





# PERSON CENTERED CARE TOOLKIT THE 8 DIMENSIONS OF LIFE

2015 CAHF QUALITY IMPROVEMENT SUBCOMMITTEE

# **CONTENT**

Introduction	3
Domains of Issues Associated with Illness and Bereavement	4
Disease Management	5
Physical	6
Psychological	
Social	12
Spiritual	14
Practical Concerns	16
End of Life Care / Death Management	18
Loss / Grief	20

# PATIENT CENTERED CARE COORDINATION INTRODUCTION

This toolkit was created in 2015 by the California Association of Health Facilities' (CAHF) Quality Improvement Government Relations Committee. The theme is the "patient" being the central force in planning their care. It includes multiple dimensions to be considered with links to more information.

This toolkit was developed to assist you to assess and care for each individual as they desire to be cared for. Once you have had time to review this toolkit, you may realize that your facility has to make some changes. Your evolution to culture change can begin with multiple toolkits found on the CAHF Member Website under the Clinical/Quality page (click here to visit the page.)

In addition to the information in this toolkit, we encourage you to explore a "Guide to Implementing Person-Centered Practice in Your Health Service" and "Coordinating Care for Adults with Complex Care Needs in the Patient Centered Medical Home." We hope that you will find this toolkit of value and will be able to utilize these resources in a manner that will improve your resident's quality of life.



#### Domains of Issues Associated with Illness and Bereavement

Patients and families face multiple issues during illness and bereavement that cause suffering.

These issues can be grouped into 8 domains.

#### **PSYCHOLOGICAL** DISEASE **PHYSICAL** MANAGEMENT Personality, strengths, behaviour, Pain and other symptoms \* motivation Primary diagnosis, prognosis, Level of consciousness, cognition Depression, anxiety evidence Function, safety, aids: Emotions (e.g., anger, distress, Secondary diagnoses (e.g., · Motor (e.g., mobility, hopelessness, loneliness) dementia, psychiatric swallowing, excretion) diagnoses, substance use, Fears (e.g., abandonment, burden, · Senses (e.g., hearing, sight, death) smell, taste, touch) Co-morbidities (e.g., delirium, · Physiologic (e.g., breathing, Control, dignity, independence seizures, organ failure) circulation) Conflict, guilt, stress, coping Adverse events (e.g., side Sexual responses effects, toxicity) Fluids nutrition Self-image, self-esteem Allergies Wounds Habits (e.g., alcohol, smoking) Loss, GRIEF SOCIAL Loss Cultural values, beliefs, practices Grief (e.g., acute, chronic, anticipatory) PATIENT AND Relationships, roles with family, friends, community Bereavement planning FAMILY Isolation, abandonment, reconciliation Mourning **Characteristics** Safe, comforting environment Demographics (e.g., age, gender, race, contact Privacy, intimacy END OF LIFE CARE/ Routines, rituals, recreation, vocation information) DEATH Financial resources, expenses Culture (e.g., ethnicity, language, cuisine) MANAGEMENT Legal (e.g., powers of attorney for business, for healthcare, advance Life closure (e.g., completing Personal values, beliefs, directives, last will/testament, business, closing relationships, practices, strengths beneficiaries) saying goodbye) Family caregiver protection Developmental state, Gift giving (e.g., things, money, education, literacy Guardianship, custody issues organs, thoughts) Disabilities Legacy creation Preparation for expected death Anticipation and management of SPIRITUAL physiological changes in the last PRACTICAL hours of life Meaning, value Activities of daily living, i.e., for Rites, rituals personal care = ambulation, bathing, toileting, feeding, dressing and transfers; for Existential, transcendental Pronouncement, certification Values, beliefs, practices, affiliations household activities = cooking. Perideath care of family, Spiritual advisors, rites, rituals cleaning, laundry, banking, handling of the body shopping. Symbols, icons Funerals, memorial services, Dependents, pets celebrations Telephone access, transportation

 $\textbf{Cardio-respiratory:} \ breathlessness, cough, edema, hiccups, apnea, agonal \ breathing \ patterns$ 

Gastrointestinal: nausea, vomiting, constipation, obstipation, bowel obstruction, diarrhea, bloating, dysphagia, dyspepsia Oral conditions: dry mouth, mucositis

Skin conditions: dry skin, nodules, pruritus, rashes

General: agitation, anorexia, cachexia, fatigue, weakness, bleeding, drowsiness, effusions (pleural, peritoneal), fever/chills, incontinence, insomnia, lymphoedema, myoclonus, odor, prolapse, sweats, syncope, vertigo

Adapted from, Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P. A Model to Guide Hospice Palliative Care. Ottawa, ON: Canadian Hospice Palliative Care Association, 2002

<sup>\*</sup> Other common symptoms include, but are not limited to:

#### DISEASE MANAGEMENT

"THE PHYSICIAN SHOULD NOT TREAT THE DISEASE, BUT THE PATIENT WHO IS SUFFERING FROM IT"

MAI MAIMONIDES

#### PRIMARY DIAGNOSIS, PROGNOSIS

The <u>Principal/Primary Diagnosis</u> is the condition established after study to be chiefly responsible for occasioning the admission of the patient to the hospital for care.

- Prognosis: A forecasting of the probable course and outcome of a disease, especially of the chances of recovery.
- Secondary Diagnoses: "All conditions that coexist at the time of admission, that develop subsequently, or that
  affect the treatment received and/or the length of stay."
- <u>Comorbidities</u>: The simultaneous presence of two chronic diseases or conditions by a patient.
- Adverse Events: (side effects, toxicity) or an adverse event is any undesirable experience associated with the use of a medical product in a patient.
- Allergies: A damaging immune response by the body to a substance, especially pollen, fur, a particular food, or dust, to which it has become hypersensitive.

#### **RESOURCES**

Decision Support Tools | Change in Condition File Cards and Care Paths:

- Acute Change in Condition File Cards (<u>Click Here</u>)
- Care Transitions Work Plan (Click Here)
- Chronic Obstructive Pulmonary Disease Resources (Click Here)
- The Congestive Heart Failure (CHF) Clinical Pathways Guideline (Click Here)
- INTERACT transfer forms, care paths, and other tools: <a href="https://interact2.net/tools.html">https://interact2.net/tools.html</a>

#### **PHYSICAL**

# "THE GREATEST EVIL IS PHYSICAL PAIN" SAINT AUGUSTINE

# "WE MUST NEVER NEGLECT THE PATIENT'S OWN USE OF HIS SYMPTOMS" ALFRED ADLER

#### **PAIN AND OTHER SYMPTOMS** (Cardio-respiratory, GI, Skin, fever, chills etc.)

- Pain Management (also called pain medicine or Algiatry): A branch of medicine employing an interdisciplinary approach for easing the suffering and improving the quality of life of those living with pain. The typical pain management team includes medical practitioners, pharmacists, clinical psychologists, physiotherapists, occupational therapists, physician assistants, nurse practitioners, and clinical nurse specialists. The team may also include other mental-health specialists and massage therapists. Pain sometimes resolves promptly once the underlying trauma or pathology has healed, and is treated by one practitioner, with drugs such as analgesics and (occasionally) anxiolytics. Effective management of chronic (long-term) pain, however, frequently requires the coordinated efforts of the management team. For additional information in regards to this topic visit the following webpage:

  www.geriatricpain.org/Content/Assessment/Pages/default.aspx
- Physical Symptoms: Many symptoms contribute to suffering near the end of life. In addition to pain, the most common symptoms in the terminal stages of an illness such as cancer or acquired immunodeficiency syndrome are fatigue, anorexia, cachexia, nausea, vomiting, constipation, delirium and dyspnea. Management involves a diagnostic evaluation for the cause of each symptom when possible, treatment of the identified cause when reasonable, and concomitant treatment of the symptom using non-pharmacologic and adjunctive pharmacologic measures. (click here for an assessment tool in the functional assessment in the elderly, assessment of older adults and geriatric tools)

#### LEVEL OF CONSCIOUSNESS, COGNITION, DELIRIUM

- <u>Level of Consciousness</u>: (LOC) A measurement of a person's arousability and responsiveness to stimuli from the environment. A mildly depressed level of consciousness or alertness may be classed as lethargy; someone in this state can be aroused with little difficulty.
- Dementia: A progressive decline in memory and at least one other cognitive area in an alert person. These cognitive areas include attention, orientation, judgment, abstract thinking and personality. Dementia is rare in under 50 years of age and the incidence increases with age; 8 percent in >65 and 30 percent in >85 years of age.

#### PHYSICAL (continued)

- Delirium: An acute confusional state, is an organically-caused decline from a previously attained baseline level of cognitive function. It is typified by fluctuating course, attentional deficits and generalized severe disorganization of behavior. It typically involves other cognitive deficits, changes in arousal (hyperactive, hypoactive, or mixed), perceptual deficits, altered sleep-wake cycle, and psychotic features such as hallucinations and delusions. CA Association of Health Facilities Quality Improvement Subcommittee (2015).
- Dementia vs. Delirium: In order to make a diagnosis of dementia, delirium must be ruled out. However, patients with dementia are at increased risk of delirium and may have both. Delirium is an acute disorder of attention and global cognition (memory and perception) and is treatable. The diagnosis is missed in more than 50 percent of cases. The risk factors for delirium include age, pre-existing brain disease, and medications. There are many causes, the most common are:
  - **□** Dementia
  - ⇒ **E** Electrolyte disorders
  - ⇒ **L** Lung, liver, heart, kidney, brain
  - □ Infection
  - ⇒ R Rx Drugs
  - □ Injury, Pain, Stress
  - ⇒ U Unfamiliar environment

#### **FLUIDS/NUTRITION**

- <u>Nutrition</u>: An important element of health in the older population and affects the aging process. The prevalence of malnutrition is increasing in this population and is associated with a decline in functional status, impaired muscle function, decreased bone mass, immune dysfunction, anemia, reduced cognitive function, poor wound healing, and delayed recovery from surgery, higher hospital readmission rates, and mortality.
- The Importance of Water: Next to oxygen, water is the nutrient most needed for life. A person can live without food for a month, but most people can survive only three or four days without water. All of us start life in a watery cradle of amniotic fluid and to this day remain water's creature. Water makes up 85 percent of the blood, 70 percent of the muscles and about 75 percent of the brain, and is present in and around each of our cells.

In the body, water acts as a solvent, coolant, lubricant, and transport agent. It's needed to regulate body temperature, carry nutrients, remove toxins and waste materials, and provide the medium in which all cellular chemical reactions take place.

# PHYSICAL (continued)

- <u>Dehydration and the Elderly</u>: Elderly individuals are at a heightened risk for dehydration because their bodies have a lower water content than younger people. An elderly person weighing 150-pounds has about seven liters less water than a young person of the same weight. As a result of this lower water content, elderly individuals can become dehydrated more quickly.
- Skin/Wounds: As the skin ages it becomes less able to perform its key barrier functions and skin breakdown becomes an increasing risk. This can have a detrimental impact on quality of life with major economic implications (Gardiner et al., 2008), so skin health is essential to the wellbeing of older people and a central component of nursing care.

Elderly wound care is a significant and important part of the duties often assigned to nursing home staff. Diabetes and other illnesses can compromise the strength of elderly individual's skin. This can result in a greater susceptibility to sustaining a wound. As a result of older skin's slower rate of healing, elderly wound care is often considered in a context of treating chronic wounds and making sure that they do not get any worse. Instead of aiming for complete eradication of a chronic wound, a health professional may opt for an approach that focuses on managing a chronic wound and keeping overall damage to a minimum. (Click here for an article from the Nursing Times.net, "Maintaining skin health in older people," published on November 29, 2012 in regards to Age-related changes in the skin of older people)

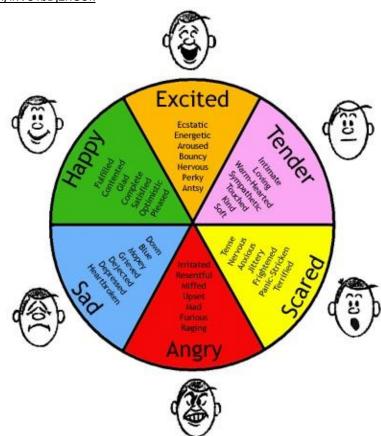
#### **PSYCHOLOGICAL**

"THE GREATEST DISCOVERY OF MY GENERATION IS THAT HUMAN BEINGS CAN ALTER THEIR LIVES BY ALTERING THEIR ATTITUDES OF MIND"

WILLIAM JAMES (1842-1910)

Psychological assessment is a process of testing that uses a combination of techniques to help arrive at some hypotheses about a person and their behavior, personality and capabilities. http://psychcentral.com/lib/what-is-psychological-assessment

- Motivation: A theoretical construct used to explain behavior. It represents the reasons for people's actions, desires, and needs. Motivation can also be defined as one's direction to behavior or what causes a person to want to repeat a behavior and vice versa. <a href="https://en.wikipedia.org/wiki/Motivation">https://en.wikipedia.org/wiki/Motivation</a>
- Depression/Anxiety: These disorders are different, but people with depression often experience symptoms similar to those of an anxiety disorder, such as nervousness, irritability, and problems sleeping and concentrating. But each disorder has its own causes and its own emotional and behavioral symptoms. www.adaa.org/understanding-anxiety/depression
- <u>Emotions</u>: An affective state of consciousness in which joy, sorrow, fear, hate, or the like, is experienced, as distinguished from cognitive and volitional states of consciousness.
   http://allpsych.com/psychology101/emotion/#.Ve4bDjZRGUk



#### PSYCHOLOGICAL (continued)

<u>Fears</u> (abandonment, burden, and death): The Top Ten Fears of Elderly Adults-Many of the fears that aging adults experience relate to the biggest challenge they say they face: staying active. According to a recent survey conducted for the Home Instead Senior Care network, seniors worry about the future, beginning with the loss of their independence.

$\Rightarrow$	Loss of independence	$\Rightarrow$	Death of a spouse or other family member
$\Rightarrow$	Declining health	$\Rightarrow$	Not being able to drive
$\Rightarrow$	Running out of money	$\Rightarrow$	Isolation or loneliness
$\Rightarrow$	Not being able to live at home	$\Rightarrow$	Strangers caring for them
$\Rightarrow$	Inability to manage their own activities of daily living	$\Rightarrow$	Fear of falling or hurting themselves

#### CONTROL/DIGNITY/INDEPENDENCE

- Control: The power to influence or direct people's behavior or the course of events. As people come under the care of others, they lose control of many aspects of their life. It is of utmost importance that the persons you care for are allowed as much control over their life and environment as possible.
- Dignity: Being treated with respect, regardless of the situation, and having a sense of self- esteem e.g., having a sense of self-worth; being accepted as one is, regardless of age, health status, etc.; being appreciated for life accomplishments; being respected for continuing role and contributions to family, friends, community and society; being treated as a worthy human being and a full member of society.
- Independence: Being in control of one's life, being able to do as much for oneself as possible and making one's own choices e.g., decisions on daily matters; being responsible, to the extent possible and practical, for things that affect one; having freedom to make decisions about how one will live one's life; enjoying access to a support system that enables freedom of choice and self-determination. (Click here for to see Canada's National Framework on Aging Principles on Dignity, Independence, Participation, Fairness and Security)

#### PSYCHOLOGICAL (continued)

#### **CONFLICT, GUILT, STRESS, COPING RESPONSES**

- <u>Conflict</u>: Faced with two or more incompatible options, motivations or impulses Freud.
- <u>Guilt</u>: A cognitive or an emotional experience that occurs when a person realizes or believes- accurately or not-that he or she has compromised his or her own standards of conduct or has violated a moral standard and bears significant responsibility for that violation. It is closely related to the concept of remorse.
- Stress: A state of mental or emotional strain or tension resulting from adverse or very demanding circumstances. (Click here to see an Adult Stress - Frequently Asked Questions)
- <u>Coping Responses</u>: Coping is expending conscious effort to solve personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict. The effectiveness of the coping efforts depend on the type of stress and/or conflict, the particular individual, and the circumstances.
   <u>https://en.wikipedia.org/wiki/Coping (psychology)</u>
- Self-Image/Self Esteem: Carl Rogers (1959) believes that the self-concept has three different components: The view you have of yourself (Self-image), How much value you place on yourself (Self-esteem or self-worth), what you wish you were really like (Ideal self). <a href="https://www.simplypsychology.org/self-concept.html">www.simplypsychology.org/self-concept.html</a>

#### SOCIAL

# "THE MOST WASTED OF ALL DAYS IS ONE WITHOUT LAUGHTER" NICOLAS CHAMFORT

#### **CULTURAL VALUES, BELIEFS, PRACTICES**

<u>Cultural Awareness</u>: An essential skill in the provision of culturally appropriate services, cultural awareness entails an understanding of how a person's culture may form their values, behavior, beliefs and basic assumptions.

Cultural practice generally refers to the manifestation of a culture or sub-culture, especially in regard to the traditional and customary practices of a particular ethnic or other cultural group. In the broadest sense, this term can apply to any person manifesting any aspect of any culture at any time. However, in practical usage it commonly refers to the traditional practices developed within specific ethnic cultures, especially those aspects of culture that have been practiced since ancient times.

- Click here for a "Life Story" Template
- www.euromedinfo.eu/how-culture-infl uences-health-beliefs.html/
- Handbook of Patients' Spiritual and Cultural Values for Health Care Professionals by HealthCare Chaplaincy 2013
- Culture Clue for Clinicians | Communication Guide: All Cultures

Relationships, Roles with Family, Friends, and Community: Humans are social creatures. Our sense of who we are and our place in the world is constantly being defined for us by the quality of our social contexts: inclusion in community, our friendships, being valued and loved, social connections in school and work, and generally our sense of whether people seem glad to see us, to want us around, and to miss us.

- Click here for University of Florida's Study on "Family Relationships in an Aging Society"
- www.alz.org/care/alzheimers-dementi a-relationship-changes.asp

#### ISOLATION, ABANDONMENT, RECONCILIATION

<u>Social Isolation</u>: Refers to a complete or near-complete lack of contact with people and society for members of a social species. It is not the same as loneliness rooted in temporary lack of contact with other humans.

<u>Abandonment</u>: Has a number of senses and is usually used within psychology in the context of humans. The term can describe the loss of emotional and psychological support resulting from neglect or desertion, particularly by one's family or one's social group. It can also be used to describe the feelings engendered in this situation, feelings of anxiety, loneliness etc.

#### SOCIAL (continued)

<u>Reconciliation</u>: The state of being reconciled, as when someone becomes resigned to something not desired. (To read more about this topic, refer to Page 222 of a Textbook of Palliative Medicine)

- Square of Care and Organization: Model to Guide Hospice Palliative Care. Ottawa, Canada: Canadian Hospice
   Palliative Care Association, 2002
- Collaborative Care Plan: End-of-Life Stage by Cancer Care Ontario

<u>Safe, Comforting Environment</u>: What impact does the environment have on us? Since the earliest times, humans have needed to be sensitive to their surroundings to survive, which means that we have an innate awareness of our environment and seek out environments with certain qualities.

First of all, humans have a strong need for safety and security and look for those attributes in their environment. We also look for physical comfort, such as an environment with the right temperature. In addition, we seek an environment that is psychologically comfortable: for example, environments that are familiar, but offer the right amount of stimulus.

• <u>www.takingcharge.csh.umn.edu/explore-healing-practices/healing-environment/what-impact-does-environment-have-us</u>

<u>Privacy & Intimacy</u>: For many older Americans, entering a long-term care facility means giving up their independence, their home, their livelihood, and many of their favorite possessions. Often adding to these major losses is the perception that the freedom and privacy to express their sexuality has also been lost. Because society tells us that sex is for the young and healthy, it is mistakenly assumed that sexual desire dwindles after a certain age. Sexual expression by residents in long-term care facilities is often misinterpreted as a behavioral problem, but it may be a sign that an important basic need the need for human touch, closeness and intimacy has been overlooked.

- Aging Well Article: Sexuality in Nursing Homes: Preserving Rights, Promoting Well-being
- The Right of Privacy and America's Aging Population by Kristine S. Knaplund
- Intimacy and Sexuality Practice Guidelines in Long-Term Care

<u>Routines</u>, <u>Rituals</u>, <u>Recreation</u>: People rely on routine to give life structure. Such habits and rituals that become part of our daily routine offer comfort when life throws us a curveball.

- Activities of Daily Living: Environment and Routines
- Annals of Long-Term Care: Engaging Nursing Home Residents in Meaningful Activities
- Assisted Living Column: Transforming Personal Care Through Ritual

#### **SPIRITUAL**

"WE CAN NO MORE DO WITHOUT SPIRITUALITY THAN WE CAN DO WITHOUT FOOD,
SHELTER, OR CLOTHING"
ERNEST HOLMES

"THE SPIRITUAL DIMENSION TRIES TO BE IN HARMONY WITH THE UNIVERSE, AND STRIVES FOR
ANSWERS ABOUT THE INFINITE, AND COMES INTO FOCUS
WHEN THE PERSON FACES EMOTIONAL STRESS, PHYSICAL ILLNESS, OR DEATH."
RUTH BECKMANN MURRAY AND JUDITH PROCTOR ZENTER

#### **MEANING, VALUE**

<u>Spirituality</u> is a more inclusive construct than religion. It is possible for a person to be spiritual without being religious in the traditional sense.

Spirituality and faith practices can improve skills for coping with stress and raise levels of happiness and general well-being.

- Psychologists agree that spirituality and faith have powerful effects on stress management and general happiness.
- Spirituality is the search for a higher, existential power, while faith is the belief that such a thing exists. Practices in both spirituality and faith can lead to greater skills for coping with stress.
- People who practice spirituality and faith are able to validate their own existences, cultivate coping abilities, view stress as short-term and external, and generate social support for stress management.
- All forms of spiritual and faithful practice, including meditation, contemplation, and prayer, allow for increases in stress management skills. (Source: "The Value of Spirituality and Faith in Managing Stress"
   Boundless Psychology or click here to see a handbook of Patients' Spiritual and Cultural Values for Health Care Professionals by HealthCare Chaplaincy 2013)

#### **ASSESSMENT OF SPIRITUALITY IN ADULTS**

Adults often need to cope with serious illness and end of life issues. Since many adults ask for help from the clinician it is imperative that the clinician incorporate a spiritual assessment into their patient/resident care. Tools are available that focus on avenues including religion but also other spirituality as defined by the person. The clinician must be careful not to impose their own beliefs as they interview and several sessions may be necessary.

#### SPIRITUAL (continued)

#### **ADDITIONAL READINGS**

- ⇒ S. Burns, "The Spirituality of Dying," Health Progress, September 1991, pp. 48-52
- ⇒ J. T. Culliton, "Commitment through the Personalization of Time," Spirituality Today, Winter 1982, pp. 335-349
- R. Delbene, Into the Light-A Simple Way to Pray with the Sick and Dying, Upper Room, Nashville, 1988
- ⇒ C. W. Ellison, "Spiritual Well-Being: Conceptualization and Measurement," Journal of Psychology and Theology, vol. 11, no. 4,1983, pp. 330-340
- ⇒ S. Kratzke and J. Moffett, "A Survey of Spiritual Needs," Visions, October 1987, pp. 1-2
- D. S. Martin and W. G. Fuller, "Spirituality and Aging: Activity Key to 'Holiest' Health Care," in P. M. Foster, ed., Activities in Action: Proceedings of the National Association of Activity
- ⇒ Professionals 1990 Conference, Haworth Press, New York City. 1991

#### LINKS TO TOOLS FOR SPIRITUAL ASSESSMENT

- The Hartford Institute for Geriatric Nursing, New York University, and College of Nursing is cited as the source. This material may be downloaded and/or distributed in electronic format, including PDA format. Available on the internet at: <a href="www.hartfordign.org">www.hartfordign.org</a> and/or <a href="www.consultgerirn.org">www.consultgerirn.org</a> | E-mail notification of usage to: <a href="hartford.ign@nyu.edu">hartford.ign@nyu.edu</a>.
- Religious/Spiritual History Assessment: A clinician's tool to facilitate inquiry about an individual's religious or spiritual history. Courtesy of Department of Psychiatry Cambridge Health Alliance.

#### PRACTICAL CONCERNS

# "IT'S ABOUT HOW YOU <u>LIVE</u> LIFE IN THE CARE OF OTHERS" GERALD THOMAS

An <u>Advance Healthcare Directive</u>, also known as <u>Living Will</u>, personal directive, advance directive, or advance decision, is a legal document in which a person specifies what actions should be taken for their health if they are no longer able to make decisions for themselves because of illness or incapacity. A living will is the oldest form of an advance directive. A living will, despite its name, isn't at all like the wills that people use to leave property at their death. A living will, also called a directive to healthcare providers and caregivers, is a document that lets people state their wishes for end-of-life medical care, in case they become unable to communicate their decisions. It has no power after death. (*Source: https://en.wikipedia.org/wiki/Advance healthcare directive*)

- An Article by Mayo Clinic: Living wills and advance directives for medical decisions
- To Download your own State's advance directives visit the National Hospice and Palliative Care Organization at: www.caringinfo.org/i4a/pages/index.cfm?pageid=3289

<u>Durable POA Healthcare</u>: A document that designates an agent or proxy to make health care decisions if the patient is no longer able to make them. The document directs the surrogate person to function as "attorney-infact" and make decisions regarding all treatment, including the final decision about cessation of treatment.

<u>Durable POA for Finance</u>: The durable financial power of attorney is simply a way to allow someone else to manage your finances in the event that you become incapacitated and are unable to make those decisions yourself. The power is granted in a document, and is not only useful for you, but can really help your family in times of crisis. More precisely, it grants someone legal authority to act on your behalf for financial issues. This person's official name depends on the state you live in, but is often referred to as your agent or as an attorney-infact.

Article by FindLaw: <u>Durable Financial Power of Attorney</u>

<u>IADL or Instrumental Activities of Daily Living</u>: Are activities related to independent living and are valuable for evaluating persons with early-stage disease, both to assess the level of disease and to determine the person's ability to care for him or herself.

Instrumental Activities of Daily Living Scale (by The Gerontological Society of America)

# PRACTICAL CONCERNS (continued)

<u>ADL or Activities of Daily Living (ADL)</u>: Are basic self-care tasks, akin to the kinds of skills that people usually learn in early childhood. They include the following: Feeding, toileting, selecting proper attire, or grooming.

- Activities of Daily Living, Environment and Routines
- Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) Checklist
- Caring.Com Article | What are activities of daily living (ADLs)?

### END OF LIFE CARE/DEATH MANAGEMENT

# "PEACE IS THE WAY, NOT THE DESTINATION" SHANNON L. ALDER

<u>Life Closure</u>: Closing Relationships and Saying Goodbye. At some point you have to realize some people can stay in your heart, but not in your life.

- Hospice | From Your Hands to God's Arms Saying Good-Bye
- Caring.com Article | How to Say Good-bye When Someone You Love Is Dying
- 2008 Toolkit developed by the CAHF Quality Improvement Subcommittee on End of Life Care
- 2009 Toolkit developed by the CAHF Quality Improvement Subcommittee on End of Life Care
- CAHF's Member Page: End of Life Care Resources and POLST
- <u>California Culture Change Coalition</u>: In 2009 the California Culture Change Coalition in partnership with the
   <u>Coalition for Compassionate Care of California</u> received a grant from the California HealthCare Foundation to
   promote person-centered end-of-life care and to encourage the use of <u>Physician Orders for Life-Sustaining</u>
   <u>Treatment (POLST)</u>.

<u>Gift Giving</u>: (e.g., things, money, organs, thoughts) 'LAST WILL AND TESTAMENT' A legal document that communicates a person's final wishes, as pertaining to possessions and dependents. A person's last will and testament will outline what to do with possessions, whether they are being left to another person, group or donated to charity, and what will happen to other things for which they are responsible, such as custody of dependents and accounts and interests management.

<u>Legacy Creation</u>: An Ethical Will (Hebrew: "Zava'ah") is a document designed to pass ethical values from one generation to the next. Rabbis and Jewish laypeople have continued to write ethical wills during the nineteenth and twentieth centuries. Writing an ethical will may seem difficult. However, it can be viewed as the writing of a love letter to your family. Ethical Wills can include personal and spiritual values, hopes, experiences, love, and forgiveness. It may well be one of the most cherished gifts you can give to your family.

- www.personalhistorians.org/resources/examples\_ethical\_wills.php
- End-of-Life Questions

<u>Preparation for an Expected Death</u>: Some people want to make plans before they die. This gives you more time to make choices about arrangements. It will also allow you to visit with family and mourn your loss at time of death without worrying about details. Encourage the person to be involved and in control as much as possible in predeath planning. You might want to contact or visit a funeral home to make arrangements.

- www.wikihow.com/Prepare-for-the-Death-of-a-Loved-One)
- Planning for an expected death resources from the City of Ottawa, Canada

<u>Anticipation and Management of Physiological Changes in the Last Hours of Life</u>: As a person dies, many different physiological changes present as signs and symptoms. Each one can be alarming if it is not understood.

National Caregivers Library: <u>Preparing for the Death of A Loved One</u>

<u>Rites and Rituals</u>: A rite or ritual is an established, ceremonial, usually religious, act. Rites in this sense fall into three major categories: rites of passage, generally changing an individual's social status, such as marriage, adoption, baptism, coming of age, graduation, or inauguration.

# END OF LIFE CARE/DEATH MANAGEMENT (continued)

<u>Peri-death Care of Family, Handling of the Body</u>: Be sensitive to the different cultural beliefs around the act of dying and special requirements for handling the body post mortem.

<u>Funerals, Memorial Services, Celebrations</u>: The process of remembering and grieving for someone is frequently governed by cultural and religious traditions in the Deceased's family or in their social group.

- Funeral & Memorial Etiquette
- Cultural Aspects of Funeral

### LOSS/GRIEF

# "WHAT WE HAVE ONCE ENJOYED DEEPLY WE CAN NEVER LOSE. ALL THAT WE LOVE DEEPLY BECOMES A PART OF US" HELEN KELLER

<u>Loss</u>: The state or feeling of grief when deprived of someone or something of value. "I feel a terrible sense of loss."

<u>Grief</u>: A multifaceted response to loss, particularly to the loss of someone or something that has died, to which a bond or affection was formed. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioral, social, and philosophical dimensions.

- Acute Grief: A definite syndrome characterized by psychological and somatic symptoms: Sensations of somatic distress that occur in waves lasting for 20 minutes to an hour characterized by: Tightness in the throat.
- <u>Chronic Grief</u>: Grieving that lasts for a prolonged or extended period of time. There does not seem to be any significant reduction in emotional distress. It does not seem to end or decrease in severity across time.
- Anticipatory Grief: Refers to a grief reaction that occurs before an impending loss. Typically, the impending loss is a death of someone close due to illness but it can also be experienced by dying individuals themselves.
  - ⇒ Fact Sheet: Grief and Loss (Family Caregiver Alliance, National Center on Caregiving)
  - ⇒ www.helpguide.org/articles/grief-loss/coping-with-grief-and-loss.htm
  - ⇒ All About Grief Free Fact Sheets
  - ⇒ Family Caregiver Alliance: National Center on Caregiving | Grief and Loss
  - ⇒ New York City Alliance Against Sexual Assault Factsheet on Grief

<u>Bereavement</u>: The period of grief and mourning after a death. When you grieve, it's part of the normal process of reacting to a loss. You may experience grief as a mental, physical, social or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness and despair.

- www.lovinglymanaged.com/
- www.bereavementadvice.org/index.php
- Sample Bereavement Care Plan Goals and Interventions
- Investing In Resolve Through Sharing Creates a Culture of Compassion Enhances Quality, Improves Patient and Staff Experience, and Supports National Standard Benchmarks - Gundersen Lutheran Medical Foundation, Inc.

<u>Mourning</u>: The actions or expressions of one who has suffered a bereavement. Conventional outward signs of grief for the dead, such as a black armband or black clothes, the period during which a death is mourned.

- www.chabad.org/library/arti cle cdo/aid/281541/jewish/The-Jewish-Way-in-Death-and-Mourning.htm
- http://healgrief.org/