

Dementia-Friendly Medical Care Narrative Medicine

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Aging is a privilege

Growing old is not a disease to be cured or defeated, but a privilege, tremendous privilege to be humbled by, to be grateful for. A privilege withheld from most of our ancestors and so many of our brothers and sisters. Let's become worthy of becoming old, by falling in love easily, holding our heart gently, holding our fears lightly, and forgiving continuously.

Ageism and Dementia-ism is a national and global challenge.

We (healthcare professionals) need to notice it in ourselves and others and mindfully address it.

Truth (as opposed to myth / dementia-ism)

Persons with dementia have value

Persons with dementia have strengths and resilience

Persons with dementia are capable of meaningful interactions

Persons with dementia can be creative and innovative

Persons with dementia can have good quality of life

You have Alzheimer's Disease

I had lost the thread
of my thoughts.
I was never one for
solitary and gloomy reflections.
I gathered up enough courage,
slowed down my breathing,
looked into her eyes,
and said,
"I have disheartening news
to give you.
Forgive me.
You have Alzheimer's disease."
We were in the
hospital chapel.
Her favorite place,
a place of great serenity
and beauty.
She closed her eyes
and nodded.
A trickle of tear
sneaked out.
She extended her hand.
I held it in mine.
I was glad we were in the chapel.



Podcast titled *Dementia Matters* by Dr. Nathaniel Chin from University of Wisconsin Alzheimer's Disease Research Center on Mild Cognitive Impairment on 1/29/25 is recommended to understand the big psychosocial implications of giving a diagnosis of MCI, Dementia and Alzheimer's.

God's Helper

Ms. Linda came to our center at the beginning of this year. In the beginning she was apprehensive about long term placement, she was frustrated at her family for leaving her and distressed about leaving her animals. Ms. Linda quickly found companionship with those around her and found she enjoyed sitting next to fellow residents, giving hugs, candy and kisses on the forehead. When COVID precautions began, Linda struggled. She became frustrated at staff reminders to social distance. After a few months Ms. Linda settled into her new way of life, visiting others from afar and waving at fellow residents as she walked through the hallway. As precautions increased due to facility exposure to COVID-19, Ms. Linda was encouraged to stay in her room to decrease her level of exposure. These increased precautions resulted in a significant increase in behaviors. Staff reported that Ms. Linda was throwing objects at the window to see if the glass would break, formulating plans to escape, threatening to kill staff if they wore the proper protective gear in her room, hallucinations of Jesus and her grandmother in her room. To help deescalate behaviors, staff would visit with Ms. Linda throughout the day, taking her on walks outside, and facilitating socially distanced family visits. Staff quickly found out that Ms. Linda enjoyed feeding the squirrels in the courtyard and watching them eat from her window. Now, twice a day Ms. Linda will seek out social services or activity staff to help her feed her "babies." There has been a visible improvement in Ms. Linda's behaviors, she feels she has a purpose in life and that she is "God's helper."

Credit: Credit for this goes to a wonderful social worker that I have the privilege to work with in a local nursing home.

Two Strangers

Two strangers
in the land called dementia.
I smiled. She smiled.
She slowly moved
her hand around my waist,
a beautiful warm side hug.
In response,
I slowly moved
my hand toward her shoulder.
While still hugging,
I said things
she didn't understand.
She said things
I didn't understand.
We smiled. We talked.
We went our separate ways.
She forgot me.
I did not forget her.
She forgot my smile.
I did not forget her smile.
She forgot my hug.
I vividly remember her hug
and cherish this memory.



My 78-year old patient has advanced dementia and significant fluent aphasia.

We (healthcare professionals) need to develop the skills of Improv to make our care more dementia friendly. Please see this video on our Saint Alphonsus Memory Center website on Caregivers Improv <https://www.saintalphonsus.org/services/memory-center/upcoming-events>

Long-Buried Sorrow

What is her yelling?
A sign, a signal
a symptom of moral anguish
calling our souls
to understand her plight.
My patient had never learned
to experience her feelings,
as there was no one
in her childhood or later
who accepted her fully,
who understood
and supported her.
And now, with advanced dementia,
long-buried sorrow
that could never be expressed
was set free and
only touch and soothing voice
can do the miracle
of bringing her some solace.
No meds, please,
No meds.



We (healthcare professionals) need to train and take time (with a team) provide trauma-informed care to our patients living with dementia.

Young-Onset Dementia Stress

Things keep breaking, Doc,
again, and again.
Everything seems broken.
Ground is always shifting.
Light is always flickering.
Dementia doesn't seem
to stop grinding
me down.
Problems won't cease
to be born,
and I am responsible
to fix them.
My grief rises.
My strength fades.
I cling to him
and he holds me.
The moment I cease
to cling to him
and he stops holding me,
my grief will engulf me
and my strength
will give out.



Wife (age 58) of my 62-year-old patient who has young-onset dementia.

We (healthcare professionals) need to understand that the grief and stress of a partner of a person living with young-onset dementia is at a whole different level.

A Blessing for Caregivers

May the love in your soul guide you.

May the courage within you overcome fears about caregiving.

May the heart within you conquer the pain involved in caregiving.

May you be given the best education and training, to overcome challenges in this journey.

May you have the commitment to care with compassion, to learn from failures, to be patient, and be the best caregiver you can be.

May you have great respect for yourself.

May you show growing compassion and patience toward yourself as you come to realize how much

the well-being of (name of the person needing care) depends on you.

May you have the wisdom to hear

the unspoken gratitude (name of the person needing care) has for you.

And, above all, may you be given the wonderful gift of meeting the beauty that is within you.

May you be blessed, and may you find life enriched by your efforts of caregiving.

Adapted from John O'Donohue's poems

Caregivers are in reality care partners (receiving as much as giving)! We (healthcare professionals) need to make caring for the wellbeing of the caregiver / care-partner a top priority.

Podcast titled *Dementia Untangled* by Banner Health on Caregiving through late-stage dementia on 11/6/24 is recommended to understand the huge impact of all the amazing love and dedication caregivers on the lives of individuals with dementia

An Angel

The nurse aide
washed the sweat
from his face
with a warm, damp cloth.
Dressed him
with deft, gentle hands.
Wheeled him
down to the dining hall.
He was as light
as a bundle of rags.
The aide was determined
to put some muscle on him.
“Don’t you worry.
I will make sure,”
the aide assured
his wife of 67 years.
“Then, you both
can plan your new adventure.”
The wife smiled, turned to me,
and said,
“She is an angel.”



My patient (90 years old with advanced dementia, lost a lot of weight) and his wife loved traveling to remote places, their “adventures.”

Staff Training Education Praise and Support (STEPS) is a key component of caring for persons living with dementia in long-term care settings and hospital settings. There are many amazing nurse’s aides that provide care that is remarkably effective in relieving suffering of persons living with dementia and at the same time is inspiring and heart-warming.