

Cultivating Competence and Compassion in Dementia Care:  
It's More Than What you Know, It's How you Show It.

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### Top 8 things...

That I wish I would have known when I started working  
with people living with dementia, that would have  
made me more competent and compassionate.




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### Kay and Einar's Great Adventure




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- The ability to do something successfully or efficiently
- Possession of required skill, knowledge, qualification, or capacity.
- Commitments, knowledge, and skills that enable a person to act effectively in a job or situation.

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Sympathetic consciousness of other's distress, together with a desire to alleviate it.

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"Not all of us can do great things, but we can do small things *with great love*."




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- By 2030, the number of estimated new cases of Alzheimer's in U.S is projected to be 615,000, and by 2050, the number of estimated new cases is 959,000.
- By 2025, the number of people age 65 and older with Alzheimer's in U.S is projected to reach 7.1 million — almost a 29% increase from the 5.5 million age 65 and older affected in 2018.
- By 2050, the number of people age 65 and older with Alzheimer's in U.S may grow to a projected 13.8 million, if no new developments are found to prevent, slow, or cure Alzheimer's.

• Alzheimer's Association. 2018. Facts and Figures.

### Scope of the Problem

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### Numbers

On

The

Rise

2018 Alz Facts & Figures Report

Nearly 1/3 of seniors who die each year in Colorado has Alzheimer's or other form of dementia.

157% increase in Alzheimer's deaths in Colorado since 2000.

Cost for caring for PLWD is estimated to total \$290 billion in 2018, and 1.1 trillion by mid-century.

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### Dementia Is...

A chronic or persistent disorder caused by brain disease or injury that is marked by memory disorders, personality changes, and impaired reasoning.

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### Umbrella of Dementia

- Alzheimer's Disease
- Vascular Dementia
- Lewy Body Dementia
- Frontotemporal Dementia

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### Alzheimer's Disease

- Is a degenerative brain disease. The most common cause of dementia--6<sup>th</sup> leading cause of death 65+
- Symptoms: Difficulties with memory, language, problem-solving and other cognitive skills that affect a person's ability to perform everyday activities.
- Difficulties occur because nerve cells (neurons) in parts of the brain involved in cognitive function have been damaged or destroyed (brain failure).

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### Dr. Alzheimer and Auguste Deter




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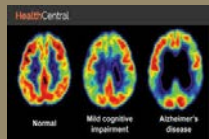
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### #1. Dementia is a Brain Disease




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### #2. No Cure for Dementia--- But not talked about as a "terminal illness."




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#3. We Often Avoid or Overwhelm  
People with Information about Dementia



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Active  
Listening  
and  
Teaching  
Back

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Mixed  
with  
What?



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#### #4. Powerful Role of Anticipatory Grief and Ambiguous Loss in Dementia




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**Anticipatory Grief:**  
The emotional pain and sadness that arises far in advance of an expectant loss or death.




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**Ambiguous Loss:**

Interacting with someone who is not fully present socially or psychologically.

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Sandwich  
Story

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#### #5. Profound Impact that Dementia Has on Relationships



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- Remember
- Plan, process and Reason
- Organize and multi-task
- Regulate mood, behavior, & impulses
- Communicate– comprehension & speech
- See– visual/spatial changes (driving)
- Coordinate fine motor skills

Dementia

Impacts

Ability

To:

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More than 15 million American's provide unpaid care. Approximately 2/3 are women— often in the “sandwich generation.”

**At higher risk for:**

Depression, anxiety, substance abuse, social isolation, chronic health problems, lower self-esteem & self-care, increased rate of heart disease and mortality rate.

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The  
Water  
Bottle  
Story

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The longer we hold it, the harder it gets.




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#6. Palliative Care can Play a Key Role in Supporting Patients and Families with mid-late stage dementia.




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To Palliate– is to “relieve suffering.”




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### Types of Palliative Care Services

Inpatient palliative care consult services– hospitals

Clinic- based palliative care

Home-based palliative care

Community Hospices

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WWW.getpalliativecare.org



Palliative  
Care




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## GET PALLIATIVE CARE

- Go to [www.getpalliativecare.org](http://www.getpalliativecare.org)
- Click on "Find a Provider"
- Enter city, state, or zip code you are searching for
- Click on hospital, nursing home, office/clinic or home

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### How To Get

### Palliative Care

1. Tell doctor you are interested in finding out more about palliative care and where it's available. Ask if you can get a referral.
2. Mention that you would like to discuss future planning (A.D's) for your medical care, or for family member with dementia.
3. Think about what quality of life means to you or your family member. Document these wishes and share with your family and medical team.

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### Palliative Care for Dementia Program

- Provides 24/7 phone support, MD consults, home visits
- Team: LCSW (dementia educator), Geriatrician, NP, PharmD and trained volunteers to provide respite to families
- Services provided: Identify MDPOA's, complete Advance Directives, discuss goals of care, prevent unnecessary hospitalizations, educate and support caregivers, improve quality of life for both people living with dementia and their caregivers.

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### Service Gaps

### for Patients

### and Families

### Impacted by

### Dementia

- End-stage symptoms don't progress in a uniform or predictable way
- PLWD aren't reliably able to report on their experience of illness, which complicates successful management of symptoms.
- Complications in mid-end stage dementia are often under-reported & treated (agitation, delirium, delusions, hallucinations, pain). Families don't know how to navigate symptoms & behaviors— become overwhelmed & isolated.

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**CHALLENGES**

- Lack of ongoing support and isolation for caregivers ( Gap related to "custodial needs")
- Often don't qualify for HBPC
- Goals of care discussions not happening, or too late in game
- Patients & families need help LONG before hospice eligibility!

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**• HOSPICE CRITERIA**

- 6 months or less model-- is poor fit for terminal dementia. Even severely demented patients may live up to 2 years.
- Must meet criteria of 7C on FAST SCALE (Functional Assessment Staging Scale)

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**FAST Scale: 7 C**

- Loss of ability to walk, dress or bathe independently
- Incontinent of bowel and bladder
- Lost capacity for meaningful conversations (< 6 words)
- Complications such as: Aspiration pneumonia, septicemia, decubitus ulcers, recurrent fevers, weight loss

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**Benefits of palliative care for dementia**



Improved symptom management & quality of life for person with dementia

Ongoing education, support and resources for caregivers.

Assistance with advance care planning, goals of care, planning for future

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Bridging the gap between what people *say they want*, and the care they *actually receive*.




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Gertie's Story




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## #7. The Need and Challenge of “Being of Service” and Treating with Compassion




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**“Service is a way the world can heal.** True service is not a relationship between an expert and a problem... It is a relationship between people who bring the full resources of their combined humanity to the table and share them generously... **Service is another way of life.”**

---Dr. Rachel Naomi Remens

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## Shortage of Geriatric health care professionals in US

- Physicians, NP's, RN's, Social Workers, pharmacists, physician assistants and case workers.
- Estimated that the US has approximately ½ the number of certified geriatricians that it currently needs.
- In 2014, 20% of Medicare beneficiaries admitted to hospice had a primary diagnosis of dementia. Dementia was the 2<sup>nd</sup> most common primary dx for Medicare beneficiaries.

• From 2017 Facts and Figures of the Alzheimer's Association

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"Often finding meaning is not about doing things differently; it is about seeing familiar things in new ways."

Dr. Rachel Naomi Remens




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# #8. Competence and Compassion are Built over Time




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We aren't born with these skills

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But we can LEARN them!




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“Service has a life of its own. A single act of kindness may have a long trajectory and touch those we will never meet or see. Something that we casually offer may move through a web of connection far beyond ourselves to have effects that we may have never imagined. And so each of us may have left far more behind us than we may ever know.” Dr. Rachel Naomi Remens




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The World NEEDS YOU!




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The  
Bell  
And  
The  
Blackbird



-- David Whyte

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For all you are  
For all you do  
Thank You



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