

ALZHEIMER'S AND OTHER DEMENTIAS: WHAT'S HARD? WHAT HELPS?

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Duke Dementia Family Support Program
www.dukefamilysupport.org

**Chapel Hill
Community
Church**

April 28, 2021

WE ARE A BRIDGE TO UNDERSTANDING YOUR OPTIONS



**A no-cost service for all NC families and professionals
caring for someone with a memory disorder**

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COGNITIVE AGING

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PROTECT YOUR BRAIN HEALTH

Actions that may help reduce risks

- Take care of your health – sleep quality, depression treatment
 - Control blood pressure, sensory loss
 - Be physically active
 - Learn new things
 - Connect with family, friends, communities
 - Join NC Registry for Brain Health
www.ncbrainhealth.org
- Brain Health as You Age: ACL, CDC, NIH

NO ONE WANTS TO JOIN THIS CLUB

“I’m becoming a passenger, and I’m not a passenger. This thing is taking me to a place I don’t want to go”

quote from film “Supernova”

“Everything is partial – it hurts like hell”

Historian living with moderate Alzheimer’s

“I’m exhausted - I must be running on fumes”

Husband of woman with moderate dementia

DEMENTIA

Dementia is an umbrella term that describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to **interfere with daily life.**



MOST COMMON DEMENTIAS

- **Alzheimer's disease**
- **Lewy Body Dementia**
- **Frontotemporal dementias**
- **Mixed and vascular dementias**
- **Parkinson Disease Dementia**

ALZHEIMER'S IS NOT

- Normal aging
- Limited to people over 65
- Contagious
- Preventable
- Curable

HE'S NOT HIMSELF

1. Memory loss, repeating questions, calls
2. Challenges in planning, organizing, problem solving
3. Difficulty or takes longer to complete familiar tasks
4. Confusion with time or place
5. Trouble understanding visual images and spatial relationships – getting lost

SHE'S NOT HERSELF

6. New problems finding words in speaking or writing
7. Misplacing things and losing the ability to retrace steps – finding lost things in unlikely places
8. Decreased or poor judgment – financial, safety
9. Challenges or withdrawal in social settings or work activities
10. Changes in mood and personality, increased anxiety

MILD COGNITIVE IMPAIRMENT (MCI)

Deficits in memory that do *not* significantly impact daily functioning.



WHAT'S HARD?

- When you have met one person with a memory disorder, you have met one person...
- Dementias are common, complex, chronic, costly, conflictual
- Insidious onset, variable progression, retained capacities – what works today or is a problem today may not be tomorrow.
- There's a stigma associated with dementia

EARLY STAGE DEMENTIA

- Need info, support, time
- Symptoms appear gradual to person and family unless event prompts decline
- Disclosure and Stigma issues – Why tell?, When?, Whom to tell and how?
- Changing relationships with care partner, family and friends
- Safety issues – financial, meds, driving
- Advance planning

MODERATE DEMENTIA

From Care Partner to Unpaid Caregiver – “Brains for 2”, activity director, loss of “me” time, patience tested, lonely, depleted

- **Increased confusion – misidentification of those close**
- **Shadowing, sundowning**
- **Resistance to needed assistance with personal care**
- **Increased safety concerns – getting lost, staying alone**
- **Respite issues**

LATE STAGE DEMENTIA

- Total personal care assistance
- Mute or difficult to understand
- Decreased mobility
- Non-recognition of familiar persons
- Palliative/hospice considerations

**WHAT HELPS PEOPLE
WITH
MEMORY/THINKING
DECLINES AND THEIR
FAMILIES**

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CDC RECOMMENDATIONS

- Access available treatments
- Access support services
- Better manage medications
- Receive counseling
- Address driving and safety issues
- Manage co-occurring conditions
- Advance planning

HELPING WITH COMMUNICATION

- **Be patient and comforting**
- **Show respect**
- **Repeat as necessary**
- **Avoid distractions**
- **Use visual cues**
- **Discuss guessing/filling in**
- **Avoid correcting and arguing**

TIPS FROM PEOPLE LIVING WITH DEMENTIA

Please don't correct me ... remember, my feelings are intact and I get hurt easily ...

I may say something that is real to me but may not be factual. I am not lying.

Don't argue — it won't solve anything.

— Canadian Early Stage Support Group

WHAT HELPS FAMILIES?



- **Treat depression/anxiety**
- **Increase pleasant events**
- **Support groups or online support**
- **Respite**

IF YOU'RE A CARE PARTNER

- Understand what it is like to have dementia
- Acknowledge your own loss
- Build a support network
 - Join a support group
- Ask for help
- Stay active and engaged

WHEN A FRIEND HAS ALZHEIMER'S

- Educate yourself about Alzheimer's
- Stay in touch
- Engage the person in conversation
- Help with the to-do list
- Give care partners a break
 - Alzheimer's Association, 10 ways to help

ARE YOU A READER?

- **The Problem of Alzheimer's by Jason Karlawish**
- **Living Your Best with Early-Stage Alzheimer's by Lisa Snyder**
- **Surviving Alzheimer's (2nd Edition) by Paula Spencer Scott**
- **Loving Someone Who Has Alzheimer's by Pauline Boss**
- **Moving a Relative and Other Transitions in Dementia Care by Laurie White and Beth Spencer**
- **When Your Aging Parent Needs Help by L. Kernisan and P. Spencer Scott**

DUKE DEMENTIA FAMILY SUPPORT PROGRAM (DDFSP) SERVICES

- **Services: No-cost, No Duke affiliation required**
 - Telephone consultation
 - Information & referral
 - E-newsletters, caregiver education videos, engagement activities
 - Online support groups
 - Memory Makers Plus

DDFSP COMMUNITY PROGRAMS IN RESPONSE TO COVID-19

- **Caregiver Connections**
- **Come Zoom with Us!**
 - *Let's Get Together!*
 - *Come Sing with Us!*
 - *Come Dance with Us!*
- **Created two new support groups**
 - **Long-Term Care Community Support Group**
 - **Person Living with a Memory Loss Diagnosis Support Group**

DDFSP SUPPORT GROUPS CURRENTLY ONLINE

- **Duke Dementia Morning Care Partner Support Group**
- **Duke Dementia Evening Care Partner Support Group**
- **Daughters Concerned for Aging Relatives Support Group**
- **Younger-Onset Support Group**

START HERE

- Duke Dementia Family Support Program
<https://dukefamilysupport.org>; 919 660 7510
- Alzheimer's Association 24/7 Helpline
 - 800.272.3900
- alzheimers.gov



QUESTIONS

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