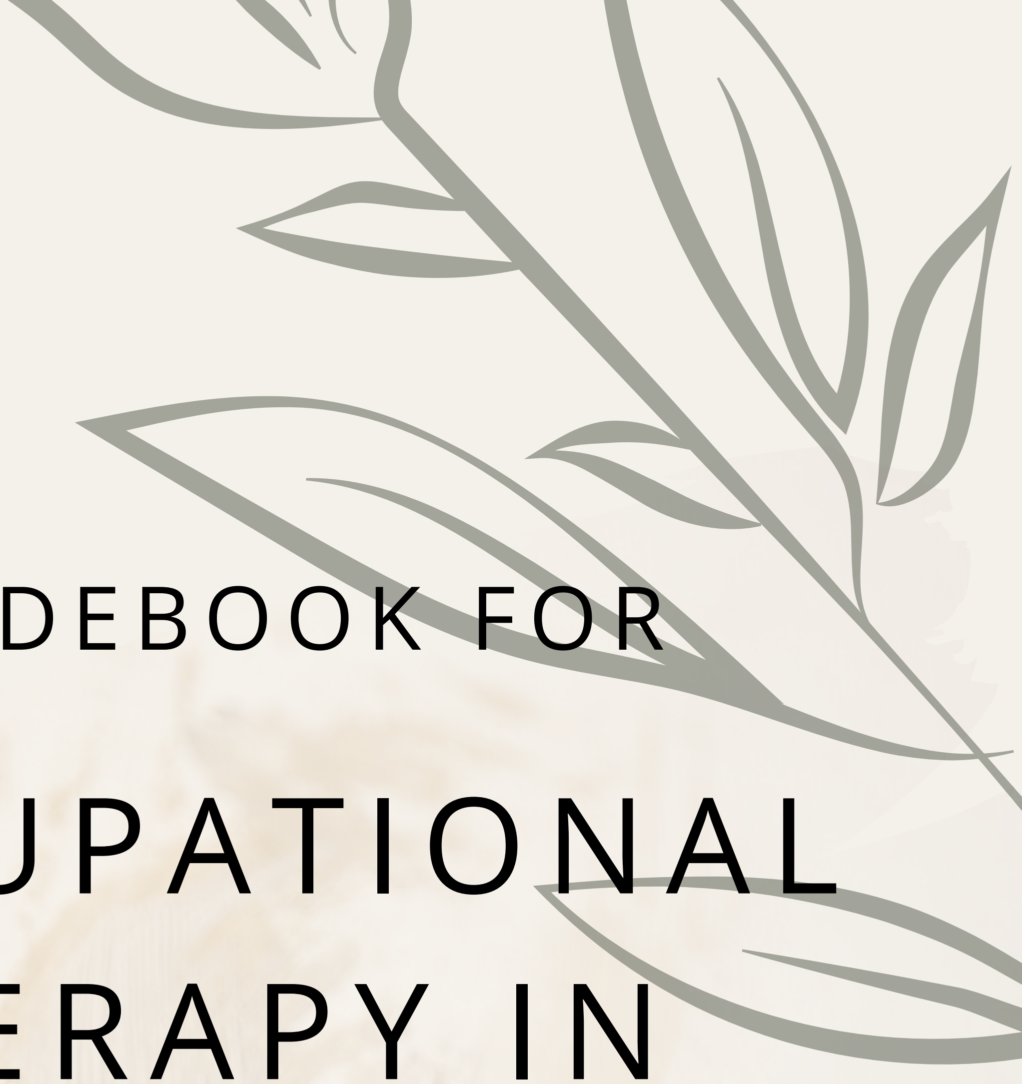

GUIDEBOOK FOR

OCCUPATIONAL THERAPY IN END-OF-LIFE CARE

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BACKGROUND

Regardless of functional status, diagnosis, or life expectancy, all individuals have the fundamental right to comprehensive healthcare at the end-of-life. Worldwide, nearly 20 million individuals need end-of-life care services; however, only 14% receive the necessary care (von Post & Wagman, 2019). Within that 14%, over 85% of hospice patients require assistance in at least one activity of daily living (ADL), though only about 10% receive occupational therapy (OT) (Mueller et al., 2021).

Individuals at the end-of-life experience decline in body functions and performance skills, as well as challenges in maintaining occupational roles, routines, and performance patterns due to motor, cognitive, sensory, emotional, and communication deficits (American Occupational Therapy Association [AOTA], 2011; Martin & Herkt, 2018). These deficits serve as barriers to occupational participation and challenge one's remaining functional capacities, inhibiting occupational engagement.

Patients at the end-of-life report extensive unmet needs in their desire to continue to engage in self-care, physical, social, and leisure activities, and other productive roles despite deteriorating capacities (Chow & Pickens, 2020). Patients express disappointment in their declining ability to perform daily tasks and mention increased dependency on caregivers and the inability to engage in desired occupations to be some of their most distressing concerns (Eriksson et al., 2016; Keesing & Rosenwax, 2011). The occupational needs of patients with terminal illnesses are typically disregarded due to the patient's lack of rehabilitative potential and deteriorating condition (Chow & Pickens, 2020).

In the absence of OT practitioners, there is little support from existing end-of-life healthcare professionals to help patients be active participants in their desired occupations. End-of-life healthcare professionals prioritize pain and symptom management with little to no emphasis on occupation, therefore, the occupational needs of patients and their desire for autonomy and occupational engagement are often neglected (Yeh & McColl, 2019; Keesing & Rosenwax, 2011).

BACKGROUND

OT practitioners are equipped to address this population's comprehensive occupational needs. The benefits of OT services are demonstrated throughout the literature which describes significant improvements in mobility, pain, mood, symptom management, independence, quality of life, and ADL scores among patients at the end-of-life (Burkhardt et al., 2011; Yeh & McColl, 2019; Javier & Montagnini, 2011; Mueller et al., 2021). OT in end-of-life care identifies and addresses the barriers and challenges to occupational participation and engagement, positively influencing engagement in meaningful occupations and enhancing quality of life until death.

The role, scope, and delivery of OT services in end-of-life care are widely misunderstood among healthcare professionals, patients, families, caregivers, OT students and practitioners (Yeh & McColl, 2019; Keesing & Rosenwax, 2011; Knecht-Sabres et al., 2019). In turn, OT services are underutilized. OT students and practitioners lack the fundamental education and training on basic principles of end-of-life care, consequently leading them to feel underprepared to work with terminally ill patients (Talbot-Coulombe & Guay, 2020). This gap in OT education and training, along with interdisciplinary misunderstanding, offers an explanation for the insufficient presence of OT practitioners and widespread underutilization of OT services in end-of-life care (Knecht-Sabres et al., 2019; Talbot-Coulombe & Guay, 2020). Overall, there is a distinct need for comprehensive training and academic preparation for OT students and practitioners to work in end-of-life care.

The purpose of this guidebook is to address the insufficient education on the role, scope, and delivery of OT services in end-of-life care. The goal is to facilitate recognition of this practice setting and its distinct need for OT services, and provide the necessary education for OT students and practitioners to recognize, fulfill, and advocate for their role in end-of-life care. Increased presence and utilization of OT practitioners in end-of-life care will promote occupational participation and engagement and enhancement of quality of life among patients at the end-of-life and their families.

SECTION

1

END-OF-LIFE CARE

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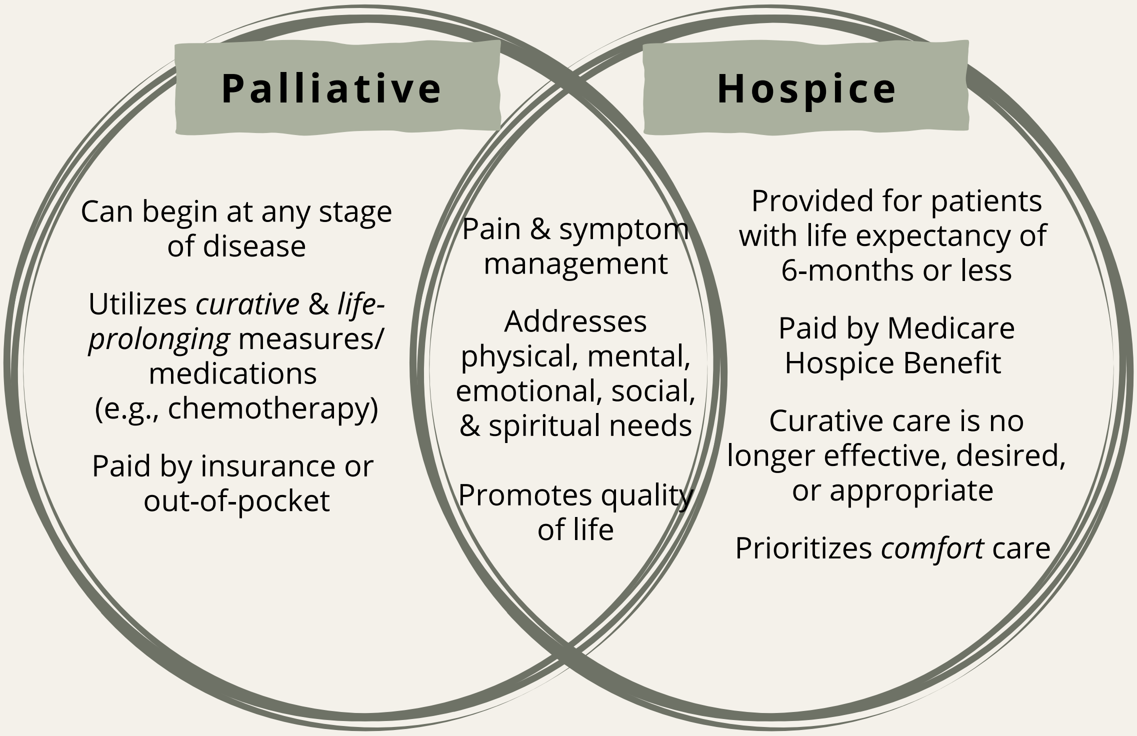
HOSPICE VS. PALLIATIVE CARE

Hospice and palliative care are services provided to patients who are at the end-of-life, typically due to a terminal illness. Hospice and palliative care both focus on pain and symptom management, and meeting the physical, mental, emotional, social and spiritual needs of patients and their families.

End-of-life care is a continuum. ***Palliative care*** is provided after a patient is diagnosed with a life-threatening illness and their symptoms are managed while receiving curative care. As the disease progresses and the patient has a life-expectancy of 6-months or less, and curative measures are no longer effective, appropriate, or desired, ***hospice care*** is provided.



Palliative

Can begin at any stage of disease

Utilizes *curative* & *life-prolonging* measures/ medications (e.g., chemotherapy)

Paid by insurance or out-of-pocket

Pain & symptom management

Addresses physical, mental, emotional, social, & spiritual needs

Promotes quality of life

Hospice

Provided for patients with life expectancy of 6-months or less

Paid by Medicare Hospice Benefit

Curative care is no longer effective, desired, or appropriate

Prioritizes *comfort* care

END-OF-LIFE CARE SETTINGS

End-of-life care can be provided in any care setting.

- While 80% of individuals prefer to die at home, only about 20% actually do (Stanford School of Medicine (n.d.), as cited in Cavallo, 2020).
- Many individuals decline hospice care due to their desire to be at home and their belief that hospice is only delivered in the hospital; however, the majority of hospice care occurs in the patient's home, whether that be in their personal residence, a nursing home, or assisted living facility (National Hospice and Palliative Care Organization [NHPCO], 2022).

→ Hospice care allows people to receive care and die at home.

Palliative care settings:

- Home
- Skilled Nursing Facility
- Long-term Care Facility
- Assisted Living Facility
- Hospice facility
- Hospital
- Group Home
- Outpatient clinic
- Long Term Acute Care Facility

Hospice care settings:

- Home
- Skilled Nursing Facility
- Long-term Care Facility
- Assisted Living Facility
- Hospice facility
- Hospital (inpatient level of care)
- Group Home

(NHPCO, 2019)

HOSPICE APPROPRIATE PATIENTS

Patients who are "hospice appropriate" have:

(1) a terminal diagnosis with a life expectancy of 6-months or less
(2) acceptance of the hospice philosophy to receive comfort care rather than curative care

There are additional clinical signs that indicate a patient may be ready for hospice care. These signs include, but are not limited to:

Decreasing intake of food and drink
Significant weight loss - even if eating full meals
Declining functional status
Frequent medication changes for symptom management
No longer wanting to go to the hospital
No longer desiring curative treatments
Increased sleeping
Decreased communication
Increased confusion
Increased falls

Hospice Definition & Philosophy

"Hospice is a coordinated program of palliative and supportive care (physical, psychological, social and spiritual) for dying persons and their families which is provided by an interdisciplinary team of professionals and volunteers under a central administration. This care is available 24 hours a day, seven days a week. Admission is on the basis of patient and family need. Hospice care continues into bereavement."

"Dying is a normal process, whether or not resulting from disease. Hospice exists neither to hasten nor to postpone death. Rather hospice exists to affirm life by providing support and care for those in the last phases of incurable disease so that they can live as fully and comfortably as possible. Hospice promotes the formation of caring communities that are sensitive to the needs of patients and their families at this time in their lives so that they may be able to obtain that degree of mental and spiritual preparation for death that is satisfactory to them"

(National Hospice Organization, 1979, as cited in Koff, 1980, pp.13-14).

MEDICARE HOSPICE BENEFIT

(Centers for Medicare and Medicaid Services, 2022)

- The Medicare Hospice Benefit provides a rate for each day a patient is enrolled in hospice which covers all medical services, equipment, and supplies.
- The daily rate provided to the hospice agency is determined by the level of care provided to the patient based on the 4-levels of Medicare-Certified Hospice.

4 levels of Medicare-Certified Hospice

Routine Home Care

Most common;
patient is generally stable and symptoms are controlled;
care is provided in the home which may be a private home, skilled nursing facility, or assisted living facility

Respite Care

Temporary care provided in a nursing home, long-term care facility, inpatient hospice facility or hospital to provide respite for family or caregivers; this care is specific to caregiver needs rather than patient's symptoms and can occur for up to 5 consecutive days

General Inpatient

Crisis-like level of care for short-term management of uncontrolled symptoms or pain; typically provided in a medical facility such as a hospital or skilled-nursing facility

Continuous Home Care

Crisis-like level of care for short-term management of uncontrolled symptoms or pain; provided in the home

The Medicare Hospice Benefit covers the following services:

Physician Services
Nursing Care
Medical Equipment
Medical Supplies
Prescription Drugs
Hospice Aide
Occupational Therapy
Physical Therapy
Speech Language Pathology
Social Worker Services
Dietary Counseling
Grief and Loss Counseling/Spiritual Care
Short-Term Inpatient Care
Short-Term Respite Care

- A one-time hospice consultation to discuss care options is also covered, even if the patient declines hospice care.
- Any other Medicare-covered services recommended by the hospice team to manage the terminal illness and related conditions may also be covered by the Hospice Benefit.

MEDICARE HOSPICE BENEFIT

(Centers for Medicare and Medicaid Services, n.d., 2022)

Medicare Hospice Benefit Eligibility

A patient is eligible for the Medicare Hospice Benefit if they have **Medicare Part A** (hospital insurance) and meet all of the following criteria:

- The hospice physician or the patient's primary care physician determines that the patient is terminally ill with a prognosis of 6-months or less to live.
- The patient accepts comfort care instead of curative care.
- A statement is signed confirming the patient's choice of hospice care rather than other Medicare-covered treatments for the terminal illness and related conditions.

What The Hospice Benefit Will NOT Cover

- Treatments intended to *cure* the terminal illness or related conditions. Patient's can discontinue hospice services at any time if they wish to pursue curative treatments.
- Prescription drugs that are not related to the terminal diagnosis.
- Care from any providers that are not set up by the hospice agency; however, patient's are able to continue seeing their primary care physician.
- Room and board if hospice services are provided in a care facility.
- Outpatient hospital visits (emergency room), inpatient hospital visits (unless arranged by the hospice team), or ambulance transportation.

Certification Periods

- The Hospice Benefit is provided in 'benefit periods'. If a patient lives longer than the expected 6-months, they can continue to receive hospice care as long as they are recertified to be terminally ill. A patient must demonstrate continued functional decline or evident disease progression and be deemed terminal by the hospice physician.
- A patient can receive hospice care for two 90-day benefit periods, followed by as many 60-day benefit periods as needed.

$$\underbrace{\text{90-DAYS}}_{1} \rightarrow \underbrace{\text{90-DAYS}}_{2} \rightarrow \underbrace{\text{60-DAYS}}_{3} \rightarrow \underbrace{\text{60-DAYS}}_{4} \rightarrow \underbrace{\text{60-DAYS}}_{5} \rightarrow \text{ETC}$$

INTERDISCIPLINARY TEAM

End-of-life care utilizes an interdisciplinary team approach to comprehensively meet the needs of patients and their families.

Medical Director

All hospice patients are under the care of a physician who specializes in end-of-life care and terminal illness. The physician is responsible for:

- coordinating the care team to develop a plan of care that caters to the patient's specific needs and wishes
- monitoring disease progression
- prescribing necessary medications for pain and symptom control
- determining patient eligibility for hospice certification and recertification

Nurse

End-of-life care nurses are specially trained to assess and manage terminally ill patients' pain and symptoms and provide skilled hands-on care. Registered Nurses or Licensed Vocational Nurses evaluate and treat the patient and family's needs in accordance with the plan of care.

Nurses Aide

Aides, typically certified nursing assistants (CNAs) provide personal care such as bathing, feeding, and dressing, along with companionship and emotional support to patients and families. If a patient resides in a care facility, the Hospice Aide will assist in patient care and provide extra support to the patient, in addition to the facility staff.

Social Worker

Social workers address end-of-life planning, developing care plans, family dynamics, arranging referrals within the community, and helping to meet the psychosocial needs of patients and their families. Additional roles of the social worker include:

- facilitating communication between the agency and family
- conflict resolution
- non-medical related issues such as insurance benefits and other end-of-life questions and concerns

Chaplain

Regardless of spiritual belief or religious affiliation, chaplains are available to all patients and families to address spiritual needs, desires, or concerns that may arise throughout the dying process. The chaplain develops a plan of care to meet the identified spiritual needs through counseling, bereavement support, and companionship. Chaplains may perform funeral ceremonies, baptisms, anointing, and provide communion if requested. Chaplains can also provide grief and loss support to hospice staff.

INTERDISCIPLINARY TEAM

Bereavement Coordinator

Bereavement specialists offer patients and their families support for anticipatory grief and grief/bereavement after the death. Families of hospice patients receive bereavement services including follow-up support letters, periodic phone calls, and grief support groups, for up to 13 months after the death of a loved one.

Occupational Therapist

Occupational therapists address the patient and family holistically by enhancing quality of life through participation and engagement in meaningful occupations. Occupational Therapists may specifically address functional mobility and patient's desires to engage in activities of daily living, roles and routines, hobbies, and leisure activities.

Physical Therapist

Physical therapists may work with patients to improve physical strength, balance, and mobility to enhance independence. Physical therapists specifically address gross functional mobility and focus intervention on bed mobility, transfers, gait or ambulation, and body mechanics. The physical therapist may also address limitations to movement including pain, weakness, range of motion, and shortness of breath.

Speech Therapist

Speech therapists address cognitive and oral functioning. Intervention focuses on comprehension of auditory and visual information, communication to express needs, and oral motor skills needed for speech production, feeding, eating, and swallowing.

Volunteer

Trained volunteers offer compassionate companionship to patients and families through engagement in activities, conversation, and/or providing respite to family members or caregivers.

FACTORS OF CARE

There are many variables to care at the end-of-life. The interdisciplinary team meets frequently to discuss each patient and their care, along with their needs, priorities, and medical/functional status. Common factors of care and topics of discussion among the end-of-life care team include:

- Communication abilities
- Family dynamic/support
- Advance Directive
- Patient and family priorities
- Faith/spirituality
- Equipment
- Positioning
- Level of functional independence (ADLs)
- Transfer status
- General health status (vitals)
- Consciousness and arousal
- Cognitive status
- Changes in medical and functional status
- Environmental safety
- Weight/BMI/weight loss
- Intake (% of food and water intake per meal)
- Nutritional status/diet
- Continence (bowel & bladder)
- Wounds/pressure sores
- Edema
- Medications/medication changes/ use of emergency medications
- Presence and management of Anxiety/Depression
- Presence and management of behaviors
- Hallucinations/delusions
- Recent occurrences (falls) and infections

COMMON DIAGNOSES

The following lists include common diagnoses, comorbidities, and symptoms seen at the end-of-life. It is important to be familiar with the diagnoses commonly seen in end-of-life care, along with disease trajectory, common comorbidities, and associated symptoms.

TERMINAL DIAGNOSES

- Dementias (various types)
- Cancers (various types)
- Progressive Neurological Disorders
  - Parkinson's Disease
  - Amyotrophic Lateral Sclerosis (ALS)
- Cardiopulmonary
  - Congestive Heart Failure
  - Cerebral Vascular Accident (CVA)
  - Chronic Obstructive Pulmonary Disease (COPD)
  - Pulmonary Fibrosis
  - Cerebral Atherosclerosis
- Aging related diagnoses
  - Senile Degeneration of the Brain
  - Abnormal Weight Loss/Nutritional Marasmus
- Organ failures
  - Kidney Disease
  - Liver Disease

COMORBIDITIES

- Major Depressive Disorder
- Diabetes Mellitus
- Post Traumatic Stress Disorder (PTSD)
- Atrial Fibrillation
- Hypertension
- Transient Ischemic Attack
- Gastroesophageal Reflux Disease (GERD)
- Anorexia - loss of appetite
- Cachexia - severe muscle wasting and loss of body mass
- Nutritional Marasmus - severe malnutrition
- Protein Calorie Malnutrition

ASSOCIATED SYMPTOMS

- Anxiety
- Depression
- Constipation
- Pain
- Fatigue
- Nausea
- Falls
- Dyspnea - shortness of breath
- Syncope - fainting/brief loss of consciousness
- Ascites - collection of fluid in abdomen
- Dysphagia - swallowing difficulty
- Aphasia - speech difficulty

STAGES OF DEATH & DYING

The process of dying typically begins well before death occurs, and can be categorized into three stages:

EARLY, MIDDLE, END

Each stage is marked by a decline in functioning and responsiveness attributed to deteriorating body functions as body systems shut down. When the active dying process begins, the body experiences physiological changes where structures and systems function more slowly.

The heart begins to slow down and exert less force, causing less blood to circulate throughout the body. With less blood and oxygen supply, the brain and other essential organs begin to slow down, and their functions begin to deteriorate.

It is important to note that although these stages are generalized, the process of dying is individualistic and unique to each individual.

(Health Direct, 2021; Morrow, 2022; Traditions Health, 2022)

Early Stage

The early stage of dying can last from a few days to several weeks and can begin 1 to 3 months before death.

Physical Signs of Dying

- The patient will begin eating and drinking markedly less than usual due to reduced appetite and thirst. This may cause mild weight loss and decreased energy.

- This loss in appetite is referred to as ***anorexia*** and is often paired with ***cachexia***, severe wasting of muscle and body fat. This is a normal part of the dying process and should not cause concern. As the patient exerts less energy and the body begins to shut down, it does not need the same level of nourishment as it once did.

- The patient may experience persistent drowsiness and increased sleeping habits as physiological changes progress.

- In this stage, active dying begins as the body begins to shut down. The patient and their family should prepare for imminent death and create closure.

(Better Health Channel, 2018; Morrow, 2022; Traditions Health, 2022)

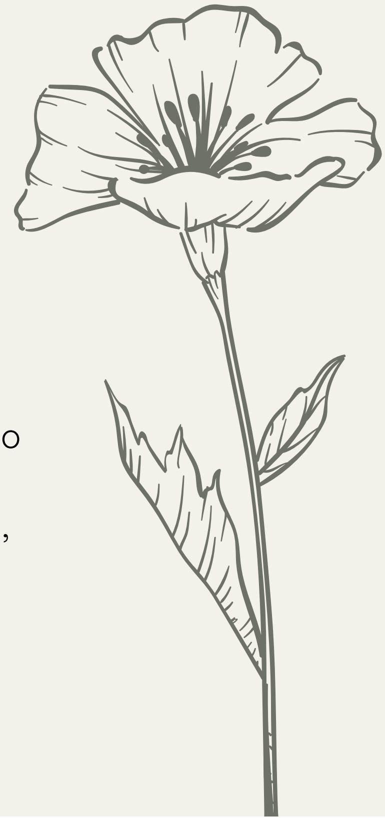
Middle Stage

In the final weeks of life, the dying process begins to accelerate. The middle stage of dying can last between a few hours and several days.

Physical Signs of Dying

- This stage is represented by changes in responsiveness and physical appearance.
- The patient may become less responsive to their surroundings and environment, and communication may diminish.
- The body's blood circulation continues to slow down conserving blood for major organs, often causing the patient's hands and feet to become colder and change color. ***Mottling*** of the skin may occur at this stage, giving a red/purple marbled appearance.
- Primary signs of death in this stage include:
  - decreased or ceased eating and drinking
  - weight loss
  - increased fatigue
  - excessive sleep
  - decreased body temperature
  - irregular pulse
  - decreased blood pressure
  - perspiration
  - disorientation
  - restlessness (referred to as ***terminal restlessness***)
  - changes in breathing
  - changes in skin color
- Sensory changes are also common in this stage, including:
  - delusions
  - illusions
  - hallucination-like visions
- Often patients will report visual images or will see and speak to loved ones who have already passed, this is referred to as ***visioning.*** These experiences are normal to the dying process, and most often bring the patient *peace*.

(Better Health Channel, 2018; Health Direct, 2021; Hospice Foundation of America, n.d.-b; Morrow, 2022; Traditions Health, 2022)



End Stage

The final stage of dying is referred to as "**imminent death**", and is when death is expected to occur within 48-72 hours.

Physical Signs of Dying

- In the final stage of dying, the patient may become increasingly disoriented and restless, and changes to breathing and continence will occur.
- Restlessness is attributed to metabolic changes, and incontinence is due to decreased muscle control and blood circulation to associated organs such as the kidneys.
- Decreased blood circulation also causes weakness in the lungs, leading to shallow, irregular, and labored breathing.
- Muscle weakness and decreased consciousness may impact the ability to effectively swallow, causing a rattling noise in the throat referred to as the ***death rattle*** or ***terminal secretions***. This gurgling or rattling sound is caused by air passing over built up saliva in the mouth and back of the throat.
- The patient may demonstrate rapid or labored breathing followed by long pauses of no breathing at all, this is called ***cheyne-stokes breathing.*** Positioning is especially important in this stage to aid breathing.
- A phenomenon sometimes seen at this stage of dying is the ***death surge*** or ***rally***, which is marked by a sudden burst of energy, talkativeness, increased appetite, or the desire to get out of bed. It is a common misconception that this indicates the patient is getting better, however, the surge only lasts for a brief period and is a sign that death is near.
- At this stage, most patients fall into an unconscious state. *Auditory functioning* is the last sense to diminish, therefore it is assumed that although unconscious, patients are still able to hear those around them, even in the moments before death.
- Once breathing has ceased and the heart has stopped beating, death has occurred.

(Better Health Channel, 2018; Traditions Health, 2022)

COMMON MEDICATIONS

Patients at the end-of-life receive medications for pain and symptom management. If the patient is receiving hospice care, unneeded medications and supplements, including those intended to cure the disease, are discontinued.

MEDICATION (GENERIC/BRAND)	FUNCTION
Acetaminophen/Tylenol	Pain
Tramadol/Ultram	Pain
Morphine	Pain/Dyspnea
Hydromorphone/Dilaudid	Pain/Dyspnea
Clonazepam/Klonopin	Pain/Anxiety/Restlessness
Diazepam/Valium	Anxiety/Restlessness/Agitation/Delirium
Lorazepam/Ativan	Anxiety/Agitation/Nausea/Insomnia/ Dyspnea
Xanax/Alprazolam	Anxiety
Seroquel/Quetiapine	Depression
Haloperidol/Haldol	Agitation/Nausea
Omeprazole/Prilosec	Dyspepsia/GERD symptoms
Apixaban/Eliquis	Anticoagulant
Senna	Stool softener
Zofran	Nausea
Radiation/Chemotherapy	Decrease tumor size for comfort and quality of life

CULTURAL CONSIDERATIONS

- The process of death and dying is often accompanied by rites and rituals associated with culture and/or religious affiliation. It is necessary to discuss cultural and religious preferences and practices with the patient and their family to ensure culturally sensitive care at the end-of-life.
- **It is the responsibility of the practitioner to:**
    - discuss cultural/religious preferences with the patient and family without judgement or interference of one's own beliefs and practices
    - educate oneself on various cultural/religious practices, specifically how they pertain to death and dying
    - understand that education on cultural/religious practices are generalized and may not be practiced by all individuals of that culture/religion
        - hence the importance of discussing cultural/religious preferences with the patient and family to clarify needs and desires pertaining to cultural/religious practices and to avoid stereotypes
    - demonstrate awareness, sensitivity, and respect for cultural/religious preferences and practices
    - understand that some cultural/religious preferences and practices may contradict standard medical practice
        - for example, some cultures do not accept pain medication at the end-of-life; however that is a standard end-of-life practice

It is the practitioner's responsibility to provide culturally sensitive care to all patients and families despite their own beliefs and practices. Practitioners should be prepared to discuss cultural and religious preferences with the patient and become educated in order to adequately meet the needs of the patient and their family throughout the death and dying process.

SECTION

2

THE OCCUPATIONAL THERAPY PROCESS IN END-OF-LIFE CARE

ROLE OF OCCUPATIONAL THERAPY

THEORETICAL PRACTICE MODELS

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

RESPECTFUL DEATH MODEL

KAWA RIVER MODEL

EVALUATION

ASSESSMENTS

GOAL WRITING

DIFFICULT CONVERSATIONS

APPROACH TO TREATMENT

INTERVENTION

MEDICAL EQUIPMENT & ASSISTIVE TECHNOLOGY

OUTCOMES

ROLE OF OCCUPATIONAL THERAPY IN END-OF-LIFE CARE

The scope of OT practice in end-of-life care is extensive.

The primary role of OT is to adapt and modify occupations, skills, and environments to achieve occupational participation and engagement and enhance quality of life until death.

The objectives of OT intervention are to:

- **Enhance occupational participation/engagement**
- **Establish meaning through occupation**
- **Maximize independence within the constraints of the illness**
- **Maintain or relinquish roles and routines**
- **Enhance quality of life throughout the remaining life**
- **Prepare for death and facilitate a good death**

THEORETICAL PRACTICE MODELS

Practitioners must look to theoretical practice models to guide the OT process due to the shortage of evidence-based practice and available literature regarding the delivery of OT services in hospice and palliative care.

Despite the absence of a universal model or frame of reference to guide OT practice in end-of-life care, the following models can comprehensively guide the OT process with the appropriate therapeutic approach to address the occupational needs of patients at the end-of-life and their families.

Model for Occupation-Based Palliative Care

directly applies to OT practice in end-of-life care and is the primary model to guide intervention throughout the dying process (Yeh & McColl, 2019)

Respectful Death Model

focuses on establishing a therapeutic relationship and encouraging dialogue between the patient, family unit, and practitioner to guide the care plan with special consideration of the patient's values and lived experiences (Wasserman, 2007)

Kawa River Model

guides intervention for grief and bereavement, both before and after the death, through a visual representation of life experiences and perceived barriers, and promotes communication of thoughts, feelings, and perceived wellness (Weis et al., 2019)

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

The Model for Occupation Based Palliative Care identifies 5 themes to guide OT intervention in end-of-life care focusing on occupation (Yeh & McColl, 2019).

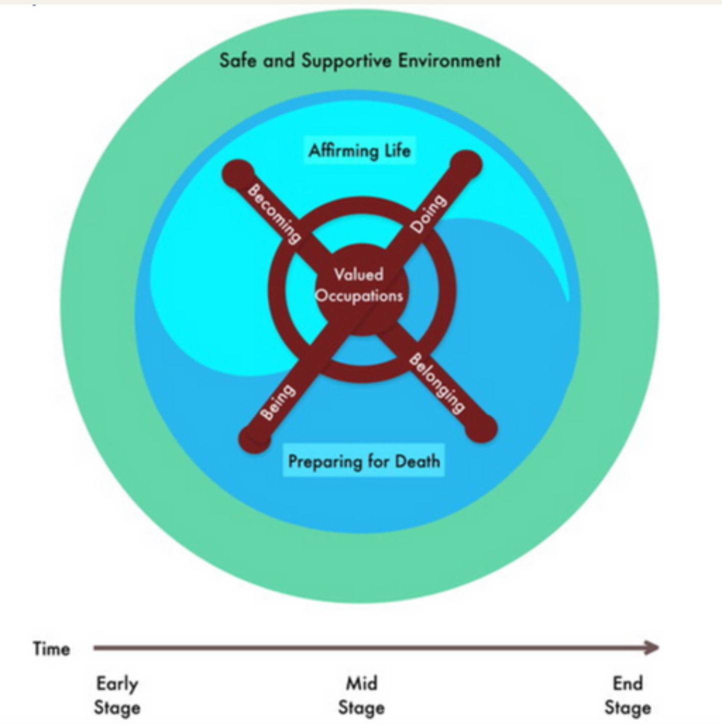
VALUED OCCUPATIONS

OCCUPATIONS OF DOING, BEING, BELONGING, & BECOMING

OCCUPATIONS CHANGE OVER TIME

AFFIRMING LIFE & PREPARING FOR DEATH

SAFE & SUPPORTIVE ENVIRONMENT



From "A Model for Occupation Based Palliative Care" by Yeh, H.-H. and McColl, M. A., 2019, Occupational Therapy in Health Care, 33(1), p.108-116 (doi.org/10.1080/07380577.2018.1544428). © Copyright 2019 by Taylor and Francis Journal. Reprinted by permission of Informa UK Limited, trading as Taylor & Francis Group, http://www.tandfonline.com.

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

VALUED OCCUPATIONS

Understanding the *valued* and *prioritized* occupations that patients desire to engage in during their remaining days, weeks, or months of life is important to maintaining a client-centered approach.

These valued occupations become the goals and center focus of treatment.

- Valued occupations at the end of life may include:
  - daily routines
  - hobbies
  - long-held dreams
  - preparing for death
  - creating a life-review
  - completing last wishes
  - discussing beliefs about death
  - discussing end-of-life choices
- Engaging in *valued occupations* helps prevent the loss of roles and personal identity and is directly associated with a **good death** experience. The practitioner must maintain a client-centered approach to help patients maintain a sense of control over the physical, social, psychological, and spiritual dimensions of their life and death (Yeh & McColl, 2019; Russell & Bahle-Lampe, 2016).

The Institute of Medicine defines a **good death** as “one that is free from avoidable suffering for patients, families and caregivers in general accordance with the patients’ and families’ wishes” (Field & Cassel, 1997, p.24).

Themes of a **good death** experience include: (Meier et al., 2016)

- preferences for dying process
- relationship with providers
- religiosity/spirituality
- emotional well-being
- life completion
- treatment preferences
- dignity
- family
- quality of life
- pain free

- Recognizing valued occupations at the end-of-life allows the practitioner to facilitate **prioritized engagement** in occupations throughout the dying process that coincide with the patient’s capabilities and facilitate a good death experience in accordance with the patient's wishes.

Prioritized Engagement is focusing occupational engagement on the patient’s priorities and desires as they change and evolve throughout the dying process, overall maintaining focus on what the patient finds meaningful in that particular stage of dying (Hammill et al., 2019).

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

OCCUPATIONS OF DOING, BEING, BELONGING, & BECOMING

(Yeh & McColl, 2019)

DOING OCCUPATIONS

- actions that the patient is actively engaged in that can be objectively observed
- may include personal care, community outings, or leisure activities

BEING OCCUPATIONS

- reinforce the patient’s sense of existence and identity, often consisting of life review and reflection, spiritual activities, journaling, and volitional narratives
- help patients cope with anxiety and uncertainty and provide them with a sense of personal worth

BELONGING OCCUPATIONS

- facilitate expressions of emotion and appreciation to others and help tie the patient to loved ones through relationship
- affirm roles and relationships through occupation; may consist of legacy projects, therapeutic groups, sharing of personal life experiences, or passing family history onto the next generations
- correspond to the commonly seen priority of spending quality time with family and friends through social participation at the end of life (Hammill et al., 2019)

BECOMING OCCUPATIONS

- promote an internal transformative process within the patient that facilitates engagement with the future, whether by consolidating his or her legacy, or preparing for death

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

AFFIRMING LIFE AND PREPARING FOR DEATH

Throughout the trajectory of the dying process, there is a delicate balance and shift between occupations that **affirm life** and occupations that **prepare for death**, especially as occupational performance declines (Bye, 1998; Bye et al., 2009; Hammill et al., 2019)

AFFIRMING LIFE

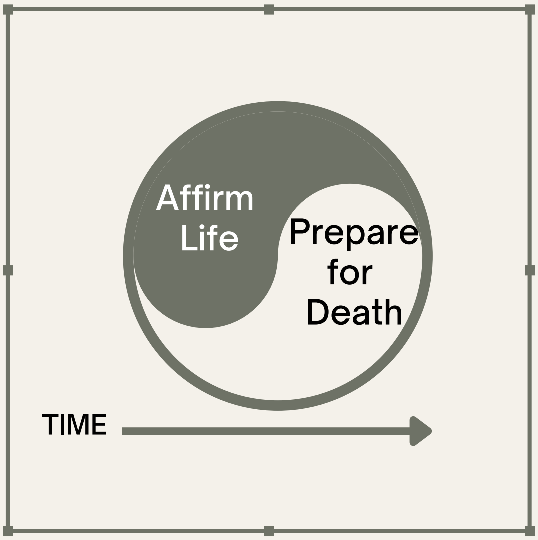
- Promoting autonomy and control
- Maintaining normal occupations despite functional declines (Bye, 1998)
- *Doing* and *Becoming* occupations

PREPARING FOR DEATH

- Enhancing comfort, finding closure with life and loved ones, and making peace with death (Bye, 1998)
- Legacy work, a *being* occupation, is often desired by patients during their transition to preparing for death (Martin & Herkt, 2018)
- *Being* and *Belonging* occupations

In this case, occupation is twofold, providing a sense of meaning to life while also serving as a vehicle with which the patient can find peace with death (AOTA, 2017).

The balance and shift between occupations that *affirm life* and *prepare for death* can be visualized as a yin-yang symbol; over time as death approaches, affirming life occupations become less pertinent, and preparing for death becomes of greater value (Yeh & McColl, 2019).



Adapted from "A Model for Occupation Based Palliative Care" by Yeh, H.-H. and McColl, M. A., 2019, Occupational Therapy in Health Care, 33(1), p.108-116 (doi.org/10.1080/07380577.2018.1544428). © Copyright 2019 by Taylor and Francis Journal. Reprinted by permission of Informa UK Limited, trading as Taylor & Francis Group, http://www.tandfonline.com.

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

OCCUPATIONS CHANGE OVER TIME

(Bye et al., 2009; Yeh & McColl, 2019)

Valued and desired occupations change over the course of a terminal illness.

The three stages of dying - *early*, *middle*, and *end* - reflect the degree of deterioration in the patient's condition and affect the patient's desires, needs, and abilities to carry out occupation (Bye et al., 2009).

EARLY STAGE

- Patient can be expected to perform full range of desired occupations.
- Intensity of occupations may require adjustment to respond to health-related constraints.
- Patient may prioritize work, life roles as a parent or spouse, or cooking dinner for their family as they did before the diagnosis.
- **'Doing' and 'Becoming'** occupations **affirm life.**

MIDDLE STAGE

- Occupations become more restricted.
- Occupations shift to accommodate the dying process.

END STAGE

- Physical and mental deterioration impede ability to engage in 'doing' occupations.
- Priorities shift to supporting relationships and social engagement.
- Prioritized occupations may include comfort, pain management, and finding closure.
- **'Being' and 'Belonging'** occupations **prepare for death.**

Throughout the dying process, the focus of intervention gradually shifts from **occupational *performance***, to **occupational *participation*** and ***engagement*.**

Understanding what the patient finds meaningful in each stage of the dying process is imperative to maintaining a *client-centered approach* to care.

MODEL FOR OCCUPATION BASED PALLIATIVE CARE

SAFE & SUPPORTIVE ENVIRONMENT

- A safe and supportive environment is essential to the delivery of OT services in end-of-life care. Whether the patient's physical environment is their home, a hospital, or inpatient facility, a safe, comfortable, and supportive environment where they can spend their final days, weeks, or months is imperative to facilitating quality of life and a good death.

- Personal and contextual environments may require modification to promote safety and autonomy and to sustain occupational engagement (Mueller et al., 2021).

- It is important to tend to both human and non-human environments, such as patient positioning, prescription and use of assistive devices, or home modification (Yeh & McColl, 2019). The patient's environment plays an integral role in their ability and opportunity to engage in occupation, directly impacting quality of life.

THE RESPECTFUL DEATH MODEL

The Respectful Death Model (RDM) is a holistic research-based practice model created to improve care at the end-of-life for patients and their families. It focuses on establishing a therapeutic relationship among the patient, family, and practitioner (Wasserman, 2007).

This model is used in OT treatment to establish the overarching climate for patient care and facilitates the rapport between the patient and practitioner.

- The purpose of the RDM is to establish a rapport and encourage dialogue with the patient and family to guide the care plan with special consideration of the values and lived experiences of the patient.
- This model requires the practitioner to view the patient as an individual rather than a disease or diagnosis, and facilitates client-centered care by understanding the patient's desires and wishes through encouraged communication.
- The RDM describes how to initiate difficult conversations about death and dying to explore the patient's and family's expectations.
- This model guides communication towards topics such as gauging the patient's understanding of their illness, who is to be involved in healthcare decisions, what are their beliefs about the future, what is their understanding of the dying process, and what are the patient's hopes and fears for the future.

RDM at a glance

- "A practical, research-based holistic tool meant to foster the education of varied disciplines in end-of-life care.
- Details the establishment of therapeutic relationships with patients and their families and, as a result, their stories are heard and incorporated into the care plan.
- Practitioners establish therapeutic relationships with their patients and families, ensuring frank dialogues about death and resultant respectful deaths."

(Wasserman, 2007, p.621)

KAWA RIVER MODEL

The Kawa River Model can be used to guide OT intervention for patients and families working through grief and bereavement.

- The role of the practitioner continues even after the death of the terminal patient. Families are offered bereavement services, covered by the Medicare Hospice Benefit, for up to 13-months after the death. Therefore, this model can be utilized to guide OT treatment for grief and bereavement, both before and after the death.
- The Kawa River Model demonstrates the natural flow of life and represents the inseparable nature of individuals, their social environments, occupations, and their natural and spiritual contexts (Iwama et al., 2009; Cole & Tufano, 2020).
- This model depicts how occupational challenges, both internal and external, impact the natural flow of one's life, represented by a river. Internal challenges are client factors, including body functions, body structures, and values, beliefs, and spirituality. External challenges include occupational patterns, contexts, environments, and activity demands (Cole & Tufano, 2020).

The Kawa River Model serves as a metaphor, encompassing the following elements, and represents the flow of life through time and space among internal and external barriers (Cole & Tufano, 2020; Iwama et al., 2009).

- **Water** represents the flow of life and quality of health, often portraying the entire lifespan through death.
- **Rocks** represent the problems and circumstances of life, which vary in size, impeding the flow of the water.
- **Driftwood** represents personal attributes as assets or liabilities that can either help or hinder the flow of the water.
- **Bottom and sides** of the riverbed represent the external environment which influences the range of flow and impacts social and relational factors.
- **Spaces** between the elements represent the opportunity for OT intervention to shift the elements of life that may impede occupational participation and can create better flow of the water.
- **Width and depth** of the riverbed depict the available capacity and opportunity for occupation with the presence of rocks and driftwood.

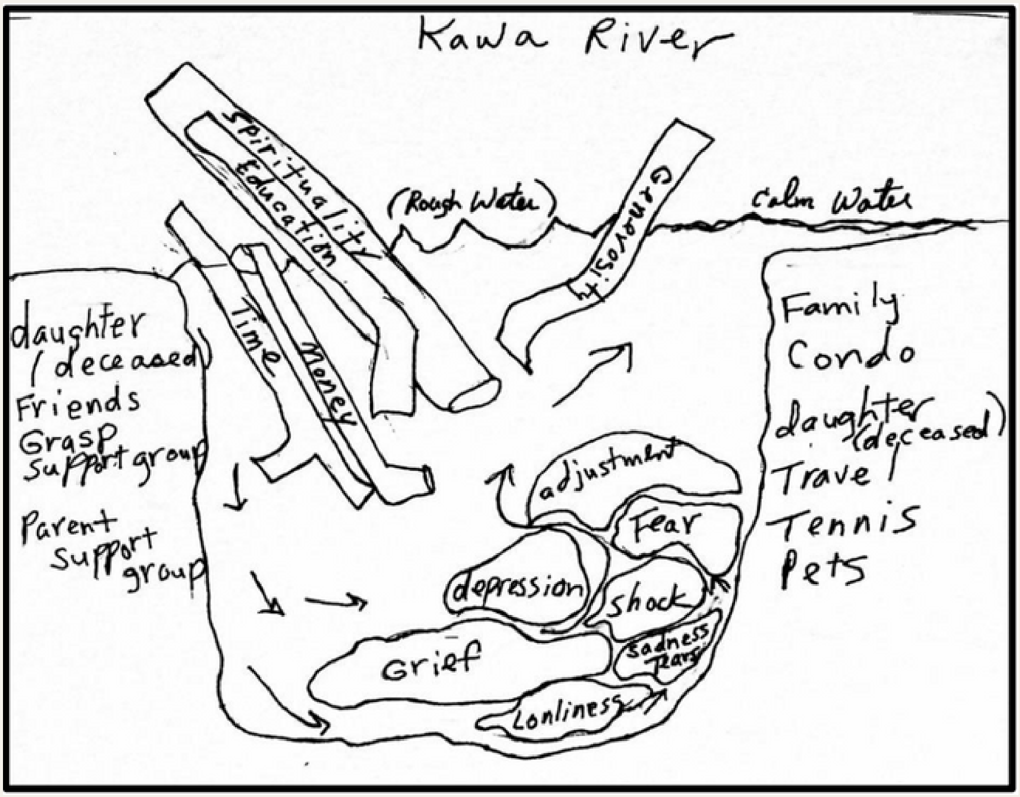
KAWA RIVER MODEL

- The Kawa River Model can be utilized in practice by having the patient/family draw their own Kawa River. This allows the individual to create a visual representation of their life experiences and perceived barriers, promoting communication of their thoughts, feelings, perceived wellness through a means of drawing.

- The Kawa River provides the griever with a mode of communication, and a method of self- and life-reflection. The drawing then guides the practitioner in initiating discussion and cultivating an understanding of how the individual views their life and their capacity for occupation and well-being following, or anticipating, loss (Weis et al., 2019).

- An image below is an example of the Kawa River Model used in OT intervention for parents grieving the loss of a child. This example demonstrates the social and personal contexts as the sides of the riverbed, the depth of the riverbed floor, the driftwood as barriers and facilitators to water flow, and the rocks inhibiting flow.

- This model provides the griever and OT practitioner with a visualization of the barriers inhibiting the natural flow of life, therefore providing a direction for intervention (Weis et al., 2019).



From "Life After Losing an Adult Child to a Drug Overdose: A Kawa Perspective," by Weis et al., 2019, The Open Journal of Occupational Therapy,7(3), p.1-14. (doi.org/10.15453/2168-6408.1488). © Copyright 2019 by Weis et al. Reprinted with permission from corresponding authors.

EVALUATION

- Evaluation identifies the patient's **needs** and **desires** combined with an analysis of performance; this determines what the patient can and cannot do, what the patient wants to do, and the supports and barriers to closing the gap between them (AOTA, 2005, 2020).
- Evaluation is ongoing, allowing necessary adjustments of treatment to be commensurate with the patient’s priorities and declining functional capacities throughout the dying process (Pizzi, 1984).
- Equipment needs and environmental modifications should be determined throughout evaluation.
- Evaluation begins with a thorough review of the patient’s diagnosis, stage of disease progression, estimated life expectancy, comorbidities, pain, medications, and level of cognition (Javier & Montagnini, 2011). Once contact is made with the patient and family, an occupational profile/occupational history, is to be developed.

OCCUPATIONAL PROFILE/HISTORY

What to include in an occupational profile/history:

- summary of occupational history
- patterns of daily living (habits, routines)
- life roles and role-related tasks
- occupational interests, values, needs, and priorities
- patient and family concerns
- identification of what is *meaningful* to the patient and family
- profiles of social history/ living environment/ religious or spiritual preferences/ support system

- An occupational profile through the patient’s narrative helps to determine which occupations are to be prioritized throughout the dying process and often results in a "bucket list", which helps facilitate *prioritized engagement* throughout the intervention process (Hammill et al., 2019).
- Utilize the occupational profile to understand the patient, family, and caregivers’ views and expectations surrounding death and dying, with special attention to the social, cultural, and spiritual influences on these beliefs and expectations (AOTA, 2005; Burkhardt et al., 2011).
- This process should be continuous throughout the duration of treatment.

The goal of evaluation is to determine what is most meaningful to the patient

EVALUATION

ANALYSIS OF OCCUPATIONAL PERFORMANCE

- Analysis of occupational performance consists of observing the patient, and in some instances, the caregiver, perform daily occupations and desired activities to determine their level of functioning, capacity for participation, and available performance skills to engage in desired activities and roles.
- This will determine the demands of the activity and identify the supports and barriers to participation within the context and environment (Burkhardt et al., 2011; Montagnini et al., 2020).
- Assess the patient’s remaining functional capacities and performance skills that support continued performance and identify adaptive and compensatory strategies and environmental modifications to *narrow the gap between the activity demands and patient’s performance skills* (AOTA, 2005; Burkhardt et al., 2011).
- Analyzing occupational performance is only appropriate if the patient desires continued participation in occupations that require specific levels of functional capacity, such as ADLs. If goals are to promote occupational engagement rather than participation, analysis of performance may not be appropriate.
- Assess environmental safety and determine environmental supports and barriers to occupation.
- Biomedical assessments such as manual muscle testing, range of motion, and perceptual testing may also be performed to assess functional capacities; however, this is only appropriate in view of occupational functioning (Pizzi, 1984).
- Assessment of caregiver skills may be necessary to determine the need for caregiver training and identify strategies for safety that are compatible with the caregiver’s skills and capabilities (AOTA, 2005; Burkhardt et al., 2011).

Understanding the patient’s goals and expectations through an occupational profile, analyzing occupational performance and skills, and recognizing the supports and barriers of the environment, provide the practitioner with the necessary information to develop a treatment plan that best supports the physical, social, emotional, and spiritual needs of the patient and their family.

ASSESSMENTS

- During evaluation, assessments may be used to establish and modify goals and determine appropriate interventions.
- End-of-life care professionals may perform a variety of assessments upon new patient admission or during recertification periods to determine functional status and track disease progression.
- Although some assessments are completed by other members of the interdisciplinary team, OT practitioners will have access to assessment results which can be utilized to inform OT intervention. OT specific assessments will be administered by the OT practitioner.
- Due to the inevitable decline in functioning that accompanies the dying process, standardized assessments may be used less frequently.
    - Non-standardized assessments that evaluate *quality of life, mental health*, and *pain* may be used more frequently at the end-of-life.
    - However, many quality of life assessments are not appropriate for patients at the end-of-life, indicating the need for a *quality of death* assessment tool.

OT Specific Assessments:

Links to OT assessments can be found under Resources on pg.48

- Palliative Performance Scale
    - Describes and tracks changes in functional status
- Karnofsky Performance Scale
    - Determines functional impairment and effectiveness of therapeutic treatments
- Borg Rating of Perceived Exertion Scale
- Kingston Caregiver Stress Scale
- Canadian Occupational Performance Measure (COPM)
- Edmonton Functional Assessment Tool
- Katz ADL
- Lawton Instrumental ADL
- Barthel Index
- Functional Independence Measure

End-of-Life Care Assessments:

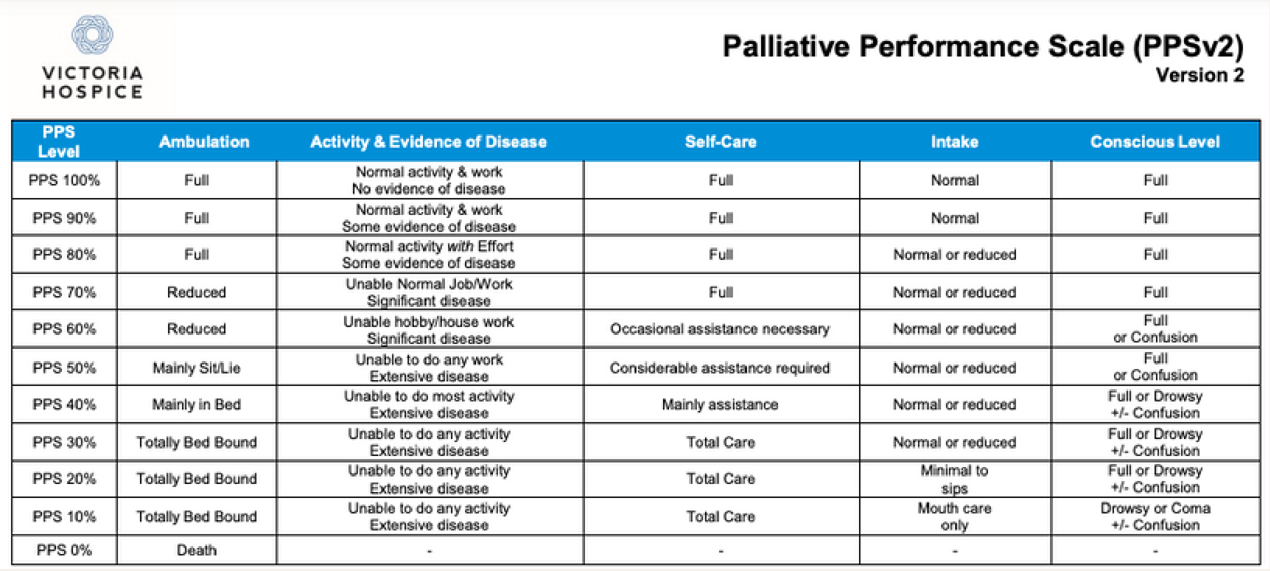
(Javier & Montagnini, 2011)

- Functional Assessment Staging Tool
    - Tracks progression and loss of function over time for patients with dementia
- Mid-Arm Circumference
    - Tracks weight loss and muscle wasting
- Body Mass Index (BMI)
    - Tracks weight loss throughout the dying process
- Palliative Performance Scale
- Karnofsky Performance Scale
- Kingston Caregiver Stress Scale
- Pain Assessment in Advanced Dementia Scale (PAINAD)
- Braden Scale for Predicting Pressure Sore Risk
- Hospice Fall Risk

ASSESSMENTS

Palliative Performance Scale

http://www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf



VICTORIA HOSPICE

Palliative Performance Scale (PPSv2)

Version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
PPS 100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
PPS 90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
PPS 80%	Full	Normal activity *with* Effort Some evidence of disease	Full	Normal or reduced	Full
PPS 70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
PPS 60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
PPS 50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
PPS 40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
PPS 30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
PPS 20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
PPS 10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
PPS 0%	Death	-	-	-	-

Instructions for Use of PPS (see also definition of terms)

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

   Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'
3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation
The items '**mainly sit/lie**,' '**mainly in bed**,' and '**totally bed bound**' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed 'bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'**Reduced ambulation**' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. Activity & Extent of disease
'**Some**,' '**significant**,' and '**extensive**' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (eg. trying to walk the halls).

3. Self-Care
'**Occasional assistance**' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'**Considerable assistance**' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'**Mainly assistance**' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'**Total care**' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake
Changes in intake are quite obvious with '**normal intake**' referring to the person's usual eating habits while healthy. '**Reduced**' means any reduction from that and is highly variable according to the unique individual circumstances. '**Minimal**' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

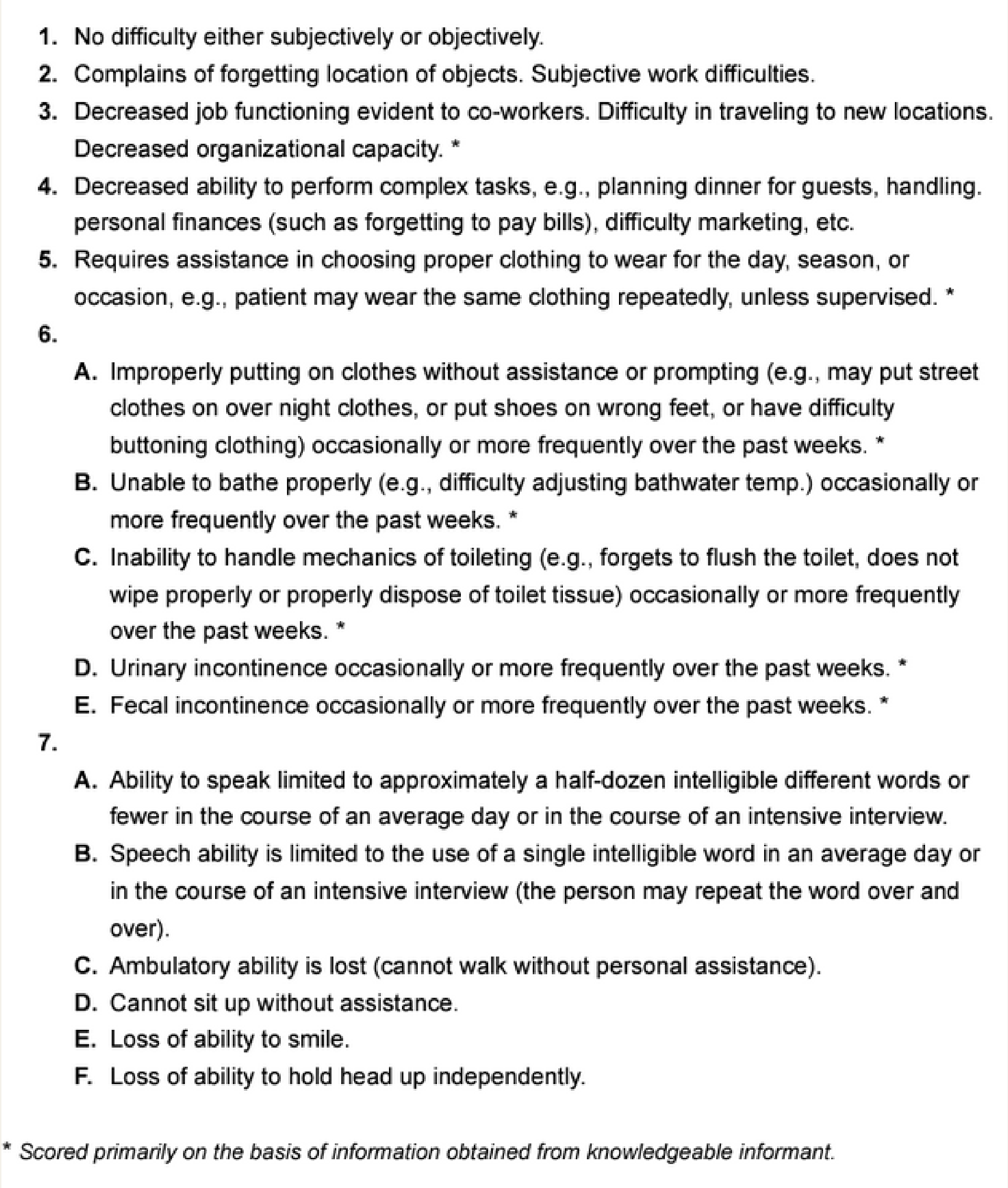
5. Conscious Level
'**Full consciousness**' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. '**Confusion**' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. '**Drowsiness**' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. '**Coma**' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

From *Victoria Hospice Society*, 2001, (http://www.npcrc.org/files/news/palliative_performance_scale_PPSv2.pdf).

ASSESSMENTS

Functional Assessment Staging Tool

https://www.capc.org/documents/download/962/



1. No difficulty either subjectively or objectively.
2. Complains of forgetting location of objects. Subjective work difficulties.
3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity. *
4. Decreased ability to perform complex tasks, e.g., planning dinner for guests, handling. personal finances (such as forgetting to pay bills), difficulty marketing, etc.
5. Requires assistance in choosing proper clothing to wear for the day, season, or occasion, e.g., patient may wear the same clothing repeatedly, unless supervised. *
6.
   - A. Improperly putting on clothes without assistance or prompting (e.g., may put street clothes on over night clothes, or put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks. *
   - B. Unable to bathe properly (e.g., difficulty adjusting bathwater temp.) occasionally or more frequently over the past weeks. *
   - C. Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks. *
   - D. Urinary incontinence occasionally or more frequently over the past weeks. *
   - E. Fecal incontinence occasionally or more frequently over the past weeks. *
7.
   - A. Ability to speak limited to approximately a half-dozen intelligible different words or fewer in the course of an average day or in the course of an intensive interview.
   - B. Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intensive interview (the person may repeat the word over and over).
   - C. Ambulatory ability is lost (cannot walk without personal assistance).
   - D. Cannot sit up without assistance.
   - E. Loss of ability to smile.
   - F. Loss of ability to hold head up independently.

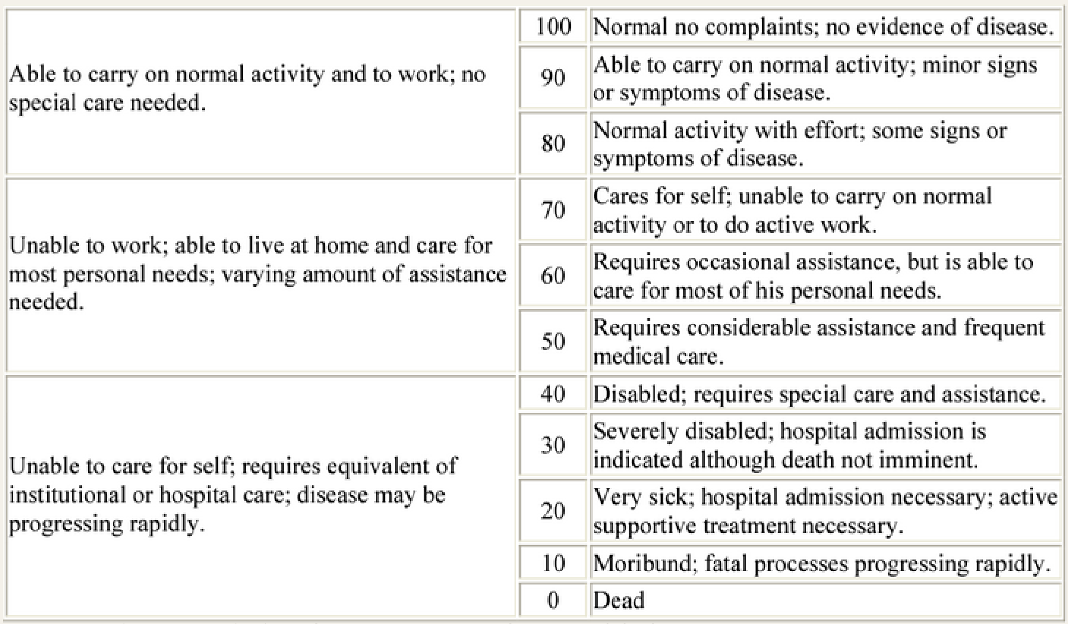
** Scored primarily on the basis of information obtained from knowledgeable informant.*

From *Center to Advance Palliative Care*, 2021 (https://www.capc.org/documents/download/962/). © Copyright 1984 by Barry Reisberg.

ASSESSMENTS

Karnofsky Performance Scale

http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf



Able to carry on normal activity and to work; no special care needed.	100	Normal no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance needed.	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of his personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly.	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead

From *National Palliative Care Research Center*, 2013, (http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf). In the public domain.

The **National Palliative Care Research Center** provides multiple valid and reliable measurement and evaluation tools for end-of-life care including those measuring:

- Pain and Symptom Management
- Functional Status
- Psychosocial Care
- Caregiver Assessment
- Quality of Life

npcrc.org/content/25/Measurement-and-Evaluation-Tools.aspx

GOAL WRITING

Therapy goals for patients at the end-of-life should reflect the declining nature of terminal illness and the dying process, and should therefore be modified frequently. Goals should focus on enhancing engagement rather than improving functional performance, and should be centered around the patient's meaningful and prioritized occupations.

Therapy goals in end-of-life care should:

- reflect the patient's desires and meaningful activities, and align with the objectives of intervention
- align with the objectives of OT intervention
- focus on enhancing *quality of life* and facilitating *occupational participation/engagement*, rather than occupational performance
- reflect the declining nature of the terminal illness, and may require frequent modification throughout the treatment process and disease progression
- not include levels of assist, unless appropriate
- not include a time stamp, unless appropriate

Therapy goals may also be written for caregivers, in which including an assist level and time stamp may be appropriate.

Examples:

- Provide adequate seating and positioning support to facilitate engagement in meaningful puzzle activity in order to maintain quality of life.
- Patient education on breathing techniques secondary to dyspnea to maintain engagement in meaningful social participation in order to sustain quality of life.
- Patient will demonstrate engagement in meaningful music to decrease feelings of anxiety and maintain quality of life.
- Patient will identify 3-5 meaningful end-of-life activities for prioritized engagement in meaningful occupations to maintain quality of life.
- Caregiver will demonstrate proper body mechanics in transferring patient from bed to wheelchair for patient and caregiver safety and quality of care.
- Caregiver will report engagement in meaningful occupations 1-2 times per week while receiving respite to facilitate occupational balance and enhance caregiver quality of life.

DIFFICULT CONVERSATIONS

- OT practitioners are equipped to engage in difficult personal conversations with patients and their families; however, conversations about the end-of-life are particularly delicate and emphasize the need for *empathy*, *active listening*, and a *systemic approach* to conversation.
- Conversations about the end-of-life should be approached with honesty, sensitivity, and patience. These conversations should occur over time, rather than all at once, and should happen after a trusting rapport with the patient and family has been developed.
- Conversation topics should reflect the patient's degree of decline (i.e., do not discuss activities of dying if the patient is still functionally capable).
- Unless the patient initiates, do not discuss death and dying on the first visit, rather focus on getting to know them as a *person* and determining what is meaningful and important to them.
- Resources such as the **Go Wish Game**, **5 Wishes** document, and **Hello Game** can be used to initiate difficult conversations and help the patient determine what is most important to them at the end-of-life. (See Resources on p.48)

- Aspects of difficult conversations:
    - determine who the patient would like to be present
    - discuss how much information and detail they would like to receive
    - determine the patient's current understanding of their situation
    - explore, acknowledge, and validate the patient and family's emotions, fears, and concerns
    - pace and tailor information to the patient's needs and level of understanding
    - foster realistic hope - provide honest and realistic information
    - encourage questions
    - be prepared to repeat information as needed
    - document patient reactions, concerns, and questions for discussion with interdisciplinary team

(Clinical Excellence Commission, 2016)

DIFFICULT CONVERSATIONS

Empathy

- Change your perspective
  - try putting yourself in the patient's position and adopt their mindset
  - do not try to make the patient's situation seem better (i.e., instead of saying "it will be OK", say, "I know this is difficult, I am here to support you")
- Recognize the patient's emotions and mirror them
  - whether the patient is happy and laughing or sad and crying, mirror those emotions and meet the patient where they are at
- Never judge the patient or their emotional reactions to their situation
- The patient's perspective is their truth, their feelings are never wrong

Active Listening

- Use appropriate body language
- Demonstrate emotion through facial expression, tone of voice, and body language
- Become comfortable with silence
- Justify the patient's thoughts and emotions
- Do NOT:
  - interrupt the patient
  - judge the patient
  - correct the patient on how they feel or what they think

Systemic Approach to Difficult Conversations

- <u>Evaluation</u>
  - establish a rapport
  - get to know the patient as a person, not an illness
  - explore the patient's understanding of their illness
- <u>Treatment</u>
  - determine what is most meaningful and important to the patient
  - focus on occupations that *affirm life*
  - continue learning about the patient and fostering a trusting relationship
- <u>Disease Progression</u>
  - reestablish what the patient finds meaningful and important throughout disease progression
  - discuss openly about activity modification and occupational changes
  - introduce occupations that *prepare for death* and "say goodbye"
- <u>End of Life</u>
  - explore questions and concerns
  - allow patient and family to express emotions and openly share thoughts while demonstrating empathy and active listening

(Davis et al., 2013; Taylor, 2008; Weiner et al., 2013)

APPROACH TO TREATMENT

A **client-centered approach** is of special importance when working with patients at the end-of-life; the priorities and goals of the patient are also those of the practitioner. Occupational therapy and end-of-life care are aligned by their foundations of client-centeredness and holistic nature of care.

- The approach to OT treatment in end-of-life care is different than that of a typical rehabilitative practice setting. The practitioner must adjust the therapeutic 'lens' in which they view treatment when working with patients at the end of life.
- In typical rehabilitative practice settings the goal of intervention is to enhance independence and assist the patient in returning to daily life occupations, utilizing establish/restore and create/promote approaches to treatment.
- Patients at the end-of-life are not expected to establish new skills or restore lost functions; therefore, a **modify** approach to treatment focusing on **adapting** and **compensating** for lost or declining client factors, and **preserving** remaining capacities is most appropriate (AOTA, 2017; Burkhardt et al., 2011).
- At the end-of-life "rehabilitation" is no longer the goal, but rather enhancing quality of life until death through engagement in meaningful occupations.

ADAPTATION, COMPENSATION, MODIFICATION, & PREVENTION

are the appropriate treatment approaches utilized to address the physical, psychological, and emotional declines that accompany the dying process and hinder occupational engagement and participation at the end-of-life.

OT Practitioners may also work to:

- **maintain** roles, performance patterns, remaining performance skills, and body functions
- **establish** new routines that align with the patient's available capacities
- **prevent** injury, exacerbation of symptoms, and isolation (by facilitating *socialization*)

(AOTA, 2005; Eriksson et al., 2016)

INTERVENTION

The scope of OT interventions in end-of-life care is extensive and will vary depending on the unique needs and desires of the patient.

A thorough review of the literature followed by thematic organization of interventions resulted in the following overarching objectives of OT intervention in end-of-life care:

- Enhance occupational participation and/or engagement
- Establish meaning through occupation
- Maximize independence within the constraints of the illness
- Maintain or relinquish roles and routines
- Prepare for death and facilitate a 'good death'
- Enhance quality of life throughout the remaining life

In addition to adaptation, compensation, and modification of occupations, skills, and environments, the literature supports interventions that target:

- occupational participation and performance
- participation and engagement in ADLs
- preparation for death
- legacy building
- patient education
- caregiver education and training
- grief and bereavement
- symptom management
- prescription of adaptive equipment and assistive technology

INTERVENTION

OCCUPATIONAL PARTICIPATION & PERFORMANCE

- **work/task simplification** strategies
  (Yeh & McColl, 2019)
- **positioning and body mechanics** to promote engagement in ADLs and social environments
  (AOTA, 2015; Frost, 2001; Hammill et al., 2019)
- **provision of adaptive equipment** for assistance with ADLs, reduction of time and effort required for task completion, and compensation for lost body functions and skills
  - grab bars
  - shower bench
  - dressing aids
  - UE supports
  - rocker knives
  - utensils
  - reachers
  - break extenders

  (AOTA, 2005, 2015; Montagnini et al., 2020; von Post & Wagman, 2019)
- **transfer training** for safety and increased participation
  (Chow & Pickens, 2020)
- **bed mobility** to promote increased independence
  (Eriksson et al., 2016; Frost, 2001)

OCCUPATIONAL PERFORMANCE VS. PARTICIPATION & ENGAGEMENT

Despite evidence reflecting positive outcomes of OT services enhancing occupational performance, the use of occupational participation and/or engagement are more appropriate outcome measures at the end-of-life.

Occupational performance assumes functional gains and fails to accommodate the inevitable functional declines that accompany the dying process.

Occupational participation and engagement, however, do not require performance skills and can be attainable throughout the dying process.

(AOTA, 2017; Chow & Pickens, 2020)

INTERVENTION

PARTICIPATION & ENGAGEMENT IN ADLS

- **Adapting and compensating ADL tasks** to align with the patient's remaining functional capacities, preserve remaining functions, increase independence, and facilitate participation
- Prescribing **adaptive equipment**
- **Addressing symptoms** that inhibit ADL participation and performance
- **Affirming life** by providing a sense of control over life and the environment, thus enhancing quality of life through ADL participation

(AOTA, 2015; Badger et al., 2016; Chow, 2015; Martin & Herkt, 2018; von Post & Wagman, 2019).

PREPARING FOR DEATH

Repairing and prioritizing relationships
Discussing death
Putting affairs in order
Making last wishes and final arrangements
Saying goodbye
Legacy building

(AOTA, 2017)

LEGACY BUILDING

Legacy works are projects or activities that facilitate life review and may result in a product that can be used to remember a loved one both before and after they pass. Patients who engage in legacy work demonstrate decreased depression and hopelessness and enhanced quality of life.

Legacy work facilitates *meaning, purpose, identity,* and *communication.*

<u>Legacy projects may include:</u>

- Scrapbook
- Recipe book
- Quilt out of clothing
- Video/audio recordings
- Writing letters
- Story telling
- Meaningful conversations
- Memory box with keepsakes
- Passing on possessions/family heirlooms

(Allen et al., 2008)

INTERVENTION

PATIENT EDUCATION

Education provides comfort to patients and their families by creating awareness and understanding of what is happening to and around them.

- Stages of the dying process and expectations of each stage
- Nature and course of the disease
- Effect of disease and dying process on occupational participation
- Techniques for breathing, positioning, and coping
- Methods to maximize functional performance/participation
- Objectives and benefits of OT intervention

(Javier & Montagnini, 2011; Montagnini et al., 2020; WFOT, 2016)

CAREGIVER EDUCATION & TRAINING

OT practitioners instill hope and provide care to caregivers just as they do with patients at the end-of-life.

- Provide caregiver education and training on patient care:
    - proper body mechanics
    - manual handling techniques
    - task simplification
    - therapy objectives
    - safe transferring techniques
    - adaptive techniques to promote safety and longevity
    - energy conservation strategies
    - exercise programs
    - adaptive equipment
    - patient positioning

  (AOTA, 2017; Yeh & McColl, 2019; Hammill et al., 2019; Montagnini et al., 2020)

- Modify demands of caregiving tasks, habits, and routines to meet the performance skills and capacities of the caregiver (Burkhardt et al., 2011).

- Decrease caregiver burden by promoting occupational balance. Caregivers often struggle with balancing caregiver demands with personal occupations, leading to *occupational disengagement* and *caregiver burnout*. Occupational balance facilitates a greater quality of life for the caregiver and quality of care provided to the terminal patient. (Hammill et al., 2019; Keesing & Rosenwax, 2011; Knecht-Sabres et al., 2019)

- Ensure that OT services toward caregivers are not limited to giving advice on equipment and manual techniques; it is within the role and scope of OT practice to address the caregivers' unique occupational needs (Keesing & Rosenwax, 2011).

INTERVENTION

GRIEF & BEREAVEMENT

- Family members and caregivers experience changes in their daily occupations, roles, habits, and routines both before and after losing a loved one.
- Caregivers' roles change once the peson they cared for has died, and family members may have to assume new roles within the family unit to accommodate those once held by the deceased. Initially, this may cause *occupational disruption*. Practitioners should be prepared to recognize an individual's disconnection from occupation during grief and bereavement (Dahdah & Joaquim, 2018).
- It is important to acknowledge that each individual experiences grief differently,emphasizing the importance of client-centered treatment.
- ***Bereavement*** is the objective reality one faces after loss and is the process of actively searching for meaning after loss. Therefore, during bereavement, families must reconstruct meaning to help them adapt to their changing world. (Dahdah & Joaquim, 2018; Hoppes, 2005)
- Meaning comes from engagement in everyday life, and occupation is an effective, intrinsic source of meaning-making; therefore, "meaning emerges from occupation, and occupation emerges from meaning" (Dahdah & Joaquim, 2018, p.12).
- ***Grief*** is one's natural reaction to loss and is not constrained by time. Grief manifests itself in emotional, cognitive, functional, and behavioral changes, and is typically expressed through emotional pain and sadness. (Pathways Health, n.d.; Zisook & Shear, 2009)
- Grief and bereavement impact the interaction between 'doing', 'being', 'belonging', and 'becoming' occupations; therefore, practitioners must re-establish meaning and harmony among these domains (Dahdah & Joaquim, 2018). Establishing new, or resuming daily occupations, roles, habits, and routines, will assist the grieving with continued occupational participation and aid in meaning-making.
- Narrative therapy can also be beneficial for the family to process the death and their grief and guide the practitioner in understanding how occupational meaning has shifted since the loss (Hasselkus, 2011).
- Artistic interventions such as therapeutic use of music, art, writing, and other modes of visual arts have been found beneficial in meaning-making and processing grief (Dahdah & Joaquim, 2018).

INTERVENTION

SYMPTOM MANAGEMENT

- **energy conservation** techniques for productive use of existing energy (AOTA, 2015; Burkhardt et al., 2011; Russell & Bahle-Lampe, 2016)
- **body mechanics** to allow for energy conservation, and reduction in pain and fatigue (AOTA, 2015)
- **positioning** to improve breathing, relieve pressure, and reduce pain and fatigue (Burkhardt et al., 2011, Frost, 2001)
- **relaxation techniques** for fatigue, stress management, and coping with life changes (Chow & Pickens, 2020; Montagnini et al., 2020)
- **techniques for symptom management** such as pain, fatigue, and stress (Mueller et al., 2021)
- **training on transitional movements** to enhance the ability to change position, promote comfort, and aid in transfers (Frost, 2001)

ADDITIONAL INTERVENTIONS:

- Socialization
- Maintaining relationships
- Medication management
- Occupational exploration
- Maintaining roles & role related tasks
- Splinting
- Positioning
- Exercise Program
- Range of motion
- Relaxation & Coping
- Seating & Mobility

MEDICAL EQUIPMENT & ASSISTIVE TECHNOLOGY

Prescription of equipment and assistive technology for modification of activities and environments is an important role of the OT practitioner in end-of-life care. All members of the interdisciplinary team may order a variety of medical equipment for patients; however, specialty pieces of equipment and technology are specific to OT practice.

- **Equipment Utilized in End-of-Life Care:**
    - hospital bed
    - bed rails
    - wheelchair
    - walker
    - fall mat
    - specialty mattresses
    - shower chair
    - geri-chair
    - oxygen concentrator
    - oxygen tank/cart
    - nebulizer
    - bedside commode
    - hoyer lift
    - trapeze bar
    - overbed table

- **OT Specific Equipment & Assistive Technology**
    - shower chair
    - bedside comode
    - raised toilet seat
    - grab bars
    - reachers
    - slide board
    - adaptive seating
    - dressing aides
        - button hook, zipper ring, adaptive shoe laces, shoe horn
    - cooking aides
        - rocker knives, adaptive can/jar/bottle openers,
    - feeding aides
        - adaptive utensils, plate guard

Note: Power wheelchairs are not covered under the Medicare Hospice Benefit. Therefore, patients with progressive neurological diseases, such as ALS, will need to procure a power wheelchair while receiving palliative care *before* enrollment in hospice.

OUTCOMES

The primary outcomes of OT intervention in end-of-life care are **occupational participation** and **engagement, quality of life** for the time remaining, and achievement of a **good death.**

It is important to note the absence of a widely accepted standardized outcome measure for OT in end-of-life care. Due to the terminal nature of dying and the end-of-life practice setting, it is difficult to measure the outcomes of OT treatment in an objective and quantitative manner.

Many quality of life assessments may be inappropriate for patients at the end-of-life due to questions regarding the future.

Some research supports the use of the *Canadian Occupational Performance Measure (COPM)* in end-of-life care (Chow & Pickens, 2020).

Overall, there is a need for further research to determine an adequate and appropriate measurement tool to assess and quantify the benefits of OT in end-of-life care.

(AOTA, 2005; Burkhardt et al., 2011; Chow & Pickens, 2020)

RESOURCES

TOOLS:

- **Barbara Karnes Booklets**
    - https://bkbooks.com/ gclid=CjwKCAiAxP2eBhBiEiwA5puhNdXQ-M_Qv5gwqk3_qw8PJ6ahA9r_Cb9ORewXQlOIemFUZoc5HMVMfRoCkGkQAvD_BwE
- **Hello Game**: "Conversation starters about Living, Dying, and What Matters Most"
    - https://commonpractice.com/collections/hello-game
- **Go Wish**
    - http://gowish.org/
- **5 Wishes**
    - https://www.fivewishes.org/
- **The Conversation Project**
    - https://theconversationproject.org/
- **Kitchen Table Conversations**
    - https://kitchentableconversations.org/

ASSESSMENT TOOLS:

- **Palliative Performance Scale**
    - http://www.npcrc.org/files/Resources/PPSv2%20English%20-%20Sample.pdf
- **Karnofsky Performance Scale**
    - http://www.npcrc.org/files/news/karnofsky_performance_scale.pdf
- **Borg Rating of Perceived Exertion Scale**
    - https://www.sralab.org/rehabilitation-measures/borg-rating-scale-perceived-exertion
- **Kingston Caregiver Stress Scale**
    - http://www.kingstonscales.org/caregiver-stress-scale.html
- **Canadian Occupational Performance Measure**
    - https://www.thecopm.ca/
- **Edmonton Functional Assessment Tool**
    - http://www.npcrc.org/files/news/edmonton_symptom_assessment_scale.pdf
- **Katz ADL**
    - http://www.npcrc.org/files/news/katz_index_of_independence_in_activities_of_daily_living.pdf
- **Lawton Instrumental ADL**
    - https://dementiaresearch.org.au/wpcontent/uploads/2016/06/Lawton_IADL_Scale.pdf
- **Barthel Index**
    - https://www.mdapp.co/barthel-index-for-activities-of-daily-living-adl-calculator-361/
- **Functional Independence Measure**
    - https://www.physio-pedia.com/Functional_Independence_Measure_(FIM)

RESOURCES

WEBSITES:

- **American Occupational Therapy Association - Fact Sheet**
    - https://www.aota.org/~/media/Corporate/Files/AboutOT/Professionals/WhatIsOT/PA/Facts/FactSheet_PalliativeCare.pdf
- **World Federation of Occupational Therapists - Position Statement**
    - https://www.wfot.org/resources/occupational-therapy-in-end-of-life-care
- **National Hospice and Palliative Care Organization**
    - https://www.nhpco.org/
- **The Medicare Hospice Benefit**
    - https://www.medicare.gov/what-medicare-covers/what-part-a-covers/how-hospice-works
- **Center to Advance Palliative Care**
    - https://www.capc.org/
- **Hospice Foundation of America**
    - https://hospicefoundation.org/

VIDEOS:

- **"I See Dead People: Dreams and Visions of the Dying"** - Dr. Christopher Kerr
    - https://youtu.be/rbnBe-vXGQM
- **"More to Dying Than Meets the Eye"** - Martha Atkins
    - https://youtu.be/vg8WAv0YT9c
- **"What Really Matters at the End of Life"** - BJ Miller
    - https://www.ted.com/talks/bj_miller_what_really_matters_at_the_end_of_life?utm_campaign=tedspread&utm_medium=referral&utm_source=tedcomshare

BOOKS:

- **Being Mortal**
    - https://www.amazon.com/Being-Mortal-Illness-Medicine-Matters/dp/1250081246
- **The Last Gifts**
    - https://www.jillianbrasch.com/the-last-gifts/
- **The Five Invitations**
    - https://fiveinvitations.com/

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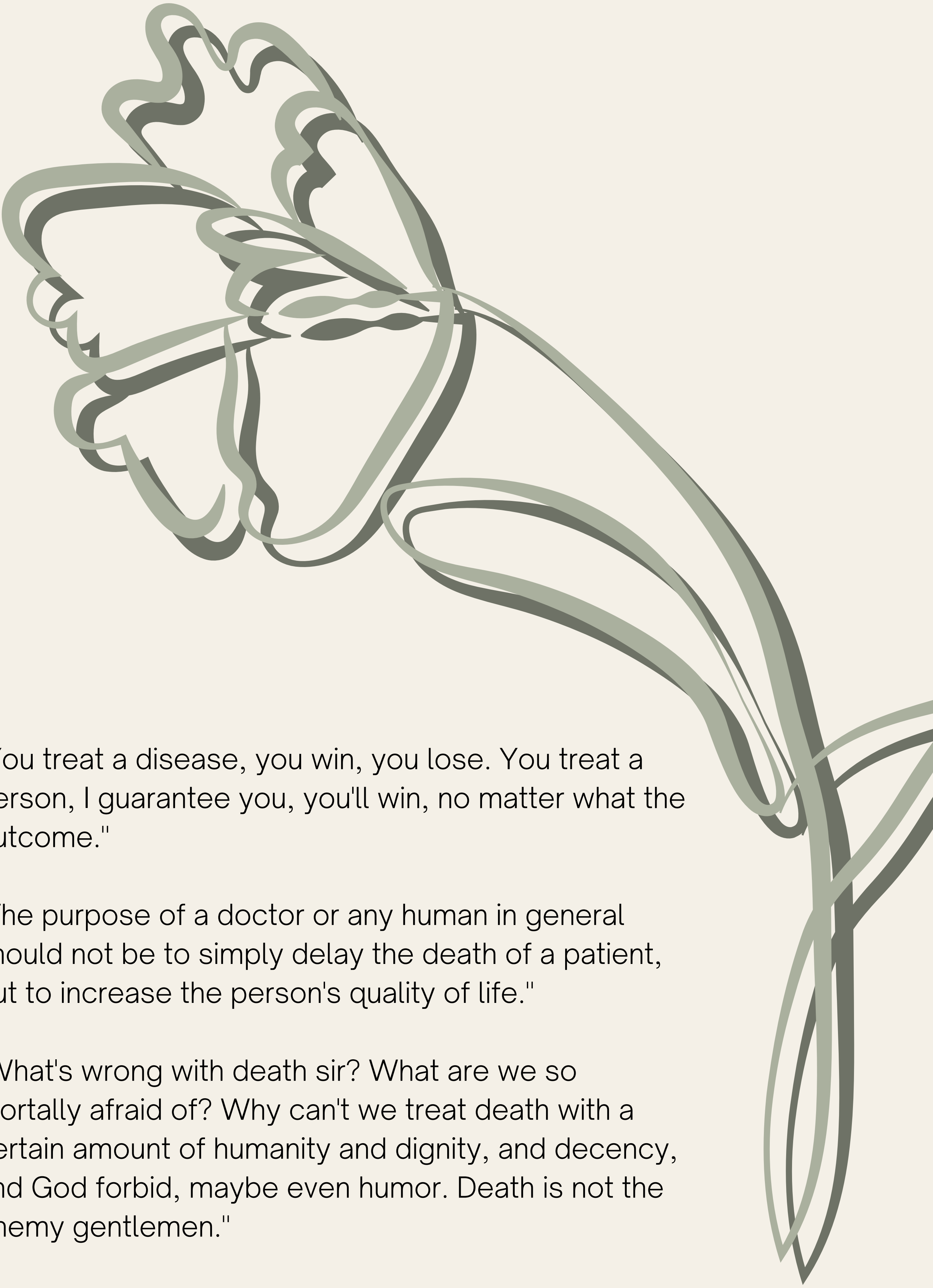

"You treat a disease, you win, you lose. You treat a person, I guarantee you, you'll win, no matter what the outcome."

"The purpose of a doctor or any human in general should not be to simply delay the death of a patient, but to increase the person's quality of life."

"What's wrong with death sir? What are we so mortally afraid of? Why can't we treat death with a certain amount of humanity and dignity, and decency, and God forbid, maybe even humor. Death is not the enemy gentlemen."

-Patch Adams (Robin Williams)