

*“At its root a parent’s love for his or her child knows no bounds.  
It is an impulse that is both primal and transcendent.*

*The same is true of a child’s love for his parents.  
This kind of love is not volitional. It is who we are.*

*We belong to one another and that,  
it seems to me, is the best part of being alive.”*

— Ira Byock, from *The Four Things that Matter Most*



## Caring and Critical Conversations: ***The Thresholds of Living, Dying and Death***

A Discussion Brief to Stimulate  
Participants’ Thinking and Conversations



**October 14-15, 2016**

Friday, October 14, 1-6:00 pm • Saturday, October 15, 8 am-noon

LifeSource Conference Center • 2225 W. River Rd. N. • Minneapolis, MN

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for educational use in this symposium*



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Caring work with individuals and families on the thresholds of living, illness, dying, death and bereavement requires attention to sacred spaces, sometimes called *thin places* between one reality and another. Talking respectfully and honestly about this continuum requires courage, self-awareness, empathy, and compassion. Doing it well requires care of staff, teamwork between caregivers and care-receivers at its best, and a commitment to enter the threshold.

### Goals of Symposium

To provide objective feedback and have improved insight about caring and critical conversations and to confidently engage in caring and critical conversations with families on the arc of living, dying and death. The following pages are PROMPTS for your critical consideration of conversations at the thresholds of living, chronic illness, dying, death and bereavement. This is not a “how-to packet” nor does it purport to address a range of issues. Rather, it is a selected group of poems, brief essays, pages, and thoughts to consider.

*The following poems were selected by Ted Bowman and members of the Symposium Planning Committee to inspire conversations at the Symposium.*

#### Words

Words have power. Ann Sexton wrote:  
*Be careful of words,  
even the miraculous ones.  
... they can be both daisies and bruises.*

Words and eggs must be handled with care.  
*Once broken they are impossible  
things to repair.* (Sexton 1975, p. 71).

Iris Murdoch, in a different form, asserted:  
*Words constitute the ultimate texture and  
stuff of our moral being, since they are  
the most refined and delicate and detailed,  
as well as the most universally used and  
understood, of the symbolisms whereby we  
express ourselves into existence. We became  
spiritual animals when we became verbal  
animals. The fundamental distinctions can  
only be made in words. Words are spirit.*  
(Murdoch 1972).

*Is there a world beyond words?* poet  
Wendell Berry asked. To which he responded:  
*There is.* Later in a poem about words, Berry  
contended that out of the silence: *we must  
call all things by name out of the silence  
again to be with us, or die of namelessness.*  
(Berry 2005, p. 20).

**It Is Those Who,  
Instead of Giving Advice,  
Solutions or Cures,  
Acknowledge the Pain  
and Touch Our Wounds  
With a Gentle and Tender Hand  
Someone Who Can Be Silent  
in a Moment of Despair  
or Confusion  
Who Can Tolerate  
Not Knowing,  
Not Curing,  
Not Healing  
and Face With Us Our Loss**

Okun and Rappaport/Nouwen



## SYMPOSIUM SCHEDULE & SESSION DETAILS

### FRIDAY, OCTOBER 14th

**1-1:30 pm** – Welcome & Introduction

**1:30-2:00 pm** – Session 1

Background and introduction of the focus of the Symposium: *Perspectives and Tools for Communicating When in the Thresholds of Living, Dying, Death and Bereavement.* A dialogue between a grief educator and a pediatric physician – Ted Bowman and Scott Schwantes.

**2-2:45 pm** – Session 2

Family accounts about caring conversations that were handled well or poorly. Emphasis on aiding all to raise consciousness of what can be helpful and not.

**2:45-3:30 pm** – Professional and volunteer accounts about caring conversations that were handled well or poorly. Emphasis on aiding all to raise consciousness of what can be helpful and not.

**3:30-3:45 pm** – Break

**3:45-4:30 pm** – Session 3

Case studies at tables to draw out as many components and attributes of well-done conversations as possible. Examples of words tone, actions, will be posted either on newsprint and / or entered into a computer for quick showing the collective wisdom of the group.

**4:30 pm** – Presentation and facilitated discussion of the results of recommended practices.

**5:15-6:00 pm** – Session 4

Comments about listening to the grief of children by Donna Schuurman, *Executive Director Emeritus* of the Dougy Center in Portland, Oregon, the first Children’s Grief Center in the US founded in 1982.

**6:00 pm** – Closing remarks and brief reception in the lobby.

### SATURDAY, OCTOBER 15th

**7:30-8:00 am** – Continental Breakfast

**8:00 am** – Welcome

**8:15 am** – “When Your Patient is Dying” – Film produced by the Dougy Center

**8:45-9:30 am** – Session 5

“Launching Support” – *Donna Schuurman* – thoughts about what Crescent Cove should consider as it moves forward to be the first pediatric palliative care and children’s hospice in the Midwest.

**9:30-9:45 am** – Brief Break

**9:45-10:30 am** – Session 6

Comments from political leaders about the current state for this effort and support for families.

**10:30-11:45 am** – Session 7

Comments from spiritual leaders on caring and critical conversations - implications for their members and communities.

Small groups – Implications of the Symposium – Mixed Member Groups

**11:45 am-12:00 pm** – Next Steps & Close of Symposium

## Fundamental Shift of Perspective

...one Sunday morning on a subway in New York. People were sitting quietly--some reading newspapers, some lost in thought, some resting with their eyes closed. It was a calm, peaceful scene.

Then suddenly, a man and his children entered the subway car. The children were so loud and rambunctious that instantly the whole climate changed.

The man sat down next to me and closed his eyes, apparently oblivious to the situation. The children were yelling back and forth, throwing things, even grabbing people's papers. It was very disturbing. And yet, the man sitting next to me did nothing.

It was difficult not to feel irritated. I could not believe that he could be so insensitive as to let his children run wild like that and do nothing about it, taking no responsibility at all. It was easy to see that everyone else on the subway felt irritated, too. So finally, with what I felt was unusual patience and restraint, I turned to him and said, "Sir, your children are really disturbing a lot of people. I wonder if you couldn't control them a little more?"

The man lifted his gaze as if to come to a consciousness of the situation for the first time and said softly, "Oh, you're right. I guess I should do something about it. We just came from the hospital where their mother died about an hour ago. I don't know what to think, and I guess they don't know how to handle it either."

Can you imagine what I felt at that moment?... Suddenly I saw things differently, and because I saw differently, I thought differently, I felt differently, I behaved differently. My irritation vanished...Everything changed in an instant.

From *The Seven Habits of Highly Effective People* (1989) by Stephen R. Covey. New York: Fireside Books, pp. 30-31.

## Metaphors Children Either Use or Can Understand

Safe space

Elephant in the Room

A Jigsaw – puzzle

Teeter – Totter

Chess – battle of two forces

What's the Weather Like Today?

Diamonds in the Rough

Word Medicine Music Medicine

Hope Blanket

I see a young boy  
Saying he's going to run away.

Deep inside,  
It's already happened.

Boy grade 8

I sit here  
all by myself  
slowly dying  
with fading health,  
not because I am  
sick or ill,  
but because  
my life's so still.

Boy grade 7

Poems from *Ten-Second Rainshowers:*  
*Poems by Young People* (1996)  
compiled By Sandford Lyne. New York:  
Simon & Schuster

## Core Beliefs – Guidelines to Consider

- 1) Understanding is more important than agreement
- 2) It's impossible to NOT communicate
- 3) Silence speaks louder than words
- 4) The direction in which you look will determine what you see
- 5) HOW things are handled is often more important than WHAT happens
- 6) Civility has two parts: generosity, even when it is costly, and trust, even when there is risk. Civility creates not merely a negative duty not to do harm, but an affirmative duty to do good. (Carter)
- 7) Listening means Listening: many people do more preparing than they do Listening
- 8) Conflict involves competing stories. Neither is right or wrong, but each story is constructed by OUR ways of: • Taking in information • Interpreting information • Making conclusions • Weaving these together in a stable story
- 9) Repeated experiences of unacknowledged and unmourned loss contribute to the dehumanization of loss...It's one thing to lose something that was important to you, but it is far worse when no one in your universe recognizes that you lost it. The failure to acknowledge another's loss is to deny that person's humanity. (Hardy)
- 10) One's history of experiences filters their experiences currently (transference)
- 11) Failure to acknowledge historical experiences can be FELT as a failure to fully understand
- 12) Identity contingencies: Things one has to deal with in a situation because you have been given a social identity because you are old, young, gay, a white male, a woman, black, Latino, politically conservative or liberal, diagnosed with a bipolar disorder, a cancer patient, and so on (Steele)

Gathered by Ted Bowman for purposes of the Crescent Cove Pediatric Palliative Care Symposium

## The Guest House

This being human is a guest house.  
Every morning a new arrival.

A joy, a depression, a meanness,  
some momentary awareness comes  
as an unexpected visitor.

Welcome and entertain them all!  
Even if they're a crowd of sorrows,  
who violently sweep your house  
empty of its furniture,  
still, treat each guest honorably.  
He may be clearing you out  
for some new delight.

The dark thought, the shame, the malice,  
meet them at the door laughing,  
and invite them in.

Be grateful for whoever comes,  
because each has been sent  
as a guide from beyond.

Jelaluddin Rum

Storying and  
Restorying After Loss  
Involves Grieving the Old Story  
Before Creating the Next  
(Not Necessarily New) Story  
---  
Listen For  
Major Components/Themes/Values  
of the Old Story  
How Can They Be Reframed in  
the Next Story

Thom/Bowman

## The Peace of Wild Things

**When despair for the world grows inside me  
and I wake in the night at the least sound  
in fear of what my life and children's lives  
may be, I go and lie down where the wood  
drake rests in his beauty on the water,  
and the great heron feeds.**

**I come into the peace of wild things  
who do not tax their lives with forethought  
of grief. I come into the peace of still water.  
And I feel above me the day-blind stars  
waiting with their light. For a time  
I rest in the grace of the world and am free.**

Berry, W. (1985) *Collected poems: 1957-1982*.  
San Francisco: North Point Press.

**Where do you find peace? When you  
experience despair or fear, where do you go?  
The “wild things” evoked peace for Berry;  
what evokes or awakens peaceful feelings  
and thoughts for you?**

## Making A Fist

For the first time, on the road north of Tampico,  
I felt the life sliding out of me, a drum in the  
desert, harder and harder to hear. I was seven,  
I lay in the car watching palm trees swirl a  
sickening pattern past the glass. My stomach  
was a melon split wide inside my skin.

“How do you know if you are going to die?”  
I begged my mother. We had been traveling  
for days. With strange confidence she answered,  
“When you can no longer make a fist.”

Years later I smile to think of that journey,  
the borders we must cross separately, stamped  
with our unanswerable woes. I who did not die,  
who am still living, still lying in the backseat  
behind all my questions, clenching and opening  
one small hand.

From *Words Under the Words: Selected Poems* (1995)  
by Naomi Shihab Nye. Portland, OR: Far Corner Books, p. 68.

**Consider a question like Nye’s query about  
dying. What are possible metaphors you would  
use in response?**

## OTHERWISE

**I got out of bed  
on two strong legs.  
It might have been  
otherwise. I ate  
cereal, sweet  
milk, ripe, flawless  
peach. It might  
have been otherwise.  
I took the dog uphill  
to the birch wood.  
All morning I did  
the work I love.**

**At noon I lay down  
with my mate. It might  
have been otherwise.  
We ate dinner together  
at a table with silver  
candlesticks. It might  
have been otherwise.  
I slept in a bed  
in a room with paintings  
on the walls, and  
planned another day  
just like this day.  
But one day, I know,  
it will be otherwise.**

From *Constance. Poems*  
by Jane Kenyon. (1993).  
St. Paul: Graywolf Press, p. 58.

*Has there been an “otherwise”  
day for you in the last months?  
If so, what part of this poem  
resonates with that event?  
Kenyon uses the word  
otherwise as a metaphor  
for “one day”.  
What metaphor might  
you choose for “one day”?  
Write a line or two of  
“otherwise” moments for you.*

## Reasonable Hope

I distinguish reasonable hope as a variant of hope.  
Classic images of hope – a butterfly, a rainbow,  
an undemanding bird that perches in one’s soul –  
set up expectations and standards that are with-  
out limit. Reasonable hope, consistent with the  
meaning of the modifier, suggests something both  
sensible and moderate, directing our attention  
to what is within reach more than what may be  
desired but unattainable.

Reasonable hope’s objective is the process of  
making sense of what exists now in the belief that  
this prepares us to meet what lies ahead. With  
reasonable hope, the present is filled with working  
not waiting; we scaffold ourselves to prepare for  
the future.

### Characteristics:

**Reasonable hope is relational**

**Reasonable hope is a practice**

**Reasonable hope maintains that the future is  
open, uncertain, and influenceable**

**Reasonable hope seeks goals and pathways  
to them**

**Reasonable hope accommodates doubt,  
contradictions, and despair**

From “Reasonable Hope: Construct, Clinical Applications,  
and Supports”, by Kaethe Weingarten in *Family Process*,  
vol.49, No. 1, 2010, pp. 5-25.

## Best Practice Principles of Spiritual Care

1. Participation, empowerment and autonomy are core underpinning values of spiritual care
2. We need to create spaces for spiritual care to occur
3. Spiritual care occurs within the context of relationship
4. Spiritual care happens in the context of family and often with family present
5. We need to connect and build on existing spirituality and, if appropriate, faith
6. Developmental and learning context is important to understand in choosing activities, resources and language
7. Metaphor can be a significant tool for spiritual care
8. Spiritual care occurs within and by a community and can offer windows of normalization
9. Meaning making helps children and young people articulate, identity and understand their spiritual needs
10. Identity may have a heightened significance in sickness
11. Concrete and visible expressions and reminders of spiritual care are important
12. Offering ‘episodes of spiritual care’ reflects the often integrated nature of assessment and interventions and the element of reciprocity

From *Spiritual care with sick children and young people* (2015) by Nash, P., Darby, K., and Nash, S. London: Jessica Kingsley Publishers, pp. 19-28.

**All the above are practice principles for adults also. Only #9 requires adaptation: Meaning making helps adults articulate, identity and understand themselves and their spiritual needs. (see Neimeyer and other writers)** Comment by Ted Bowman

