

- Higher Self

- The human spirit

Spirit

“A deep inner resource that continually seeks out and promotes life.

Although intangible, it manifests itself through different capacities such as the capacity for joy, for awe and wonder, for courage, for wisdom and understanding, for peace etc.”

(Byrne M, 2004)

Spirituality

Awareness and ongoing engagement with this inner resource and its manifestations

Our dialogue with Life / God / Wisdom

*Spirituality is the aspect of humanity that refers to the way individuals seek and express **meaning** and purpose and the way they experience their **connectedness** to the moment, to self, to others, to nature, and to the significant or sacred.*

- Consensus Conference, USA

<http://www.ncbi.nlm.nih.gov/pubmed/19807235>

Spirituality is concerned with the deepest levels of human experiencing, the places of ultimacy, value, and deepest meaning for our lives.

(Mercer,2006, p503)

Spirituality seems to be about

- Connection
- Meaning
- Faith and belief
- Living fully
- Values (including hope, love/compassion, congruence, integrity, dignity)
- Transcendence
- Becoming
- Trust / Letting go – yet active involvement

When Death Comes - Mary Oliver

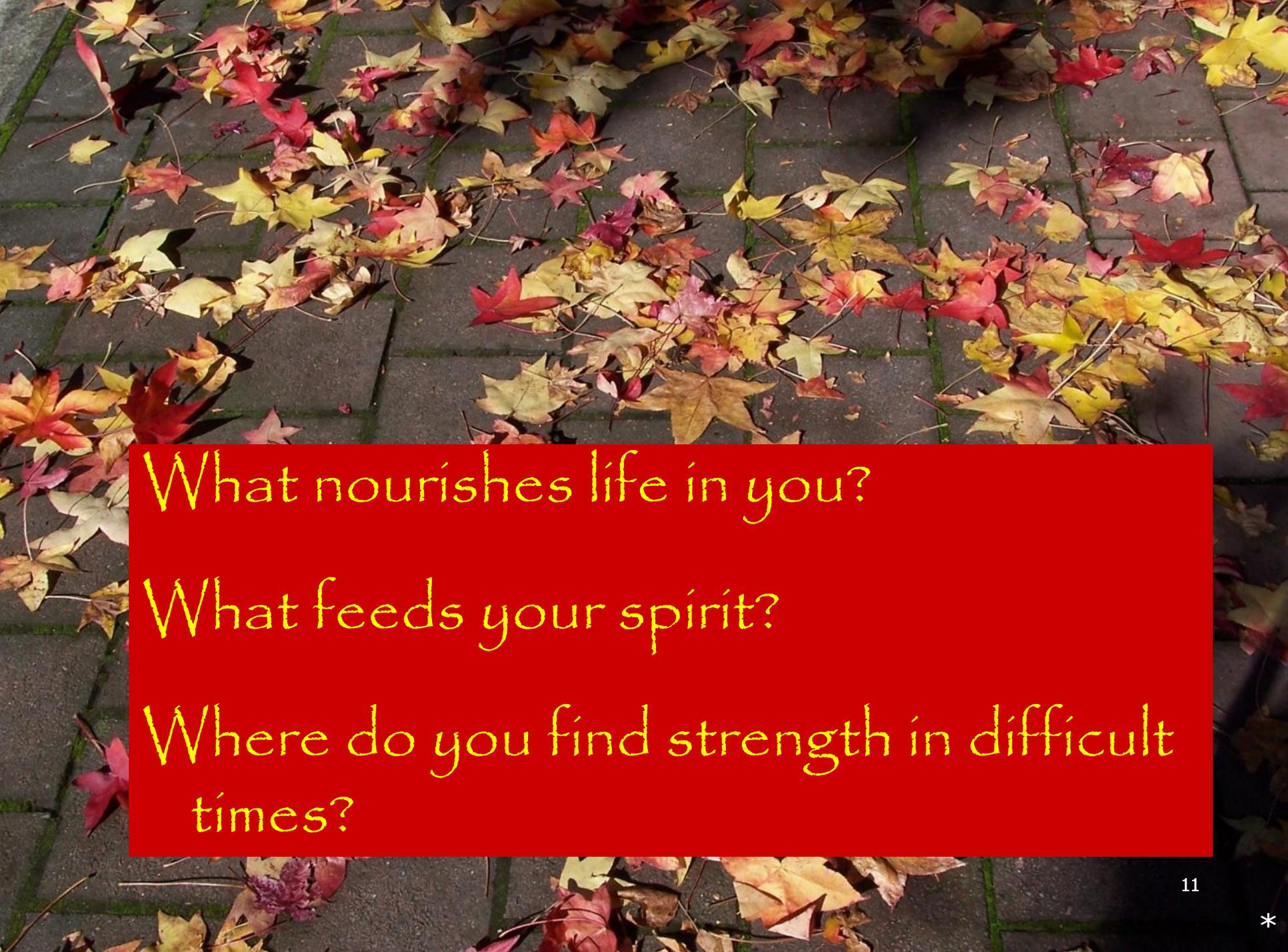
When death comes
like the hungry bear in autumn
when death comes and takes all the bright coins from his purse
to buy me, and snaps his purse shut;
when death comes
like the measles-pox;
when death comes
like an iceberg between the shoulder blades,
I want to step through the door full of curiosity, wondering;
what is it going to be like, that cottage of darkness?
And therefore I look upon everything
as a brotherhood and a sisterhood,
and I look upon time as no more than an idea,
and I consider eternity as another possibility,
and I think of each life as a flower, as common
as a field daisy, and as singular,
and each name a comfortable music in the mouth
tending as all music does, toward silence,
and each body a lion of courage, and something
precious to the earth.

When it's over, I want to say: all my life
I was a bride married to amazement.
I was a bridegroom, taking the world into my arms.
When it's over, I don't want to wonder
if I have made of my life something particular, and real.
I don't want to find myself sighing and frightened
or full of argument.
I don't want to end up simply having visited this world.

Mary Oliver

Expressions of spirituality

Depend on
personality,
culture (social, religious & family),
the times in which we live,
life experiences and developmental capacities.



What nourishes life in you?

What feeds your spirit?

Where do you find strength in difficult times?

Common spiritual paths

- **Nature** – garden, sea, the bush, wilderness
- **Relationships** –self, transcendent (God, Life, wisdom), family, friends, community.
- **Aesthetic pursuits** – art, poetry, music etc
- **Metaphysical pursuits** – silence, meditation, prayer, ritual, philosophy

There is No One Right Way!

Open to great diversity.

Care of the Spirit



Care of the whole person

A strengths model of care

We meet the person at soul level ...

we relieve them of the burden of being seen
primarily as the sick one, the frail one...

and we honour the significant journey
they are on.

Screening & assessment

Discernment, not assessment?

Screening:

- “Are you at peace?” (Steinhauser et al)
- Support needs (Hegarty, Currow, Olver, Abernethy, 2011)

Spiritual history

Assessing strengths and resources, as well as needs.

Validated tools – e.g. FICA

Caring for the spirit

- To create a space – safe & contained
- To be with & to bear witness
- To engage the depth
- To support them in accessing resources –
past + new; inner + outer

Opening & Holding a Space

A space for what?

Opening & Holding a Space

- For presence & listening
- Where it is possible to “experience the experience” (Peter Barr)
- Where the mystery and paradox of life can unfold – open to the unknown

“A safe place to suffer”

(Stedeford A, 1987; p73-4)

Listening

Life questions us and we must give answer.

Victor Frankl

Life is “not a problem in need of a solution, but a mystery in need of evocative comprehension.”

(Marcel, 1950)

3 Kinds of Listening

- Diagnostic listening - *listening for*
- Empathic listening – *listening to*
- Contemplative listening – *listening with*

(Byrne M, 2011)

Contemplative listening

- Companion on life's road
- Listen 'with' ...as the client becomes aware of the big questions
- As our small story is seen within a larger framework, the story of life itself
- the mutuality of human to human
- "Do you see what I see?" ...a cry not to be left alone. It is a plea for recognition of our mutuality as human beings.... - *Margaret Byrne*

Contemplative listening

“the vulnerability of listening and having no answers”

(Lunn, 1990)

“living the questions...”

(Rainer Marie Rilke, 1934)

“Dying people in particular are often in a purgatory of routinized communication, and they crave silence.”

(Halifax J, 2009, p 109)



“...tasting the waters of our own existence” Rumi

Ways of opening a listening space

- Relaxation and stillness
- Silence / solitude
- Counselling that engages in pondering
- Engaging with nature
- Engaging with the arts- poetry, music etc
- Rituals
- Prayer and meditation
- Imagework and dreamwork
- Supportive relationship - presence

Signs, symptoms and symbols

“We forget that the strongest influences upon our lives are always symbolic. Contrary to common belief, we do not respond to the actual or the concrete - we respond to what each event, relationship or feeling means to us symbolically.”

(Reeves, 1999, p73)

Language of the spirit

Symbolic – image, metaphor, story – meaning

Poetry – Mary Oliver, Tagore, John O'Donoghue ...

Art

Silence – beyond words...Tagore

Embodied – dance, touch,
laughter, tears...



Are we losing the language to speak of experiences of the spirit?

Is the psychological and clinical language (the common language of HCP) enough or appropriate language to speak of experiences of the spirit?

Do we hear the language and recognise “signs, symptoms and symbols” of spiritual distress or wellbeing of our patients?

Who speaks and recognises this language?

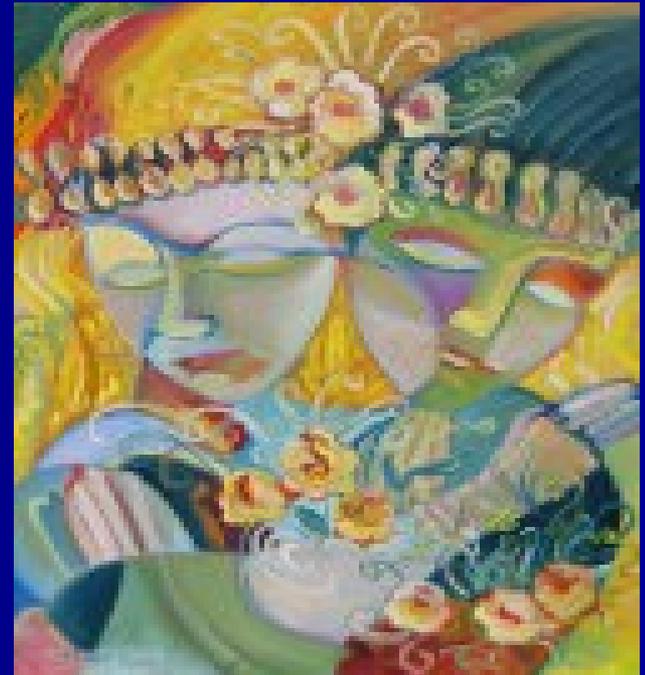
Do we have an understanding of possible /
common spiritual experiences – beyond the
psychological and physical only?

If someone is quiet...what do we assume?

If they are struggling with beliefs, what do we
assume?

In bearing witness...

we witness
both to
their suffering
and to their truest self.



Engaging the depth

- “On holy ground”
- Creativity, play
- Recognise our limits and patients’ limits
 - call in those more knowledgeable p.r.n.
- Patient-led, patient-centred work

Who cares for the spirit?

- 4 levels of involvement

Marie Curie Cancer Care, 2003, Spiritual and Religious Care Competencies for Specialist Palliative Care

<http://www.ahpcc.org.uk/pdf/spiritcomp.pdf>

- Specialist and generalist model

What is needed to do this work?

Imagine you are lying in a bed...facing your diagnosis of advanced, non-reversible disease...perhaps struggling... perhaps peaceful...

This work requires of us

Often, a shift!

“There is a danger in the ‘helping professions’ – that we respond to spiritual and existential suffering as we do to physical pain or other symptoms; that we try to control or fix it.”

(Hegarty M , 2007, with reference to Gregory & English, 1994.)

Shift from “heroic journey” to pilgrimage with

(Michael Kearney with reference to classical mythology)

“When we honestly ask ourselves which person in our lives mean the most to us, we often find that it is those who, instead of giving advice, solutions, or cures, have chosen rather to share our pain and touch our wounds with a warm and tender hand. The friend who can be silent with us in a moment of despair or confusion, who can stay with us in an hour of grief and bereavement, who can tolerate not knowing, not curing, not healing and face with us the reality of our powerlessness, that is a friend who cares.”

(Henri J.M. Nouwen, *The Road to Daybreak: A Spiritual Journey* 1990)

Requires

- A capacity and willingness to be with the patient in the Mystery of what's happening – and to stay with them in the struggle
- To let go of the need to know – to live in the not-knowing with serenity
- To stay open to possibilities

Requires

- To let the patient take the lead
- Deep reverence for the wisdom of the other's spirit (*They* take the lead; *they* are in control...)
- Recognition of the language of the spirit

Requires

A mindful presence: “giving deep attention to what is happening in the present moment”
....without feeling we have to change it

A capacity to be present with equanimity in the suffering and anguish of the patient’s journey
(“Strong Back, Soft Front”)

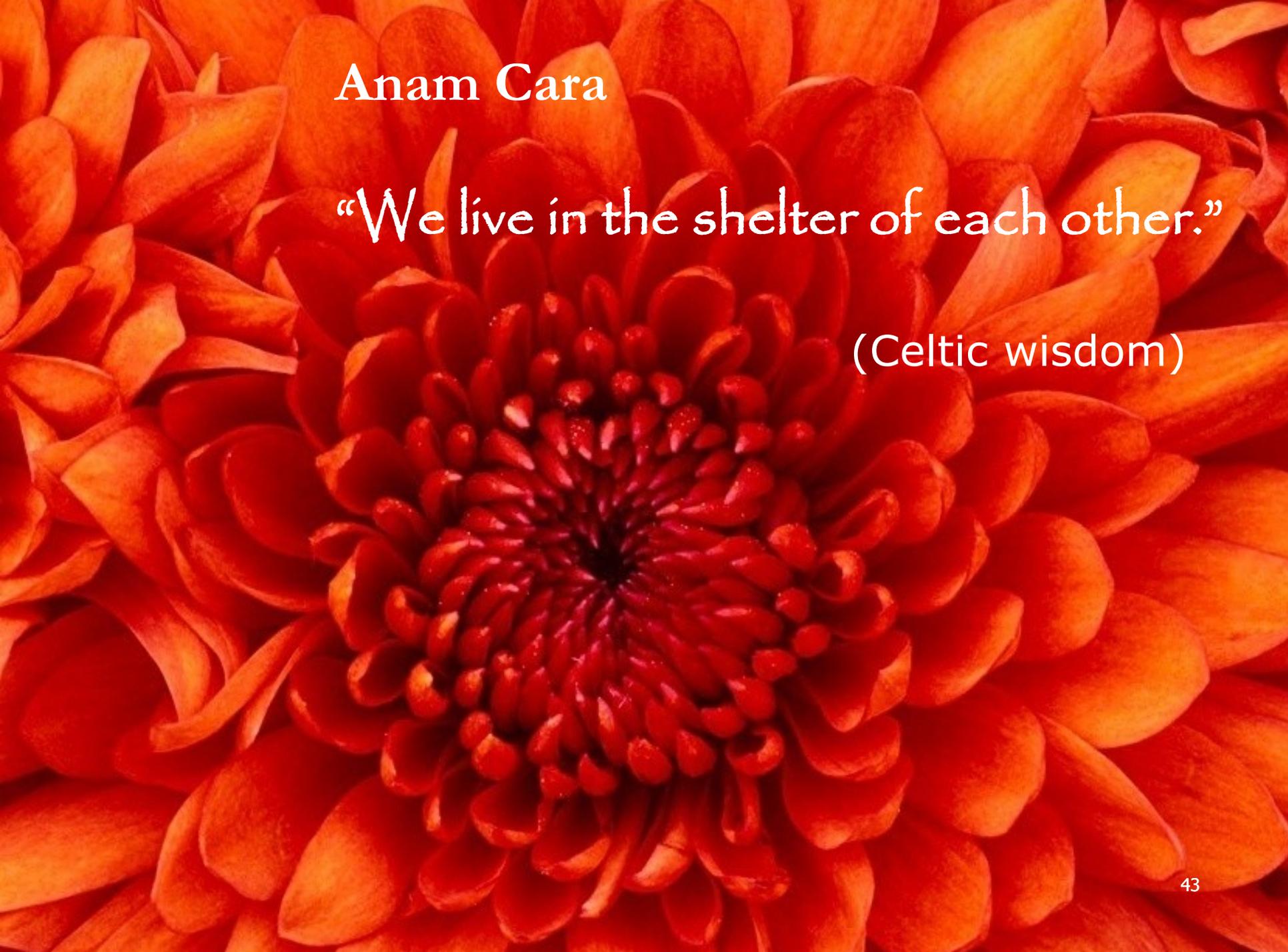
Requires

Doing our own spiritual / inner work;
having a regular spiritual practice.

Self care.

Requires self awareness

A willingness to recognize & withdraw
projections re spirit/spirituality,
so to come with an emotional 'clean slate'
and open mind & heart,
letting go even of expectations,
to be able to accompany the person
on their Own journey.



Anam Cara

“We live in the shelter of each other.”

(Celtic wisdom)

Summary

- Approach – fixing to presence & facilitation
- Assess - strengths, resources, needs
- Who has the skills, knowledge, attitudes to care for the spirit for this person?
- What are our roles / levels of care within team?
- When do I refer on?
- How do I develop my own capacities for this work?

Resources

Halifax, J. 2009 Being with Dying: Cultivating Compassion and Fearlessness in the Presence of Death. Shambhala: Boston.

Puchalski C 2006 A Time for Listening and Caring, Oxford: Oxford University Press.

Aldridge, D 2000, Spirituality Healing and Medicine: return to the silence, London: Jessica Kingsley Publishers.

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