

Spiritual Care: We're all in this Together

Dementia Care 2018

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Workshop Description

All personal interactions have the potential to touch the human spirit in ways that are healing and life-giving. This workshop will explore everyday ways that staff in Personal Care Homes can contribute to the spiritual health of residents – and at the same time experience renewed meaning and purpose in their jobs.



Spirituality is as relevant for the non-religious as it is for the religious because it is about the fundamental meaning of being human. - Malcolm Goldsmith*

A healthy spirituality:

- **Moves us:** toward love and compassion, truthfulness, meaning, hope, connectedness, wholeness, gratitude and forgiveness
- **Provides answers:** to life's existential questions
- **Associated with:** greater wellbeing & ability to cope with suffering; to move past despair

**Spirituality and Personhood in Dementia. Albert Jewell (ed.)*

Four longings

1. To live a meaningful and purposeful life
2. To feel a sense of connectedness
3. To live with trust and hope in an uncertain universe
4. To experience a sense of belonging to something greater than ourselves

- Frain, 2010



Benefits of a healthy spirituality

Attending to our spiritual life enables us to access inner resources of strength, keeps us energized with hope and faith.

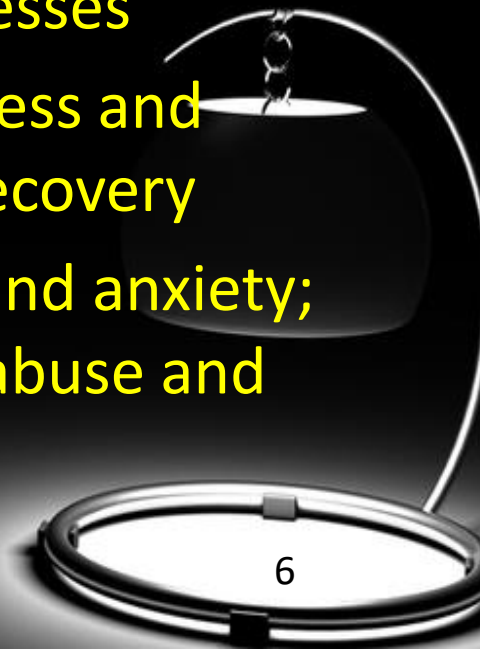
-Robert Gerzon

- connects us with inner resources of resiliency: strength & stability for coping with adversity
- feeds our sense of gratitude and hopefulness
- helps us come to terms with suffering and death



Health outcomes (Puchalski & Ferrell 2010, 4)

- **Quality of life (QOL):** meaning, purpose and capacity for growth, even with advanced disease
- **Mortality:** those with regular spiritual practices tend to live longer
- **Coping /resiliency:** will to live, less death anxiety; ability to cope with illness, manage pain and life stresses
- **Better health outcomes & recovery** from illness and surgery. A key component in mental health recovery
- **Mental health:** lower measured depression and anxiety; and substantially reduced risk for substance abuse and suicide



Spirituality and Illness

Illnesses are deeply meaningful events within people's lives, events that often challenge people to think about their lives quite differently. Spirituality sits at the heart of such experiences.

John Swinton, PhD.
University of Aberdeen,
Centre for Spirituality, Health and Disability



Assumptions

- We have all been touched by the lives of persons who live with Dementia
- We all have our moments of helplessness, guilt, fear, despair
- We can all learn from each other's experience: successes and disappointments
- You are here because you are a front-line Health Care worker, family member or support person for someone who lives with Dementia



Personal Care Home Standards

Standard 18: Spiritual and Religious Care

Reference: *Personal Care Homes Standards Regulation, Section 32*

The operator shall ensure that an organized spiritual and religious care program is provided to respond to the spiritual and religious needs and interests of all residents.

Expected Outcome: Residents are free to practice their individual spiritual and religious customs and residents' spiritual needs are met in a way that enhances their quality of life.

Performance Measures

#	Measure	Facility Rating	Comments	Review Team Rating	Comments
18.01	Residents have access to the spiritual advisor(s) of their choice.	<input type="checkbox"/>	<input type="checkbox"/>		
18.02	The home hosts regular religious services and spiritual celebrations.	<input type="checkbox"/>	<input type="checkbox"/>		
18.03	Special spiritual and religious observances are accommodated when possible.	<input type="checkbox"/>	<input type="checkbox"/>		
Scoring methodology: <ul style="list-style-type: none"> • There are no pass/fail performance measures. • Of the 3 measures: <ul style="list-style-type: none"> ◦ If 3 measures are met, standard is met. 					

Effective: January 1, 2015 Continuing Care Branch

Manitoba 

Health, Seniors and Active Living

Spiritual Assessments

- What is the client's Spiritual orientation (Religious, non-religious, etc.)
- What role does Faith have in their life (helpful, hurtful, indifferent)
- What Beliefs & Values are most important to the client
- Changes & Losses experienced in life
- Resources for Coping
- What gives meaning, purpose and hope now?
- Is there a Religious affiliation
- Is there a Connection to a Community of Faith
- Important religious / spiritual practices



Patient Dignity Question - Chochinov

What do I need to know about you as a person to give you the best care possible?

- “I was fiercely independent.”
- “I took great pride in my work as a nurse.”
- “I am a survivor of the Residential School system and I’m afraid of people in positions of authority.”

Harvey Max Chochinov, Dignity Therapy

Care Planning

- *If you've seen one person with Dementia, you have seen **one** person with Dementia.*
 - Every person is unique and worthy of our full attention
 - Finding out each individual's personal preferences and needs is hard work... and very rewarding



Identity of the Person with Dementia

- We are inherently relational creatures
- Being in Community is good for your health
- Spiritual Care is not about learning new competencies; it's about looking at your competencies differently



Examples

- Pain: when you are in pain you cannot think about the things that matter to you (God, family, friends)
- Giving good pain medication can be a spiritual practice that helps the suffering person to get back in touch with the important things in their lives
- Assistance with ADLs (Activities of Daily Living) can be a portal to a deeply personal and spiritual dimension of care



Being Loved For Who I Am

“If I do get dementia, I hope that I will be loved for who I am, even if who I am is difficult for me and for others.”

➤ That’s a pretty tall order!



Being Loved For Who I Am

Who will I be when I have forgotten who I think I am?

How could I expect people to love this stranger that I've become?



Broken community

“My loved ones and friends stay away, fearing my disease. Even my own family stands at a distance.” – Psalm 38:11

“You have taken away my companions and loved ones. Darkness is my closest friend.”

– Psalm 8:18

(Parallel laments may be found in many faith traditions)



What makes you who you are?

- Dementia doesn't take away your Personhood
- The problem with people with dementia is not that they forget
- The problem with people with dementia is that their community disconnects from them and forgets their story

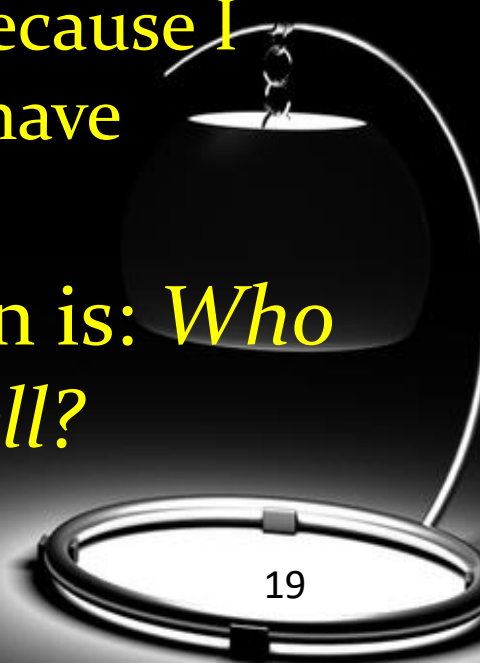


What makes you who you are?

➤ The memory problem does not lie with the person who has Dementia, but with their Community.

➤ E.g. If I want to know things about my childhood I have to ask my mother because I don't remember even though I don't have Dementia.

➤ The memory is there... the question is: *Who is going to remember your story well?*



Stigma reduces Personhood

- *“She is not the person she used to be.”*
- *“I’d rather kill myself if I end up like that.”*
- *“I’d rather remember him the way he was.”*

John Swinton



The Problem with Defectology

- The technician, Doctor, Nurse, Rehab Aide, etc. sees the defect and decline named Dementia.
 - We label the condition because it helps us understand
 - Focus on Disease
 - Damage
 - Cognitive Impairment
 - Behavioural issues
 - Emotional problems
 - Highlight what is broken
 - Favorite word “Deficit”



Defectology leads to

- Disempowerment
- Infantilizing
- Intimidation
- Labeling
- Stigmatizing
- Isolation
- Ignoring
- “Dementia is a hard condition to be around”



From Defectology to Relationship

- Dementia is as much *relational* and *social* as it is *neurological*
- Relationship affirms personhood
- Good care is relational care
 - Relate properly and authentically
 - Personalize care and surroundings
 - Offer shared decision-making
 - Interpret behaviour from the person's viewpoint
 - Make the relationship as important as the care tasks



Entryways to Spiritual Connection

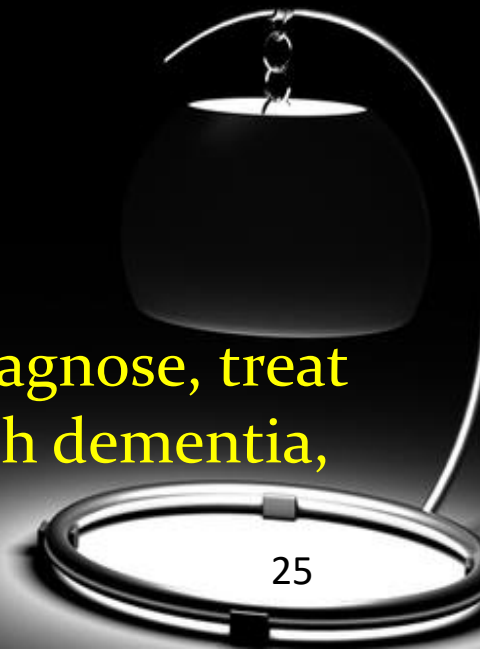
- The Body remembers
- Rituals, rites, practices
- Posture of worship
- Sacraments
- Saluting the flag, handshake
- Singing songs learnt in childhood
- Poetry



The Power of Story and Counter-Story

- People with dementia gradually lose the ability to tell their own stories.
- Other stories about them told by doctors, neurologists, nurses, society, media, family and friends eventually become the dominant story.

(This is not a critique of those disciplines that diagnose, treat and seek a way to improve the lives of people with dementia, but a reflection on reality).



The Power of Story and Counter-Story

Key question for a Persons with Dementia:

“Who will tell my story well when I have forgotten who I am?”



Community

- We need to shift the way we do community and how we keep Persons with Dementia in community.
- Personal Care Home Staff become a huge part of their new community.
- Cheers: a place where everybody knows your name, and they're always glad you came!
- Hospitality

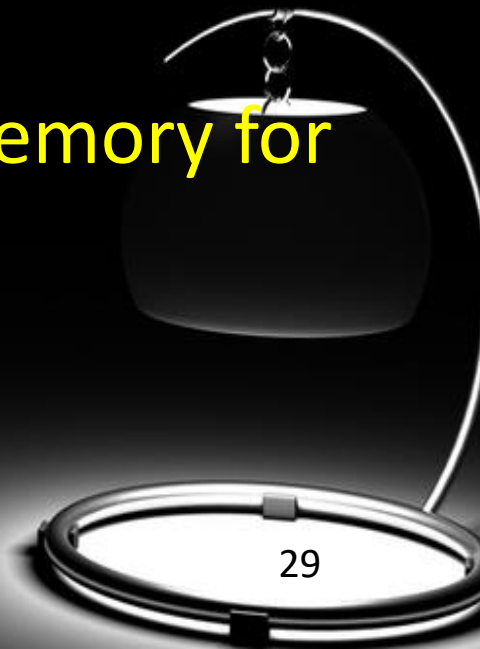
Community

- Give the sacrament of the present moment.
- Slowing down creates space for love; it says, *“It is good that you are here. It is good that you exist!”*



Community

- Living in the memories of God, family and friends
- The problem is not that persons with dementia forget; the problem is that persons with dementia are forgotten.
- We are the people who hold their memory for them.



Nick – Keeper of my memories



This is the story of my life. Yet it is more than that. What I tell you here is typical, not only of my life but, of all of Ukraine and those who lived there. It is a way to understand all the people who lived there in the early years before the beginning of Communism and what followed.

Early Recollections
 You were born in the year 1889. I do not remember you in the morning. You'd light a candle and see your sister, Svetlana, leaving so quietly and gently waking me with your ever so saddened face bedewed with tears. You were singing. Back then, I did not know this, and merely sat by and did not know this. I do remember that the entire work had a lady servant and children. You sang "your raven-black horse son's falcons you chased away".
 You also sang the following song:
 "When I recall my experiences up until today, for friends like yourselves about the war back in faraway Ukraine, I remember that I left my mother behind. Through the village there marched an army regiment as she walked heavily over to the headquarter. Those men didn't stand a chance to get those officers had clubbed his mother's day and fly to my dear Mother, mother will not leave."



The Role of Staff in Spiritual Care



Time Out



- Nurses, HCAs, other Staff already have so much to do, in an environment that is currently quite stressed and stressful due to system changes.
- They may also be experiencing Spiritual distress due to the effects of change.



Not More... But more Intentional

- Spiritual Care is not about learning new competencies; it's about looking at your competencies differently.



The Role of Staff in Spiritual Care

- Spiritual Care Generalists
- Team Huddles
- Working from your Spiritual center
 - Self-Awareness is key
- Put on your mask first – Self-Care



Spiritual Distress

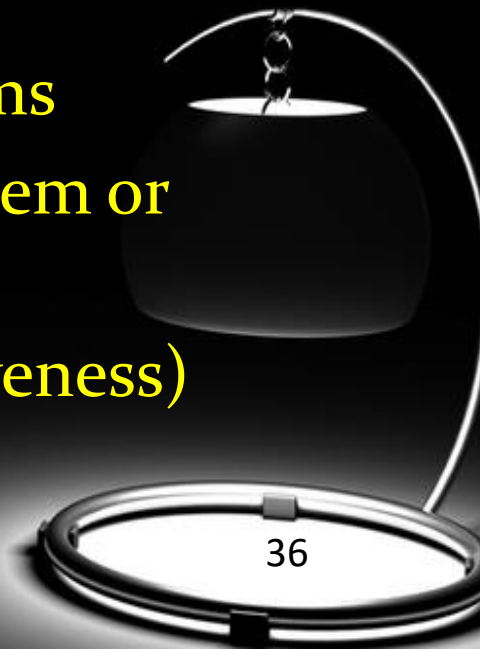
“Impaired ability to experience and integrate meaning and purpose in life through connectedness with self, others, art, music, literature, nature, and/or a power greater than oneself.”

Hall, Hughes, Handzo, 2016



Indicators of Possible Spiritual Need

- Seeking spiritual help
- Being afraid to fall asleep at night or other fears
- Feeling a sense of emptiness; loss of direction
- Talking about feelings of being abandoned by God/higher power
- Anger at God/higher power
- Having pain and/or other physical symptoms
- Questioning the meaning of life, belief system or meaning of suffering
- Inability to reconcile differences (*un-forgiveness*)



Indicators of Spiritual Need

- End-of-Life Protocol (Final Days/ Final Hours) has been initiated
- Expressing a Wish to Die
- Self-destructive Behaviour
- Sudden Change in Health condition
- Request for Ritual or Sacrament
- Loss of Meaning and Purpose
- Loneliness
- Guilt
- Fear



Indicators of Spiritual Need

- Abandonment
- Feeling like a Burden
- Grief, Loss, Bereavement
- Anger / Bitterness
- Low Self-esteem
- Depression, Sadness, Despair
- Ethical Dilemma – values are at odds with reality
- Questions about Advance Care Plan
- Questions about Medical Assistance in Dying



Opportunities for Spiritual Encounters

- Every human encounter offers an opportunity for compassionate and healing interactions with residents and families.



Working from your Spiritual center

- How well do you know yourself?
- What is your Spiritual / Religious orientation?
- What (if any) is your affiliation with a Faith Community or Spiritual support system?
- Do you attend religious services?
- How much / how often do you pay attention to the needs of your spirit?
- In what ways do you nurture your spirit?



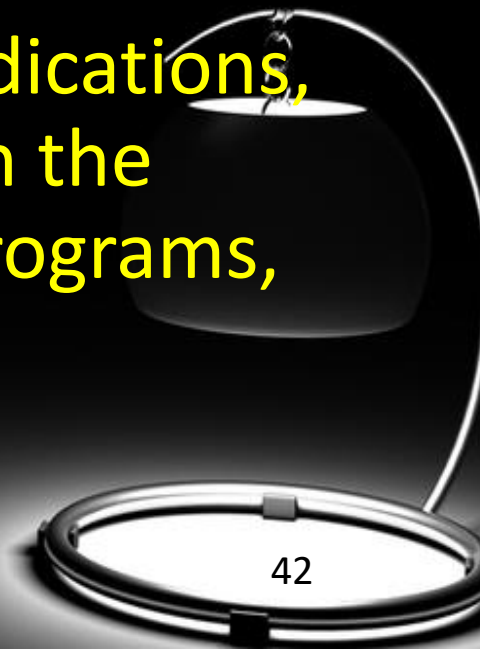
Working from your Spiritual center

- Are you able to articulate your beliefs and values?
- Do you know your own Philosophy of life?
- Does your Philosophy of life include a spiritual dimension?



Working from your Spiritual center

- How do you bring your own Spirituality into the workplace?
- How is your Spiritual / Religious orientation appropriately reflected in the way you do your job?
 - E.g. in the way you administer medications, do morning care, meal assist, wash the floors, volunteer, run recreation programs, etc.



The “little things”

- Everyday sacred encounters
- Coming to know the other as person
- His/her unique life history
- Likes and dislikes
- Idiosyncrasies

Tracy J. Carr, Sandee Kicks Moore, Phyllis Montgomery, [What's so big about the 'little things': A phenomenological inquiry into the meaning of spiritual care in dementia.](#) 2011



The “little things”

- Initiating intentional acts to foster personhood
- Does not require a lot of time or technical skill
- An intimate respectful openness to the person’s preferences
 - E.g. painting nails, having a cup of tea, setting hair, playing crokinole



The “little things”

➤ Intentional caring actions

“ It doesn’t take much... it could be just taking their hand and walking down the hall with them. It doesn’t have to be anything big at all... we (health care providers) love doing stuff like that and they [persons with dementia] love it.”

Michaela – an LPN

The “little things”

- An element of planned spontaneity
- An unhurried relational approach
- Caring contributes to a sense of personhood and fosters a connection between persons



The “little things”

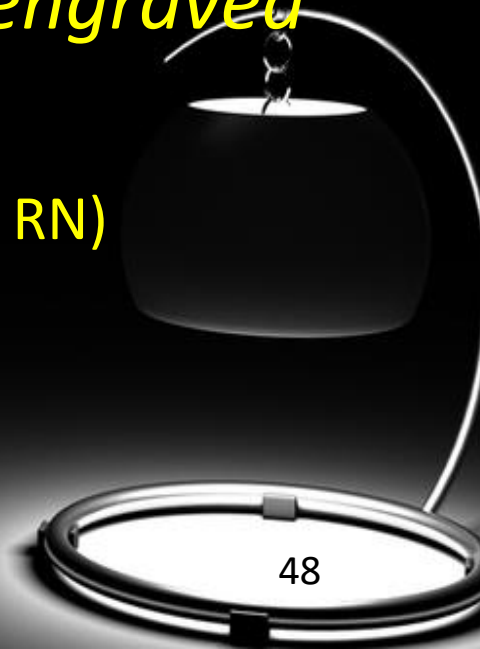
“In addition to attributing sacred or spiritual value to these everyday human encounters, the little things were also described as the inclusion of religious acts in their care, for example singing hymns, saying prayers, and reading scripture.”



The “little things”

“These patients, confused or not, they can remember the hymns, and they can remember the prayers. They may not remember their names, but once these prayers are said or the hymns are sung, they know them. It’s engraved right in their minds. It’s amazing.

(Irene, RN)



The “little things” include

- Listening
- Gentle touch
- Comforting
- Being present (vs. rushing to complete a task)
- Providing basic comfort measures
- Establishing Trust
- Building relationships
- *‘the holy resides in the ordinary’*



The “little things”

“Spiritual care for persons with dementia can provide opportunities for the one caring to feel valued, cared-for, and connected. It can serve to enlarge the purpose and meaning of the care provider’s own lives and work.”



Connecting Spiritually

- *“What do I need to know about you as a person to give you the best care possible?”*
 - Reading the Chart – Spiritual Assessment
 - Personal & Psycho-Social history
 - Spiritual Care Plan
 - Dialogue with the Resident and/or Family
 - Taking an honest interest in the Person



Connecting Spiritually

- Discuss the Resident's Spiritual needs with other staff
 - Team Huddles (Confidentiality within the Team)
- Discuss the Resident's Spiritual needs with their clergy or the Chaplain
- Refer when you're in over your head



Barriers to Connecting

➤ Caring for persons with dementia is viewed as a job:

“I find most dementia patients really don’t focus on that [spirituality] too much. It’s more their families that need it. Maybe in palliative care they need it a little bit more, where they have patients that are dying, but in the day to day, not too much. I think some of them like the church services on the weekends and stuff like that, and some of them go during the week to the services. Otherwise I don’t think that they need a lot.” - A nurse

Barriers to Connecting

- Perception that dementia prevents individuals from 'focussing' or 'understanding'
- Disconnection from the person on the part of the one caring
- Failure to understand the meaning of spiritual care in the broadest sense – to provide meaning and purpose



Making a Spiritual connection

“Fundamentally, even when a person with dementia cannot connect with the nurses, chaplains, and other direct care providers, these caregivers can still make an effort to connect with that person.”



The Essence of SC in Dementia

“... is rooted in the promotion of personhood through intentional caring attitudes and actions. In this sense, spiritual care is not something reserved for someone or something that is done in isolation of other aspects of care. Rather, there is an essential sacredness to genuinely caring for the personhood of another.”



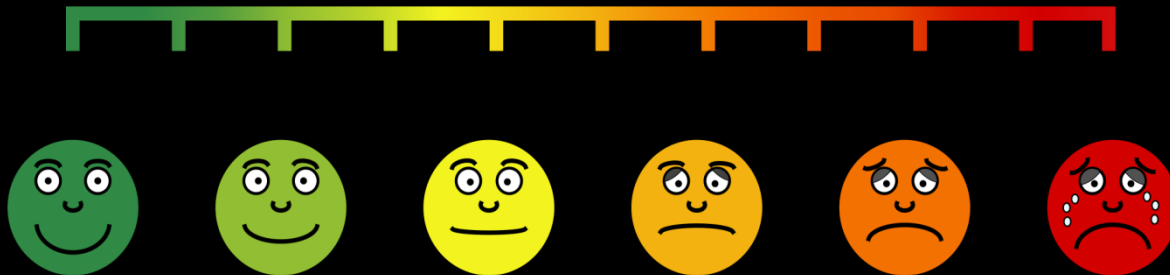
Positive Outcomes

- Persons with dementia expressing gratitude
- Appearing peaceful or settled, even happy
- Have an increased Quality and Enjoyment of Life
- Health Care Providers expressing satisfaction and fulfillment in their work



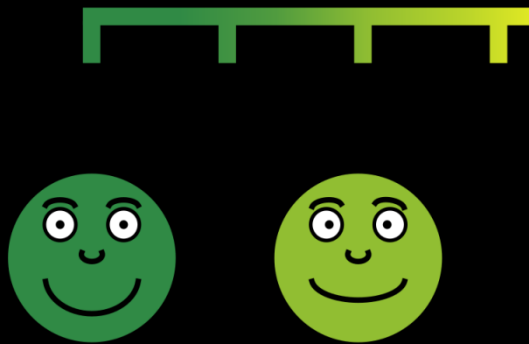
Your level of comfort

- How comfortable do you feel discussing Spiritual and Religious concerns with Residents and Family members?



Your level of comfort

- What further resources do you need to feel more comfortable?



Simple Spiritual Self-care

- Prayer, meditation, and contemplation (intentional silence)
- Communing with beauty, nature
- Meaningful ritual – religious worship or otherwise
- Spiritual support groups and other deep and meaningful connection



Simple spiritual Self-care

- Creative expression (music, art, photography, dance, cooking, gardening)
- Journal writing
- Inspirational reading or music
- Service and simple acts of kindness
- Cultivate joy and laughter (play)
- Reconciliation with self and/or others (forgiveness)



Being intentional about Self care

- Connecting with our own personal sources of hope, comfort, meaning, strength, peace, love and connection



Life Lesson: Put on your own oxygen mask before assisting others.



*seriously.
you can't help anyone if you're dead.*



Resources Consulted

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Resources

