Helplessness & Hopelessness:  
The Volunteer’s Role  
in Finding Meaning

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Today’s Presenter: Gary Gardia

Gary currently works as a speaker and consultant in all areas of healthcare, especially hospice. He was the Volunteer/Volunteer Manager section leader for NHPCO for 6 years and was instrumental in developing their Volunteer program Resource Manual.

He began his hospice career as a volunteer in 1983. Since then he has worked in many capacities leading a variety of teams and departments including volunteers, social workers, bereavement, education, patient care teams and has served in a hospice vice-president role.

Gary holds Master degrees in Education and Social Work. He received NHPCO’s “Heart of Hospice Award” for developing innovative programs to meet the needs of caregivers and the bereaved and in 2015 received the national organization Social Work Hospice and Palliative Network (SW HPN) Excellence in Education Award. He has worked as a psychotherapist in private practice with a specialty in grief and loss, personal growth and development and substance abuse. Gary led the development of NHPCO’s Hospice Volunteer Program Resource Manual as well as the recent update/revision.
What We will Cover in This First of Two Webinars for Volunteers:

- Take a look at how helplessness and hopelessness can prevent people who are ill and their loved ones from living fully for the time that remains
- Discuss the critical nature of “finding meaning in loss” and the volunteer’s role in participating in these conversations
- Define and describe “door openers” and explore the skills that can assist us in moving with the flow of conversation instead of backing away
- Present a series of techniques that are helpful in assisting people (individuals and families) to feel a sense of usefulness and helpfulness, even when confronting serious illness

Consider This Thought:

How might hospice look if we were to be as aggressive at “treating” helplessness and hopelessness as we are at treating pain and symptom management?

And then this thought:
Volunteers can play a critical role in achieving this.
“The pain of the mind is worse than the pain of the body.”

Publilius Syrus
author, 1st century BC

“Studies have shown that a person’s ability to savor experiences predicts their degree of happiness.”

Both helplessness and hopelessness interfere with people’s ability to “savor experiences” in their remaining days.

Scientific American Mind. Volume 21, Number 4 September/October 2010

Research conducted by psychologist Jordi Quoidbach of the University of Liège in Belgium
Could it be that the real issue is less about a “fear of dying” and more about an intense desire to stay alive?

Imagine you discover that you will die within the next two months. What would cause you the most anxiety?

How does the concept of “hope” change when we think of what people do not want to lose... versus what they fear lies ahead?

People say:
“Hospice is not about giving up hope... we assist people to redefine hope.”

This is not entirely true. It is about both... for many people it is about giving up hope for a cure.

But it is also about our ability to assist people to redefine hope. Our work lies in both areas.
Interventions

Allow time to talk about hopelessness

- Watch out for “fixing comments”
- Examples are:
  - “You need to stay strong”
  - “Focus on the positives”

This is the time to use active listening skills.

Consider Mindfulness

For all of us, much of our stress comes from the energy we give to thoughts of the past and the future. (Worry) Mindfulness is about “being in the moment”.

To help introduce the concept of mindfulness in a way that feels comfortable to the person you are with, consider the language you use:

- Let’s focus on this moment right now
- Maybe we need to hit the pause button for a second
- How about right here and right now?
- Maybe this is about patience?
- Redirect your thoughts: what was your favorite vacation?
- How are you breathing right now?
- What is that on your arm?
Benefits of Mindfulness

- Stress relief overall
- Reduce “suffering’
- Pain/symptom management
- Improve sleep
- Assist with maintaining patience
- Relieves stress on relationships
- Reduce overwhelming sadness

Techniques/Interventions Volunteers Can Use

Just have a conversation with the person about “right now”. Stay focused on the present and then redirect back to the present moment if the conversation goes to “worry” places. “Tell me more about how you are feeling right now.” or “I would like to know more about what you were just saying.”
Introduce “Combat Breathing”

- This breathing strategy has been used by first responders, the military and athletes to focus, gain control and manage stress. In addition, it appears to help control worry and nervousness.
  - Breathe in counting 1, 2, 3, 4
  - Stop and hold your breath counting 1, 2, 3, 4
  - Exhale counting 1, 2, 3, 4
  - Repeat the breathing

- Be careful about using this terminology though. “Combat breathing” may work well for a person who was in the military but maybe not for others.
- Also, adapt the length of time the person holds their breath to account for capabilities/diseases, etc.

Gratitude Technique

Ask the person you are with if this might be a good time to think about the people who have helped out, have offered support, and/or who are important to you. Maybe this is a good time to think of ways you might say thank you.

Once again, this is a way to focus back on the here and now.

“Who are the people in your life you are grateful for? Think about including people outside your closest circle of support.”
Mindfulness & Relaxation

- Breathing: breath control or breath awareness
- Imagery
- Audio/video resources
- Distraction
- Positive reminiscence
- Refocusing
- Focused and intentional activities: reading, listening, watching, smelling (aroma therapies)

A Really Good Book:
The Mindfulness Toolbox:
50 Practical Tips, Tools & Handouts for Anxiety, Depression, Stress & Pain
By Donald Altman, M.A., LPC
Helplessness

It is not uncommon for people who are seriously ill to begin to feel helpless.

Those feelings tend to increase as the disease progress.

We all know that just getting a cold or the flu causes us to feel a sense of lack of control over our lives. Take a moment to consider the effects of serious illness.

Interventions

- Before jumping in and “helping” see if the person might like to do the activity for her/himself.
- Find out what people are capable of doing and see if you can turn that into an activity of some sort.
- Offer to assist with creating a photo album, journal, etc… with personalized thoughts and messages for loved ones.
More Interventions

Consider the possibilities: maybe the photo album activity might best be accomplished between Grandma and grandchildren (for example).

You may want to set this up as Grandma “teaching” grandkids about things she learned in life... important life lessons.

Always ask “Is this an activity that I might be doing with them... or would it be better for me to help set this up so they can do it on their own?”

And...

- Take a “teach me” approach
  - Tell me what you have learned in life
  - I would love to learn more about that from you. (Take notes?)
- Ask them to tell you their stories
- Tell them when they have offered something that you find helpful or useful
Finding Meaning as a Way to Assist with Both Helplessness & Hopelessness

- As humans we are always trying to make sense of the world around us and life events as they occur.
- Research shows that people who are able to find meaning in their losses “recover” better.
- This may be more about **not** finding meaning or what happens when we feel cheated, abandoned, or punished.
- Meaning can include “sense-making” or “benefit-finding”.

Interventions for Volunteers

- Watch for “door openers” and don’t be afraid to ask “Would you like to tell me more about that?”
- Be careful about “closing doors” when someone approaches a topic. We do that with fixing comments, changing the subject (often because of our own discomfort with the topic), giving advice, inadvertently redirecting.
- Ask the question “What do you feel all this means?” or “How do you make sense out of this?”
The worst part about being strong is that no one asks if you are okay.

It is alright to feel helpless sometimes, as long as you know you are loved.

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Thank You!

Questions?

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