

Keeping Hope in Giving and Receiving Care: Challenges for Families and Those Around Them

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Goals

Explore hope as key in supporting care partners

Describe challenges in keeping hope alive

Goals

Define losses that affect hope

Identify strategies for keeping hope

Assumptions

- Families are those you “count on.”
- Families have strengths and concerns.
- Each family is unique.

Assumptions

- Caregiving is difficult.
- Family systems aren't static.
- No one approach fits all.
- Family members may be at different places along the family developmental cycle.

Assumptions

- Culture affects family systems.
- Carers can build on resiliency and reciprocity.
- The “frail” have much to teach the “well.”

A CareSharing Approach

- Person receiving care +
- Person receiving care =
- CARE PARTNERS

Care Partnering

- Includes all involved in care
- Builds on reciprocity and resilience
- Leads to respect
- Is balanced
- Can occur even with mental and physical changes

Reciprocity

- Mutual sharing despite physical or mental limits
- Emotional and spiritual growth enabled for care partners
- Encouragement for care partners to be all they can be

Hope's Important Role

- Hope must be reasonable, based on individual situations.
- Hope evolves to reflect changes.
- Seemingly “unrealistic” hope must not be extinguished.

Attributes of Hope

- An experiential process
 - A rational thought process
 - A relational process
 - A spiritual/transcendent process
- Farran, C.J., Herth, K.A. & Popovich, J.M. (1995). *Hope and Hopelessness: Critical Clinical Constructs*. Thousand Oaks: Sage.

Hope as a Rational Thought Process

- Goals
- Resources
- Active Process
- Control over own destiny
- Time

Hope and CareSharing

- Reflect on family's strengths and inner resources.
- Stress family resiliency.
- Focus on sharing and learnings that bring joy.
- Emphasize interdependency.
- Listen to stories.

Maintaining the role
of “family member ”
for the person being
cared for is KEY for
keeping hope for all.

It is Possible to Share

- Laughter
- Love
- Joy
- The “spiritual” and the “creative”

Grief and Loss: Major Challenges to Maintaining Hope for Care Partners

Losses in Caregiving

- Relationship changes
- Changed plans dreams
- Companionship
- Shared intimacy
- Sense of meaning
- Spontaneity

Issues of Grief and Loss

- Grief Overload
- Anticipatory Loss
- Ambiguous Loss
- Unrecognized Grief

Grief Overload

- Myriad losses build layer upon layer.
- Losses are often not acknowledged by others.
- There may be diminished internal resources for “bouncing back” from losses.

Anticipatory Loss

- Concern about expected losses
 - Financial
 - Mental
 - Physical Abilities
 - Communication
 - Dying and Death

Ambiguous Loss

- A “rollercoaster” of changes and expectations
- Care partners can feel confused as illness and mental changes fluctuate.
- Naming is difficult.

Unrecognized Losses

- Losses that for some reason cannot be named or processed
- Losses that occurred earlier in life that resurface in caregiving challenges

Exploring Hopeful Family Relationships

- Long term positive interactions?
- History of conflicted family relationships?
- Family strengths? Rituals or spiritual traditions?

Exploring Hopeful Family Relationships

- Past positive interactions that could be used now?
- New skills to be learned?
- Best way to offer assistance?
- Community networks?

Keeping Hope

- Change from a “crisis mentality” to a “comforting presence.”
- Use of small steps can move from stigma and stagnation to “well-being.”

Keeping Hope

- Entire family is the “unit of service.”
- The person cared for has an important family role.
- Use the “gifts” of all ages.

Strategies

- Build on the internal resources of a family.
 - Sense of humor
 - Faith
 - Good communication
 - “True Grit”

Strategies

- Teach limit setting.
- Model effective communication skills.
- Assist in negotiating barriers to service provision.
- Stress contingency planning.

Strategies

- Use learnings from care partners.
- Build on “community” to support families.
- Encourage reasonable hope.
- Keep hope alive in providers.

Strategies

- Use of spiritual support where available.
- Build “sacred spaces.”
- Assist persons to have success in small increments.

Strategies

- Use creativity.
- Build on effective coping skills.
- Help develop new skills.
- Utilize education.

Creative Avenues for Family Sharing

- Music
- Art
- Stories
- Poetry

What is Needed for Hope

- Grit
- Grace
- Resilience
- Acceptance of realities
- Effective coping
- Community

“Hope is an Act of
Collaboration. It Cannot Be
Achieved Alone. We Offer
Grains or Fragments of Hope to
One Another So That
Everyone’s Sense of Possibility
Can Grow. In this Way We Can
Do Together What Might Seem
Impossible Alone.

Kathleen Fischer

Resources

Boss, Pauline. (2011). *Loving Someone Who Has Dementia: How to Find Hope While Coping with Stress and Grief*. San Francisco: Jossey-Bass.

Richards, Marty. (2009). *Caresharing: A Reciprocal Approach to Caregiving and Care Receiving in the Complexities of Aging, Illness or Disability*. Woodstock, VT: Skylight Paths Press.

WA State Dementia Action Collaborative. (2017). www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan

Resources

- Alzheimer's Poetry Project
<alzpoety.blogspot.com>
- Freye Museum
<http://freyemuseum.org/here_now_programs>
- Memory Café <www.alzpoetry.com>
- Modern Museum of Art:
<[www.moma.org/meet me](http://www.moma.org/meet_me)>
- Songwriting Works
<www.songwritingworks.org>
- Time Slips <www.timeslips.org>

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