



# Caregiver's CORNER

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Caregiver's Corner

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# Caregiver's Corner: Spirituality & HD

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## A Disclaimer & Clarification

This presentation represents my views and understanding about spirituality. In part, it has been shaped by my personal experiences and readings on the topic of spirituality and life. While I use some quotations and stories of others, they have still been filtered through my perspective, and I have chosen them as opposed to others.

There are numerous approaches and interpretations to spirituality. What helps you in your spiritual journey is the right path for you. It may change over time, or it may not. I encourage you to honor it and pursue whatever is effective for you in the present moment.



## Another Definition

4. Our spirituality is living our deepest reality, our deepest truth, our deepest value, into the world. Our spirituality is the unfolding of who we are, and our richest integrity from the deepest places of our hearts into the ordinariness of our living. The first step in this process is accepting ourselves in our own awful beauty and dignity. . . . It is something we must always do, something we are never finished with, for our lives are constantly unfolding, always a work in progress. Genuine spirituality requires that we be ready to change, to let go of this and embrace that, to be ready when the call comes to return to the journey, the motion, be it outward or inward, be it to adventure or to return home.

~ The Rev. Kenneth W. Collier

## A Word about Origins & History

- The word spirituality comes from the Latin word ***spiritus***, which means breath, and thus the word refers to that which gives us life.
- It's use in the English language is a rather recent phenomenon...



## Spirituality and Religion

**Spirituality does not have to be associated with an organized belief system.**

“There is no need for temples; no need for complicated philosophy. Our own brain, our own heart is our temple; the philosophy is kindness.”

~ The Dalai Lama

“The spiritual journey is individual, highly personal. It can't be organized or regulated. It isn't true that everyone should follow one path. Listen to your own truth.”

~ Ram Dass



## Spirituality and Religion

- I believe it is very rare to have a spiritual experience in a place of worship like a church, mosque, temple, or synagogue. Yes, it can happen, but not often.
- Organized religion provides a sense of community which can aid an individual in discernment and understanding of spiritual experiences.
- Religion can also encourage the pursuit of one's spirituality and perhaps help you define its meaning and purpose in your life.
- Again, religion can be helpful, but it is not a necessary component of spirituality.



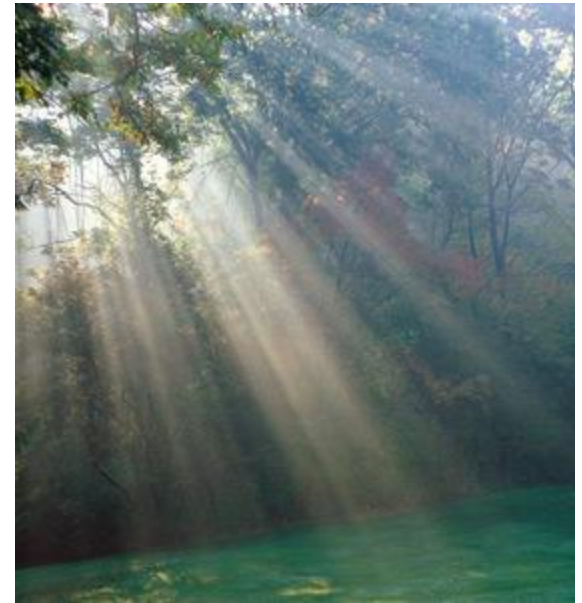
# How Can Spirituality Help?

“Spiritual practices tend to improve coping skills and social support, foster feelings of optimism and hope, promote healthy behavior, reduce feelings of depression and anxiety, and encourage a sense of relaxation.”

<http://www.umm.edu/altmed/articles/spirituality-000360.htm>

## **Spirituality has been linked to:**

- Better health
- Less hypertension
- Less stress, even during difficult times
- More positive feelings
- Less depression
- Greater psychological well-being
- Superior ability to handle stress



## Other Benefits of Spirituality

In addition to health benefits, having a strong sense of spirituality can also help in the following ways:

- Spirituality can give you a higher *quality of life* in general
- Spirituality can give you a greater *sense of peace, purpose, and belonging*
- Spirituality can give you a higher degree of *hope and optimism*
- Spirituality can give you a sense of *personal empowerment* to help others
- Spirituality can give you a more determined *commitment to ethics and morality*

## Spirituality & Grief



- Spirituality helps us to define meaning in our lives, and as such, it can help sustain us during grief.
- Often, a loving, listening ear can sustain and help us work through our grief over the loss of loved ones.
- Being heard in our grief can cut through the sense of aloneness and despair.
- Appropriate readings can also serve as a strength and support during periods of grief, helping put the loss in its proper place and perspective.

## The Role of Tradition and Rituals

- Helps individuals to mark significant events and realizations
- Gives one a sense of familiarity and predictability
- Can offer comfort and security, and ease distress
- Can be a source of inner strength
- Leads one to a deeper level to a sense of belonging or fitting in



## How Can the Healthcare Team Help?

- Listening to fears, hopes, pain, and dreams of the person with HD, as well as those of the caregiver
- Taking a spiritual history
- Being attentive to all dimensions of patients and their families: body, mind, and spirit
- Incorporating spiritual practices as appropriate
- Involving chaplains as members of the interdisciplinary health care team

Adapted from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1305900/>

# Exercise: Relaxation Response Technique

1. **Repeat a word, sound, phrase, prayer or activity that has meaning for you** (e.g., “one,” “peace,” “Om,” “Sh'ma Yisroel,” “The Lord is my shepherd,” “Insha'allah,” “Hail Mary, full of grace,” jogging, breathing techniques, knitting).
2. **Passively disregard intrusive thoughts that come to mind and return to the repetitive focus.**

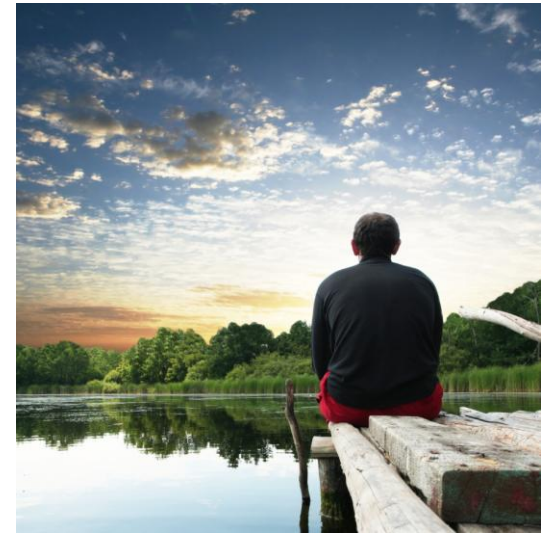
## Physiologic effects of the relaxation response

- Decreased metabolism
- Decreased rate of breathing
- Decreased blood pressure
- Decreased muscle tension
- Decreased heart rate
- Increased slow brain waves

Information from Benson H. Timeless healing: the power and biology of belief. New York: Scribner, 1996.

# Getting Started with Spirituality

- **First, identify what gives you a sense of inner peace, comfort, strength, love and connection**
  - You can do this by taking a *spirituality assessment*
- Try out a given discipline or practice, see if it fits for you.
  - If it doesn't, move on and experience other approaches toward spirituality.
- You can also read some of the various books on spirituality, regardless of type of spirituality.
- Check with your spiritual leader should you belong to an organized group.



# The FICA Spirituality Assessment

## **F – Faith and Belief**

Do I have a spiritual belief that helps me cope with stress? With illness? What gives my life meaning?

## **I – Importance**

Is this belief important to me? Does it influence how I think about my health and illness? Does it influence my healthcare decisions?

## **C – Community**

Do I belong to a spiritual community (church, temple, mosque or other group)? Am I happy there? Do I need to do more with the community? Do I need to search for another community? If I don't have a community, would it help me if I found one?

## **A – Address in Care**

What should be my action plan? What changes do I need to make? Are there spiritual practices I want to develop? Would it help for me to see a chaplain, spiritual director, or pastoral counselor?

From: <http://www.gwumc.edu/gwish/clinical/selfassess.cfm>



# Spiritual Orientation Inventory

- ❖ Transcendent Dimension
- ❖ Meaning & Purpose in Life
- ❖ Mission in Life
- ❖ Sacredness of Life
- ❖ Material Values
- ❖ Altruism
- ❖ Idealism
- ❖ Awareness of the Tragic
- ❖ Fruits of Spirituality

<http://cla.calpoly.edu/~bfiorito/soi.html>

## Improving Spiritual Health

- Requires a certain amount of discipline
- Practice, practice, practice, and did I say practice?
- Often involves a time for reflection, meditation, or yoga.
- May often include doing good deeds for others and/or acting on behalf of social justice issues.
- May also include a practice of gratitude





## Practices to Increase Attention

- meditation, prayer or contemplation
- walking a labyrinth
- use of a spiritual director or therapist
- the practice of gratitude
- the practice of giving
- journaling

# Physical Practices to Increase Attention

- Hiking
- Jogging/ running
- Bicycle riding
- Archery
- Tea ceremonies
- Martial arts
- Dancing
- Yoga



## Other spiritual practices: *forms of disciplining the self*

- The practice of compassion, which in turn leads to...
- Working for social justice issues
- Voluntary poverty
- Living in a hermitage – alone to commune with nature and self



## Spiritual Self-Care

Set aside time every day to do the things that help you spiritually.

- Community service or volunteer work
- Meditation/Quiet thinking
- Nature walks
- Sports
- Yoga
- Attending religious services/praying



*It is no different than being a star athlete or musician. It takes work and **practice, practice, practice...***

# Spirituality Resources

- Go online and search for “spirituality” or “non-religious spirituality”
- Spiritual Inventories
  - <http://www.gwumc.edu/gwish/clinical/selfassess.cfm>
  - <http://cla.calpoly.edu/~bfiorito/soi.html>
- The George Washington Institute of Spirituality and Health:  
<http://www.gwumc.edu/gwish/aboutus/index.cfm>
- Beliefnet: [www.beliefnet.com](http://www.beliefnet.com) is an independent spiritual website that is not affiliated with any spiritual organization or movement
- Spirituality & Health: <http://www.spiritualityhealth.com/>, the website for Spirituality & Health magazine, contains online resources, articles, quizzes, and other information.
- Numerous houses of worship from a variety of faith traditions may be of help.

## Some of the books and authors which I have personally found helpful:

Brussat, Frederic and Mary Ann (1996). Spiritual Literacy: Reading the Sacred in Everyday Life. New York, NY: Scribner.

Hanh, Thich Nhat (1975). The Miracle of Mindfulness. Boston, MA: Beacon Press. This book in addition to a number of others by Thich Nhat Hanh.

Janis, Sharon (2000). Spirituality for Dummies. Foster City, CA: IDG Books Worldwide, Inc.

Rolheiser, Ronald (1999). The Holy Longing: the Search for Christian Spirituality. New York, NY: Doubleday.

Collected works of the Sufi poet Rumi.

Many of the poems by Mary Oliver as well as others, like e e cummings, and Longfellow. Additionally, the writings of Thoreau often are inspirational to me.