

Spirituality In-Service

Quality Palliative Care in Long Term Care Alliance

Facilitators Guide



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For more information regarding the project please visit www.palliativealliance.ca or email our team at palliativealliance@lakeheadu.ca

Introduction

Spiritual care is a core element of palliative care (World Health Organization, 2002). While chaplains and spiritual care advisors have a particular role and expertise in this area, there is growing recognition that all staff and volunteers have the potential to provide basic spiritual care.

Training offered in spiritual care can be affirming to Front Line Workers, putting a name to the important work that they do everyday—working with residents on their spiritual journey.

Purpose of the Workshop

Participants in this workshop will have the following learning outcomes:

- Appreciation of the need for spiritual care delivery in long term care especially with residents who are in need of palliative and end-of-life care.
- Understanding that spirituality is an everyday way of being. We live our lives from a spiritual perspective. We use it as a daily support, as it plays out in our daily actions. It can even be seen in the manner in which physical care is provided at bedside.
- Highlighting the importance of Front Line Workers who provide care to residents with kindness, compassion, empathy and respect, often feeling like family members of the residents.

Background for Facilitators

Facilitators

Thank you for utilizing this toolkit developed by the QPC-LTC Alliance and identifying the importance of educating front line staff on spiritual and religious care and their role in providing this care. It is recommended that the person facilitating this workshop have some background in spiritual care, however this person does not require formal training. This toolkit is to be used as a guide. Please feel free to adapt the presentation to fit your needs while facilitating. Personal stories can help enhance this tool. The next few sections will outline the importance of follow-up and confidentiality; please remind participants of these issues prior to beginning the workshop content.

Follow-up

From previous experience in piloting this curriculum in communities, we have found that the education provided may trigger past memories and / or a grief response. It is beneficial for the community to have a plan in place for follow-up of issues that may arise. This plan should identify connections to mental health practitioners, spiritual care, grief counselors and/or social workers and be in place before the education program begins.

Confidentiality

While confidentiality of participants cannot be ensured in this type of learning session, advise participants that confidentiality is important to maintain. Ask them to not disclose personal stories shared by others outside the learning environment.

Personal Loss Questionnaire

It is suggested to start with a questionnaire about personal loss, which assists participants in gaining an awareness and understanding of feelings around their own personal losses. This is important when providing care since providers naturally go in to a resident's room with their own history. If there is a lack of understanding about how one relates to loss, s/he can be triggered by events that occur at the bedside. Spiritual Care should be available to help participants process feelings that may arise as they recall past experiences. An example personal loss questionnaire is provided on the following page.

Questionnaire

Personal Awareness of Loss Exercise

This exercise will help you to consider your own experiences of loss and to realize the amount of personal information you have about grief.

Please complete the following worksheet. It will require some time for thought and for exploration of feelings. It is important to take care of yourself as you do this exercise. Do what is comfortable for you.

Spiritual Care is available to help support you process your feelings that may arise as you recall past experiences.

- List three losses you have experienced. Choose losses you feel comfortable to recall at this time. You may not wish to consider significant losses at this time.**

2. Describe the reactions you experienced when these losses occurred.

Feelings/Emotions

Behaviours (or how you express yourself)

Thoughts

Physical Reactions

Spiritual Reactions

3. What was helpful? (that you did, that others did) What was not helpful?

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Palliative Care in Long Term Care

1. Focus of palliative care is changing
2. Long Term Care Homes are deemed a person's home
3. Goal is for people to die in their own homes, if at all possible
4. Importance of Front Line Workers (including Personal Support Workers) in providing spiritual care

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- Historically, when we talked about palliative care, we thought of people in hospice palliative care units or people with cancer. With recent changes in the health care system people requiring palliative care, but whose medical condition is relatively stable, are now able to live in the more home-like setting of the long term care facility.
- Long term care homes become people's homes when they can no longer remain in their own homes. Thus, it is important that palliative and end-of-life care be provided in long term care homes so that the resident may remain at 'home' until he or she dies.
- Spirituality becomes more relevant to many as they enter the final stages of their life.
- Front Line Workers (including Personal Support Workers) play an important role in providing spiritual care.

Relationships between Residents and Staff

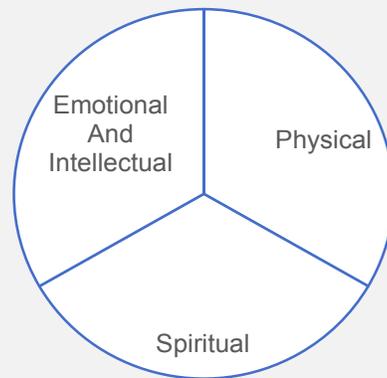
- Front Line Workers provide 80% of the direct care of residents in long term care
- Front Line Workers may have daily or weekly contact with the resident's family members, friends and significant others
- Research indicates that residents and front line workers develop a bond that they describe as being "family" like

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- Front Line Workers provide over 80% of the direct care of residents in LTC. They come into contact with the residents on a daily basis and are involved with them in all aspects of their daily activities.
- They are also involved with the resident's family members, friends, and significant others, and would have contact with them, if not daily, then on a weekly basis.
- Research indicates that in order to assist Front Line Workers in feeling comfortable with providing all aspects of care, they need affirmation in their ability to provide not only the physical care, but also the holistic, spiritual, and emotional support that is so integral to the residents well being.

Holistic Health Model



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- As holistic beings, we are composed of our body, our emotional and intellectual state and our spiritual being.
- Our spirituality is expressed in how we find meaning in life.
- Each part of our being is affected by the other, i.e., physical illness creates fear/anxiety (emotions) and affects our thoughts (depression), which then causes us to question the meaning of life.

Change in Spiritual Care Needs When Death is Near

- Impending confrontations with death may prompt a person to engage in spiritual reflection
- Spiritual care is regarded as very important for many terminally ill patient
- Growing separation of the concepts of spirituality and religion

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- All of us can provide basic spiritual care at the bedside for a resident. You do not need to be a Spiritual Care Associate. More in-depth conversations can be desired when death is near, so it is important that you feel comfortable with what you are doing or the conversation you are having.
- There is a growing distinction between spirituality and religion, and it is important to understand the difference between spirituality and religion.
- People who have never gone to church or who state they don't really have any religious affiliation still have a spiritual part of their being which should be attended to, especially when they are terminally ill.

Religion

“is more about systems, a social institution that is joined or organized by individuals who share the same beliefs, traditions and rituals.”

- Is characterized in many ways by its boundaries

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- A definition that came out of the Palliative Medicine Journal suggests that religion is more about systems, a social institution that is joined or organized by individuals who share the same beliefs, traditions, and rituals.
- It is characterized in many ways by its boundaries.
- Religion is often confined to an institution and defined by its traditions, rituals, and dogma.

Spirituality

“ May be used by those who wish to move beyond institutional religions, and can be defined as a personal search for meaning and purpose in life, which may or may not be related to religion”

- there is difficulty in defining its boundaries

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- Spirituality is much more about a broader personal search for meaning and purpose in life. This may or may not be related to religion.
- One may find meaning in life through their affiliated religion but that's not necessarily a tenant of spirituality.
- Spirituality is about finding a purpose or meaning for one's life and at the end-of-life it often becomes crucial to have a sense of purpose when faced with the dying process. People often seek to know that they have made a difference in the world, and that the world is different because they've been in it.
- Its very difficult to put boundaries or a box around spirituality.

Spirituality

- Embedded in everyday life
- Plays out in daily interactions and used as a daily support
- Seen in the manner in which physical care was provided
 - Kindness, empathy, compassion, respect, sensitivity, comfort, warm acceptance and gentleness, treating a stranger like family
 - Could involve partnership with residents, sharing decisions, offering choice and support, respect for the dignity uniqueness and nobility of human life

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- Spirituality is ingrained within us, we live our lives from a spiritual perspective. It plays out in our daily interactions and we use it as a daily support.
- It can be seen in the manner in which physical care has been provided at bedside: when front line workers do their care with kindness, empathy, compassion and respect they become almost like family to the residents. Residents often share on a much deeper level when they sense that there is that level of respect and empathy and true caring—that the staff aren't just there to get their job done.

Spirituality

- Seen as building trusting, intimate, meaningful healthcare giver-patient relationships
 - Therapeutic and healing
 - Should extend to family and friends
 - Could involve facilitating connections to community and social supports
 - Being present
 - Journeying with
 - Physical proximity, touch or simply just sitting with, holding the resident's hand
 - Listening to stories
 - Genuine desire to understand

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- The day to day interactions between Front Line Workers and residents creates an opportunity for a therapeutic and healing relationship to take place.
- When the resident can talk about what's been happening in their life, what's had meaning for them, this can bring some spiritual healing. Just talking about that to someone who really has a listening ear and a compassionate manner can bring comfort and peace.
- Front Line Workers are on a daily or weekly basis also in touch with the resident's family and friends. The Front Line Worker can extend that caring and compassionate attitude by listening to the friends and family's concerns as well. That is also a form of providing spiritual care.

Spirituality

- Studies have shown that palliative residents have similar needs and desires as they face the end of their lives.
- Sharing stories
 - Meaning of their lives
- Expressing Gratitude
 - For their lives, family members etc.
- Relationships
 - With self and others
 - With nature and music
 - With God, a higher being, something 'other'

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- Front Line Workers may be wondering how they can provide spiritual care to the residents, or what that would look like.
- Just listening to the residents and allowing them to share their stories provides them with an opportunity to reflect on the meaning of their lives. It gives them an opportunity to express gratitude for their own experiences in life and also towards their family members. It gives them a chance to reflect on their relationships, how they've developed relationships with others, within themselves, and with whatever it is they envision as bigger than themselves.
- It gives them a sense of being able to talk about their relationships with their higher being, whatever that means to that resident—God, the Other, the Holy, or the Creator, the Sacred—those kinds of images come to mind when you're talking about relationships and are things that can really enhance a person's sense of the sacred or the spiritual.
- Music is something that can be used at bedside with the residents. Also nature, like bird sounds and being outside can bring back a sense of connectedness to others and to creation.

Relationship with Self (for the resident)

To feel, and have affirmed, some sense of control over decisions and daily activities

- Sense of self-worth
- Values, wholeness and understanding
- Self-acceptance and peace

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- When we are looking at the idea about the relationship with the self, what does that mean?
- It means that we feel affirmed within ourselves that we still have some sense of control over our decisions and our daily activities. When people are in an institution they find it hard to feel a sense of independence or a sense of having any control. Schedules put in place by the facility mean you get up at a certain time, you bathe at a certain time, you eat at a certain time, you do recreation at a certain time, you go to bed at a certain time. This affects one's sense of self worth, it affects one's values, and one's sense of being as a whole person. It affects how one feel attempts to find peace in life.
- Having to adhere to someone else's schedule is difficult and affects the way you feel inside about yourself. It's important to be able to have someone such as a Front Line Worker to provide affirmation and a sense of value in other ways.

Relationships with Others

To experience meaningful relationships

- Companionship
- Ability to give and receive love
- Sense of being able to contribute to others

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- A sense of true relationship provides meaning in life, a sense of worth and value as a person.
- You're not JUST a staff member that comes in and just does your tasks, such as bathing, or dressing, but by spending those extra minutes it will provide a sense of companionship. When people know your name, when they smile at you, when they know what you take in your coffee, those kind of things are meaningful and builds that sense of relationship.

Relationship with Nature and Music

1. Being in touch with beauty of nature
2. Music can be uplifting and create inner peace

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- People can really relate to nature. Taking the residents outside to witness the beauty of nature, weather dependent, can really uplift them.
- Music can also be uplifting and create that sense of inner peace. They say music is the language of the soul. And through experience music has been shown to relax residents or open them up to share their stories.
- Relationships between the Front Line Worker and the resident can be enhanced by the use of these modalities and help the resident feel that they are cared for.

Relationship with God or a Higher Being

1. Feeling protected or safe
2. Feeling comforted and peaceful
3. Feeling less lonely or anxious

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- When facing the end of life one tends to reflect on their own understanding of what happens after physical death. Questions or conversations with residents may turn to their belief in God, a higher being or a sense of the sacred.
- In these conversations it is important to provide a sense of safety and protectedness or openness for the resident to ask questions or discuss ideas. An open willingness to explore with the resident their experience or belief system, without impressing the Front Line Worker's own beliefs upon them, provides comfort and peace for the resident and helps alleviate feelings of loneliness or anxiety.

Possible Interventions

RESIDENT

1. Encourage story telling – Life Review
2. Touch
3. Music or Snoezelen® Room
4. Reading – poetry, meditations, prayers
5. Pictures
6. Ritual
7. Conversation
8. Writing letters to family/friends
9. Recording feelings
10. Hospice Northwest Volunteers
11. Community Supports

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- Validate that a lot of these things such as story telling, touch, pictures are things they are already doing. However, some of these things will be new and not practiced before. Further support may be needed.

What is it that the Front Line Worker can actually do to provide that spiritual care at bedside?

1. We can encourage residents to tell their story, which from a spiritual perspective we would call a life review.
2. Touch, as appropriate, and as welcomed by the resident. You always have to be very careful when you're talking about touch with your resident that you know of their physical condition. You wouldn't want to be coming up and, for instance, shaking someone's hand that has arthritis. Touch is important, and of course Front Line Workers provide touch because of their tasks. Just be aware of how you provide that touch. That you're not doing it in a rushed rough manner, but you're doing it with sensitivity and compassion so there's a gentleness about it.
3. In some LTC facilities there is the ability to use the Snoezelen room and as we talked about already, music can be very important.

MORE NOTES ON NEXT PAGE

4. Some people really enjoy having poetry read to them, and meditation and prayer can be very helpful for some people as well.
5. Sharing stories about the pictures that are at bedside. Many times when you are giving care to a resident you will find lots of pictures around the room. And just to take the time, 2 or 3 minutes to ask what this picture is all about, or to ask them to tell you the story. This is a whole other way for residents to open up their lives with the Front Line Worker, and this really shows the resident that you are interested.
6. Providing rituals. They don't have to be complex. It could be as easy as doing the same thing with the resident when you go in every morning.
7. Entering into conversation.
8. Helping them to write letters to family or friends, and sometimes you don't even have to mail those letters. Sometimes if people are experiencing some angst about some past relationship that hasn't worked out the way they hoped, and they are facing the end of their life, they just need some way of getting that out. The resident knows its not going to get mailed or sent, but just to have that opportunity to say what they need to say to get it out can help.
9. It also ties into the next one with recording feelings. You can provide your resident with a small tape recorder if they'd like to speak messages to their loved ones.
- 10/11. We have Hospice Northwest Volunteers in our community who are trained on how to visit with people who are in need of palliative care. To connect them with the residents is also a really good resource along with other community supports that are out there.

Possible Interventions

SELF

1. Awareness of your own loss history
2. Awareness of your own belief system
3. Awareness of what brings you comfort
 - Nature
 - Exercise
 - Meditation
 - Music
 - Reading
 - Ritual
 - Friends
 - Counsellor

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- Self care is of utmost importance for the Front Line Worker in the palliative care setting.
- Working closely with residents touches our own lives. This is why it is important to understand and be aware of our own loss history and our own belief system.
- It is imperative in providing spiritual care that one's own beliefs do not become the focus of interactions with residents and unless we understand our own beliefs we may inadvertently be passing on thoughts that do not fit with the beliefs of the resident.
- It is important that we find ways to take care of our own emotions outside of the long term care facility. These (#3) are some possible ways we can provide self-care.

Possible Interventions

TEAM

1. Monthly support sessions
2. Sympathy Cards
3. Memorial Services
4. Debriefing as needed
5. Ritual (ie. Blessing of a Room)

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- Possible interventions for the team:
- We can institute a monthly support session for the team members. It gives staff an opportunity to talk about anything they've found particularly difficult with their residents. Such as maybe their resident has just been told something upsetting, or someone has moved away, and because of the level of care that the staff provides, they are affected by this news.
- Sympathy cards can be sent out whenever there is a death, and all the members of the team have the opportunity to sign the card. It gives them an opportunity to deal with their own sense of loss and grief.
- There are memorial services within the facility. Depending on where you work, it will be scheduled appropriately to meet the needs of your LTC home. It helps the staff to be able to attend a service, because a lot of the time you may be working when the resident's funeral service is held, and sometimes not being able to go may leave you with an unsettled feeling that may linger.

MORE NOTES ON NEXT PAGE

- Your Spiritual Care Associate can be instrumental in providing debriefings as needed. If there has been a particularly difficult death or your resident has been with you for an extended period of time and you feel like they have become just like family, you may need a debriefing when that person dies. It may help staff deal with their own grief.
- Sometimes, when there is a death, we may go into the room and have a very small service to cleanse the room, and say thank-you to the person who has left that room, and to also bless that room for the next person that will be coming in.



Possible Interventions

Family / Friends

1. Pamphlets (Examples)

- Food for Thought
- Someone You Love Is Dying
- Easing the Pain
- Miles to Go
- Information to Help You In Your Grief

3. Memory Books

4. Ritual

5. Stories

2. Books

- Final Gifts
- The Next Place
- Heaven Is Real
- Parting

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- Possible interventions that can be provided for family and friends are listed here:
 1. There are many helpful pamphlets. For instance, Food for Thought helps family members get a better understanding when the resident may not be eating the way they used to. The Front Line Worker can be the one that hands them out to family members. There are a lot of other good materials that are out there.
 2. There are books that can be read such as Final Gifts, Heaven is Real. Parting has a lot of good concrete, practical suggestions that one can use at bedside. For example, applying hand lotion to the resident to soothe the skin. This book comes highly recommended.
 3. For any young children that may be involved in the final stages of a resident's life, a memory book can be created. This activity is something that is specific to each LTC home, so check with Life Enrichment staff.
 4. Rituals are important, can bring closure, and are a way of saying farewell.
 5. Stories are also important and vital for meaning-making.

Conversation Aids

1. Who is the most important person in your life?
2. What is the most important event you remember?
3. What is your most memorable experience?
4. What are you grateful for, and why?
5. Who or what makes you feel happy or at peace. Why?
6. How do you want to be remembered?
7. How do you express emotions like love, fear, anger?
8. Where or when do you experience peace in your life? (nature/family, etc.)
9. What brings you comfort when you are in pain or afraid?
10. From what source do you draw strength in order to cope?

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Recommend doing some role playing to illustrate what these conversations would look like.

- Sometimes Front Line Workers are unsure as to how to enter into the deeper conversations (instead of just talking about the weather or what's for breakfast), this slide just relates to some suggested conversation aids that can help people get a littler deeper with their conversation at bedside.

Questions for further thought...

1. What is my scope of practice in providing spiritual care?
2. How do I know when to contact a spiritual care specialist?
3. How, where and when do I document spiritual care activities?
4. Other?

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- The Front Line Worker may ask what is my scope of practice in providing spiritual care? For many people trained in care giving, just having three or four extra minutes to sit at the bedside and listen to the resident's story is enough.
- There may be a need to contact your spiritual care specialist and knowing when to do that is another question that you might want to think about for your own particular LTC home – when it would be advantageous that someone trained in spiritual care be called—when that referral can be made.
- An example of an indicator when a referral could be made: When you come in in the morning, and your resident starts asking, or saying things like, “I haven't been to church in 10 years. I was raised Roman Catholic and my religion tells me that if I don't go to church that when I die, I am going to go to hell.” A comment, or conversation like this would be an indication that a resident is seeking spiritual guidance. It's important to be sensitive to other people's belief systems and not try to fix or convert people.
- Document when a person is talking about a difficult relationship or needing healing in relation to some specific aspect. Charting a comment as to why you think that a resident needs a visit would be helpful for the spiritual care associate.

References

- Edwards, et al., *Palliative Medicine*, *The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: a meta-study of qualitative research*, <http://pmj.sagepub.com/>, July 2010

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