

Care for the Caregiver; Can You Feel the Pain In My Heart Too?

Workshop Hand Out – June 11th, 2020

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Key Points

- In many ways caregiving someone to end of life is like the experience of motherhood and parenting. It asks an individual to serve outside of themselves. A call to know a greater, unconditional love.

Finding Balance in Chaos

- New normal is always changing for the patient and those around them
- Helps to understand the journey of the individual (both patient and loved one) prior to arriving to the last stage of life (hospice/palliative care). As an example, if they have cancer, what was their oncology experience like prior to arriving in hospice?
- Take time to observe, *blend*, and not impose
- Listen, be curious
- Explore the supports available in the person's personal, medical, spiritual, and psychosocial sphere
- Knowing the loss history can help with support not only in the dying phase but in grief after

Pre-Death Loss/Anticipatory Grief

- Review of Alan Wolfelt's three aspects of loss. Loss of self, security and meaning. This will impact both the dying patient and care giver(s)

Dig Deeper to Find Courage/Strength

- Survival instinct is strong
- Attitude has big impact, which includes finding ways to feel gratitude despite the challenges at play
- Self care – What is it really? May be different than what some expect.
- Spirituality/religion important explorations for those when facing an unknown. If there is no faith find out what brings the person comfort? As an example, the beauty of nature

Caregiver Holds Many Roles

- Spouse, partner, family member, friend
- Support to children
- Nurse
- Sounding board
- Advocate/protector/communicator
- MAID – ethical challenge for some

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- What are the caregiver's rights in the discussion? So much is focused on the patient - important to acknowledge impact on caregiver's lives

Suffering

- Just witnessing someone suffering and feeling helpless can cause a form of suffering
- Suffering can occur for the care giver during and after death in grief
- Reflect on how you hold space for someone who is suffering. Allow time for your own grief and process for all that you witness – personally and professionally

Find Purpose in Suffering

- Viktor Frankle's work and book *Man's Search for Meaning*
- Deep spiritual work to find meaning in suffering – bearing witness to it
- When patient's physical pain is controlled, emotional and spiritual pain often surfaces more fully
- Caregiver can suffer – before, during and after death
- Work continues after death as caregiver grieves and heals

The Importance of Love, Compassion and Empathy

- Finding trust when there is fear and uncertainty
- Beyond a Romantic Ideal
- Sexuality and intimacy change in expression but are still vital for connection and care
- Important not to forget loving oneself when in the role of caregiver
- Unconditional love – in serving another

Reminded of the Gift of Life/Power of Each Moment

- Caregiver does their own life review
- Encourage to capture voice and embrace tactile experiences while they can
- Value of time becomes heightened
- Love is the most powerful thing

Dr. Alan Wolfelt's Companionship Philosophy

<https://www.centerforloss.com/wp-content/uploads/2015/10/Introduction-to-Companionship-the-Bereaved-by-Dr-Alan-Wolfelt.pdf>

How Can We Do Better Self Care?

- Begin by exploring your own well being. Take time to grieve the losses you have been present to both personally and professionally

Way to Support the Caregiver

- Help them to get more resourced

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- Find team members; friends, relatives, and professionals they can rely on
- Remind them of the importance of their own self care needs, health and well being
- For professionals – find better ways to honour your own process
- Attitude is key during this journey. Time is precious and moments can never be re-captured in the same way again. What are the gifts? Cherished memories?

See Resource/Reading list for more helpful information.

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