

# IDENTIFYING INDIVIDUAL & FAMILY WISHES RELATED TO CULTURE AND FAITH ACROSS A LIFESPAN

PRESENTERS:

**ARLENE MARGOLESE**, *Manager, Faith & Cultural Services / Volunteer Services*

**REENA**

- Has been with Reena for 22 years
- Married and proud mother of 4, grandmother of 9
- Educational background includes social work and gerontology
- Chair of ETA Vaughan (Empowerment Through Achievement), a women's shelter in the City of Vaughan
- Past Board member of CCAC of York Region, Gallanough Library, Tel-Aide (Jewish Distress Line)

**JOHN GUIDO**, *Regional Coordinator*

**L'ARCHE DAYBREAK**

- Regional Coordinator for all nine L'Arche communities in Ontario with L'Arche Daybreak being one of those communities



**CAROL CHUNG**, *Coordinator of Parish Outreach & Volunteers*

### **MARY CENTRE**

- Has recruited volunteers and has connected individuals supported by Mary Centre with the faith community of their choice for the last 13 years
- A Developmental Services Worker graduate
- Has worked front-line in this field for quite a few years
- Has a very strong Catholic family background, and has a nephew who is a priest, who is a constant advisor/resource to her in her Faith Outreach work

**DR.NEIL CUDNEY**, *Director Organizational Culture & Pastoral Ministries*

### **CHRISTIAN HORIZONS**

- Served with Christian Horizons in various capacities since 1987
- Worked with a variety of social service organizations prior to joining Christian Horizons
- In his role as Director of Organizational Culture and Spiritual Life, has traveled throughout the world speaking, teaching, lecturing and partnering with NGO organizations, academic institutions, faith and culture groups and families.
- Speaks on topics such as Understanding and Guiding Organizational and Team Cultures, Implementing Vision/Mission Statements, Conflict Resolution, Grief and Loss, and Theology of Disability
- Education: B.A. Social Work & Sociology, Masters of Theology, Doctorate in Organizational Culture & Business Ethics





- Supports faith, culture and accessibility choices for people with developmental disabilities
- A sign post for developmental services in Ontario, bringing families, government and community faith & cultural leaders together
- Objective is to raise public awareness of the need for appropriate supports including spiritual & cultural respect & participation

# AGENDA:

- Understanding the Importance of Sensitivity with Respect to the Faith and Cultural Beliefs of Others
- Understanding the Importance of Participation in Faith & Cultural Life Cycle Events
- Understanding the Importance of Faith and Culture in the Process of Dying
- Understand the Importance of Faith and Culture in the Grief / Death Experience



# INTRODUCTORY STATEMENT

By: Arlene Margolese

- We're not here to tell you what the traditional, cultural or religious beliefs are related to Christianity, Judaism, Islam, Hinduism or Buddhism.
- We ARE here to tell you that it is important – even IMPERATIVE – that you put your OWN beliefs and values aside and help the people you are meant to support, either as a family member or as a caregiver, according to their and their families' spiritual traditions, values and cultures.
- This is another great opportunity for you to continue to do your best work by dignifying and honouring the traditions of the people you support who depend on you and look up to you for guidance by honouring THEIR faith and cultural value base.



# Understanding the Importance of Sensitivity with Respect to The Faith and Cultural Beliefs of Others

Arlene Margolese



# FAITH & CULTURAL SENSITIVITY

- Most Cultures Have Common Spiritual
- or Religious Belief, Values, Customs, language, laws and arts typical of their particular communities.
- What we eat, wear, learn, where we live or work are all part of our culture.
- Sometimes we find people from other faiths and cultures strange and because we don't understand their religious values or traditions, we may find their behaviours funny and can't help laughing at them.
- At one time or another, we were all strangers ourselves.
- Be sensitive to others. Think before you speak – or act.



# FAITH & CULTURAL SENSITIVITY

- A very wise man once said:

*Ultimately, whoever hates,*

*hates his brother*

*And when he hates*

*his brother,*

*he hates himself.*



# FAITH & CULTURAL SENSITIVITY

- ❖ Be Sensitive to Others – Think Before you Act

- ❖ DO NOT Speak Your Native Language in Front of Others who don't Understand

If you speak a language other than English at work, think how you would feel if others are talking a foreign language in front of you. That's how your fellow staff members and the people you support feel when they can't understand what you are saying when talking to your friends in your native tongue.

- ❖ Be Friendly and “Inclusive”

We know how important “inclusion” is for our folks and we constantly promote it, not always realizing that we, ourselves, are “excluding” other people by not being friendly towards them or speaking our language in front of them or just eating our lunch with our own group of people and “excluding” them.

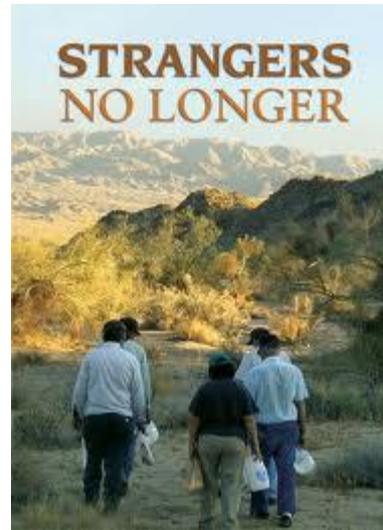


- FAITH & CULTURAL SENSITIVITY
- Internalize the following principles:
  - All people are valuable and not one of us is better than anyone else.
  - No one is perfect - we all make mistakes.
  - In some ways, we are just like everyone else on earth, sharing the same feelings.
  - All people, no matter who they are, where they come from, what they believe, how they act, or what they look like deserve respect and compassion.
- Each of us is responsible for our own actions and we need to treat other people the way we want others to treat us

# FAITH & CULTURAL SENSITIVITY

Live by the **“GOLDEN RULE”**

**“DO UNTO OTHERS AS YOU WOULD HAVE  
OTHERS DO UNTO YOU”**



# The Golden Rule Across the World's Religions -

## Thirteen Sacred Texts

### **Bahá'í Faith** / *Bahá'u'lláh*, **Gleanings**

Lay not on any soul a load that you would not wish to be laid upon you, and desire not for anyone the things you would not desire for yourself.

### **Buddhism** / *The Buddha*, **Udana-Varga 5.18**

Treat not others in ways that you yourself would find hurtful.

### **Christianity** / *Jesus*, **Matthew 7:12**

In everything, do to others as you would have them do to you; for this is the law and the prophets.

## **Confucianism** / *Confucius, Analects 15.23*

One word which sums up the basis of all good conduct...loving-kindness. Do not do to others what you do not want done to yourself.

## **Hinduism** / *Mahabharata 5:1517*

This is the sum of duty: do not do to others what would cause pain if done to you.

## **Islam** / *The Prophet Muhammad, Hadith*

Not one of you truly believes until you wish for others what you wish for yourself.

**Jainism** / *Mahavira*, **Sutrakritanga 1.11.33**

One should treat all creatures in the world as one would like to be treated.

**Judaism** / *Hillel*, **Talmud, Shabbath 31a**

What is hateful to you, do not do to your neighbour. This is the whole Torah; all the rest is commentary. Go and learn it.

**Native Spirituality** / *Chief Dan George*

We are as much alive as we keep the earth alive.

## **Sikhism** / **Guru Granth Sahib, p.1299**

I am a stranger to no one; and no one is a stranger to me.  
Indeed, I am a friend to all.

## **Taoism** / **Lao Tzu, T'ai Shang Kan Ying P'ien, 213-218**

Regard your neighbour's gain as your own gain and your neighbour's loss as your own loss.

## **Unitarianism** / **Unitarian principle**

We affirm and promote respect for the interdependent web of all existence of which we are a part.

## **Zoroastrianism** / **Shayast-na-Shayast 13.29**

Do not do unto others whatever is injurious to yourself.

# FAITH & CULTURAL SENSITIVITY

## CLAY DISKS

A man was exploring caves by the seashore. In one of the caves, he found a canvas bag with a bunch of hardened clay disks. It was like someone had rolled clay disks and left them out in the sun to bake.

They didn't look like much, but they intrigued the man, so he took the bag out of the cave with him. As he strolled along the beach, he would throw the clay disks one at a time, out into the ocean, as far as he could. He thought little about it, until he dropped one of the clay disks and it cracked open on a rock.

Inside was a beautiful, precious stone! Excited, the man started breaking open the remaining clay disks. Each contained a similar treasure. He found thousands of dollars' worth of jewels in the 20 or so clay disks he had left. Then it struck him. He had been on the beach a long time. He had thrown maybe 50 or 60 of the clay disks with their hidden treasure into the ocean waves. Instead of thousands of dollars in treasure, he could have taken home tens of thousands, but he had just thrown it away!

It's like that with people. We look at someone, maybe even ourselves, and we see the external clay vessel. It doesn't look like much from the outside. It isn't always beautiful or sparkling, so we discount it. We see that person as less important than someone more beautiful or stylish

or well known or wealthy. But we haven't taken the time to find the treasure hidden inside that person.

There is a treasure in each and every one of us. If we take the time to get to know that person, then the clay begins to peel away and the brilliant gem begins to shine forth.

May we not come to the end of our lives and find out that we have thrown away a fortune in friendships because the gems were hidden in bits of clay.



# Identifying Individual and Family Wishes Related to Culture and Faith Across a Lifespan

Carol Chung (Mary Centre) and John Guido (L'Arche)



# As children, we are shaped by the faith and culture of our family

The rituals, traditions, foods, and language of our families and communities shape our values and give our lives meaning.

There are formal and informal rites of initiation in families and communities.



# Story of Alia



Alia was a beautiful young woman who touched many people's lives with the depth of her inner peace and her radiance when she danced. To know her was also to know her large Pakistani-Canadian family who kept Alia at the center of their family celebrations and religious observations.

# What Matters Most

The bulk of (my) work has really focused on creating inclusive schools and inclusive work places, but when you spend time talking with young people (with disabilities), those conversations quickly turn to things that matter like families, like friendships, like faith.”

-Summer Institute on Theology and Disability (2012)



**Erik Carter**

Associate Professor of Special Education  
Vanderbilt University

# Does Faith really matter to people with intellectual disabilities?

- *My faith is somewhat or very important to me....*
  - **87% people with disabilities**
  - **84% people without disabilities**

**NOD/Harris Interactive (2000)**

# How do we know this?

## Listen to them and to their families.

"Faith and Flourishing Project" Erik Carter

### Weekly/yearly:

- 87% pray at mealtime
- 66% pray at bedtime
- 72% read/listen to scripture
- 67% listen to religious music
- 70% pray with family
- 88% celebrate religious traditions

### Weekly/yearly:

- Worship services 87%
- Religious education 62%
- Social events 60%
- Youth groups 36%
- Prayer meetings 43%
- Music team/choir 16%
- Rites of passage 19%

# Individuals and their families often do not receive the support that they need.

## Issue

- Spiritual or religious activities are seldom recognized as an important aspect of life or included in individual planning for people with intellectual and/or developmental disabilities. Some individuals may need assistance to participate in their chosen spiritual activities or faith communities.
- Individuals with intellectual and/or developmental disabilities and their families also face a mixed response from faith-based communities, even though many faith communities have established model programs and strategies for including people with disabilities. Spiritual resources and faith communities are an underused resource in the community for people to exercise choice, develop relationships and social networks, demonstrate respect for cultural and family backgrounds, and serve others.

**Joint Position Statement of AAIDD and The Arc (2010)**

# Rites of Passage from Childhood to Adulthood



# Adulthood

Adhering to the wishes of individuals and families in the traditions, rituals and rhythms of their faith and culture brings constancy, comfort, meaning, relationships, support and belonging amidst all the changes of their lives.

# Supporting Individuals

- It is critical that direct support professionals see our roles as facilitators in the faith and cultural life of the people we support.
- Person-directed planning and Individual Support Plans should include individuals' and their families' choices in faith and cultural traditions and practices and the supports that they need to live them well.

# John's Story

When John moved out of his parents' home, his family requested that he be involved as an altar-server in his new parish. Over 10 years later, John still serves at mass every Sunday and is very proud of carrying the cross in the procession.



# Some Practical Ideas of Support

- a) Learn about the faith and cultural calendar of holy days and festivals and help the individual choose what to celebrate in their home, family and/or community and who can support them.



# Some Practical Ideas of Support

- b) Work with the family and/or volunteers to support the individual to not only get to their faith or cultural community but to participate, build relationships and share their gifts.



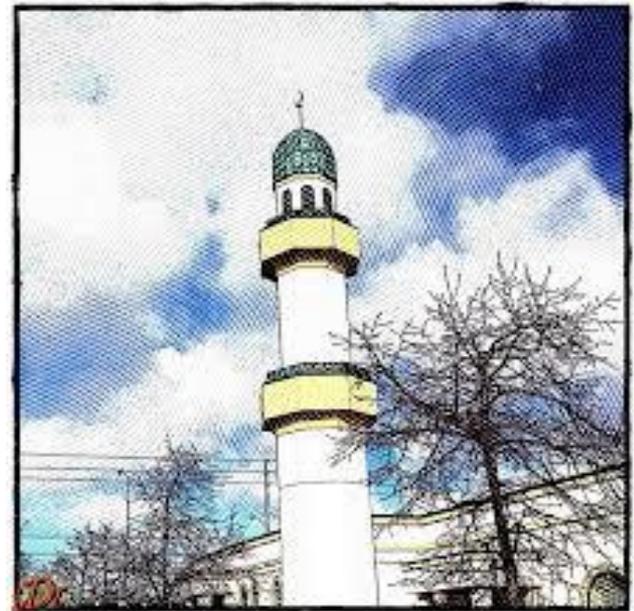
# Some Practical Ideas of Support

- c) Find ways to value and highlight each person's culture and faith within the home –e.g. a cultural meal: inviting a leader from that cultural or faith group to participate in an evening or event with the person.



# Nissim's Story

Soon after Nissim arrived at Mary Centre a connection was made with her mosque as it was very important for her. She attends the mosque for prayers 2 days a week, and this is a staple in her life, especially as she meets her elderly mom at the mosque.



# What is my role of support?

- Even though you may not agree with, or be a part of the faith or culture group of the individual you support, as direct support professionals, we must learn to not only put aside our way and our beliefs, but also to learn how to conduct ourselves so as not to offend or lessen the experience and expression of the individual and their community. We may actually discover some of the gifts of other communities that can enrich our lives.

*“When God is imaged through the lens of disability it becomes clear that God’s love and grace are not contingent on physical appearance or ability or on sensory or mental acuteness, but only on the capacity to receive God’s love and grace.”*

-from a paper written by Jane S. Deland, in the *Journal of Religion, Disability & Health*, Vol. 3, Num. 2 1999.



# Gladys' Story

- Gladys was raised in a very spiritual Christian home, and her faith in Jesus remained deeply rooted in her throughout her life. When Gladys came to live in one of Mary Centre's residences after her parents died, as direct support professionals, we facilitated her attendance to her church by enlisting the help of a volunteer.
- The members in her faith community continued to reach out and include her in every activity that occurred there.

# Palliative Care

- Gladys became very ill with cancer, and asked to have palliative care in her home. This was a challenge for her support staff, but they honoured her wishes.
- Gladys died in her home with support staff & family members around her, but her love for the Lord sustained and lifted her up to the end, and she had a peaceful death.

# Understanding the Importance of Faith and Culture in the Process of Dying

Arlene Margolese



# THE PROCESS OF DYING

## DEATH:

- ❖ Part of the Cycle of Life
- ❖ A Human Experience all Must Face
- ❖ There is Wisdom in Traditions & Rituals of Religions & Cultures
- ❖ One of the Most Difficult Things to Face in our lifetimes, but can be most rewarding
- ❖ The presence of loved ones around the person who is dying is usually more important than what is done or said. Knowing that family members are there and supporting each other helps lessen the stress on the individual. If you feel comfortable doing so, hold the person's hand and recount pleasant memories. Even if they are unconscious, there is much research showing they often hear what is said and we want their last memories to be pleasant ones.



# THE PROCESS OF DYING

- ❖ Most Religions have Process for Confession and asking Forgiveness
- ❖ Sometimes need to Step Aside – Leave Room for Faith
- ❖ Be Sensitive to Religious Values / Traditions of Person who is Dying
  - It's hard **not** to impose your own strong religious beliefs on the individual and even the family but you must remember that for those of us who are staff, our work as staff is to become an honouring presence, honouring the faith and beliefs of the person who is dying. That doesn't mean that you are rejecting your own beliefs. It is a difficult message for many of us, but it is imperative that at this time, we must suspend our own beliefs and concentrate our efforts on the person we are supporting.
- ❖ If you can be sensitive and understanding of the faith and culture of that individual, you will have done your job well.



# THE PROCESS OF DYING

## SHE'S GONE!

I am standing upon the seashore.

A ship at my side spreads her white sails to the morning breeze,  
and starts for the blue ocean.

She is an object of beauty and strength and I stand and watch her until, at length, she is only a ribbon of white cloud, just where the sea and sky come to mingle with each other.

The someone at my side says  
*"There – she's gone!"* Gone where?

Gone from my sight, this is all.

She is just as large in mast and hull and spar as she was when she left my side – and just as able to bear her load of living freight to the place of her destination.

Her diminished size is in me – not in her,  
and just at the moment when someone at my side says:  
*"She's gone"*, there are other voices ready to take up the glad shout  
*"there she comes!"*  
....and that is dying.

By: Col. David Marcus,  
The Haganah Forces, Israeli Army

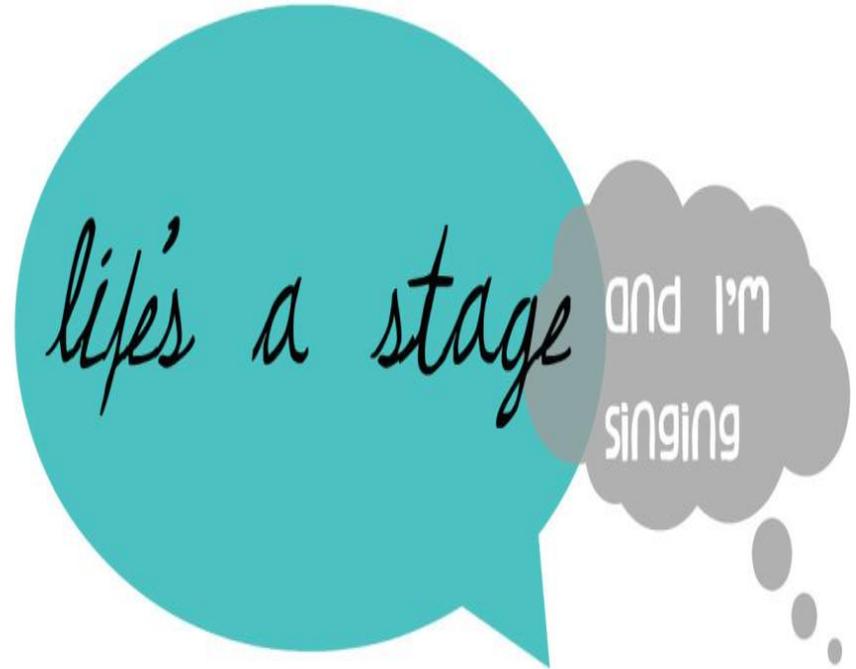


# Understanding the Importance of Faith and Culture in the grief/death experience

Dr. Neil Cudney



# Imagineering



- As the Actor
- As Cast Member
- As the Audience

*One of the times that we tend to find ourselves uncritical and most connected to our own faith and culture is in the 'valley of the shadow of death'. Our identity, our meaning, our belonging is both challenged and confirmed in these moments. The reality is however, that many that find themselves in supported systems find their ability to connect with their faith and culture communities and life cycles to be greatly compromised. While our conversation here is mainly focused around grief that is initiated by a death loss, it certainly is not the only grief experience that generates deep feels of loss, disequilibrium and the need to connect to faith and culture.*





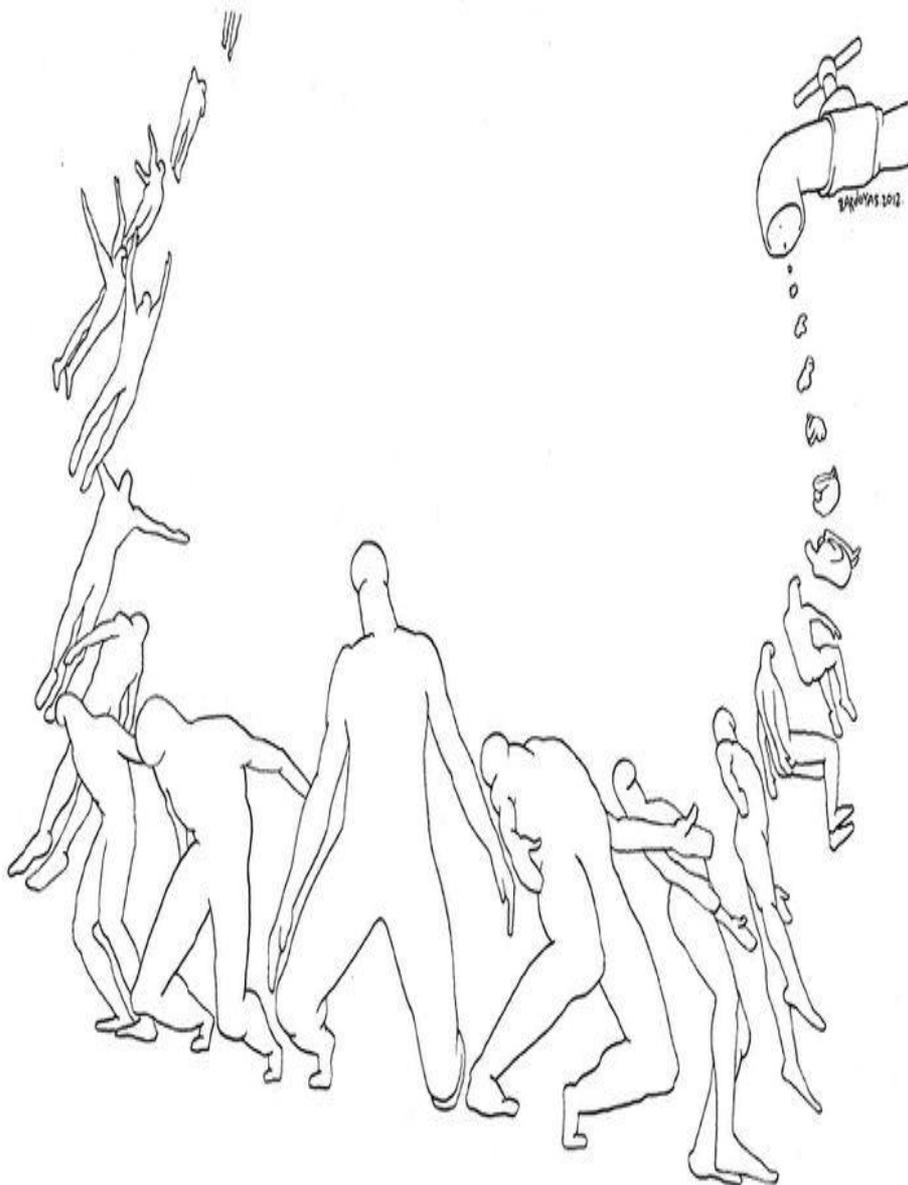
*Although death is a significant source of the experience of grief and loss, they are not the only ones. Secondary grief and loss experiences can have as a considerable and lasting effect.*



## ***Key myths:***

- 1. People with Developmental Disabilities do not grieve*
- 2. People with Developmental Disabilities are not aware of their grief*
- 3. It is better for those with Developmental Disabilities to not be a part of the rituals around death*
- 4. People with Developmental Disabilities are assumed to be like children, who is it assumed do not mourn*

*Source David Kennedy – grief therapist  
Peterborough Hospice*



*Faith and Culture play a vital role in people's life cycle. The traditions, rituals and rhythms bring constancy, comfort, relationships, meaning, belonging and support. It is important for us to note that our own role with the person supported may be transitory, while families, faith and culture communities tend to remain constant. As direct support professionals it is critical that we see our roles as facilitators into the family, faith and cultural life cycles of the people we support. How we embed and honour those expressions in a person's life cycle while being supported by an agency is a critical and primary responsibility. They can be too easily lost in the demands and pressure of agency/staff care.*