

# Newly Diagnosed?

Resources for you to process, connect and move forward



Alzheimer's Institute &  
Sun Health Research Institute

Hello there,

If you have recently been diagnosed with early-stage cognitive changes, we want you to know that it is normal to experience feelings of confusion, doubt, and even fear.

**YOU ARE NOT ALONE.**

You may be feeling isolated, uncertain, or even relieved when hearing these words for the first time. However, once you talk with others who have a similar diagnosis, you may realize that our lives still have meaning and relevance. You are not defined by your diagnosis.

Many of us have gone through this, and we want you to know there are opportunities to connect, learn and find friendship to help you with the challenges. Inside this packet you will find helpful information and community resources. Caring people are willing to listen and help us move forward with our lives. Despite our diagnoses, we still have love and much to share. We encourage you to participate in all the world has to offer.

Banner Alzheimer's Institute Early-Stage Advisory Council  
- a compassionate community of patients and professionals.

*Karen, Leonard, Mary, Nancy, Sandy and Sharon -  
Living with Early Memory Loss*

*Barb, Deidra and Heather - Banner Alzheimer's  
Institute Team*



# Hope

Hope - such a powerful word!  
Without it we would be lost.  
Days without meaning,  
Days feeling helpless,  
Wasted days.

But days filled with hope –  
What a glorious thought!  
I no longer drift, I have a purpose.  
I have renewed strength to face the future.

Yes, the news given to me was unexpected,  
Yes, I know the days ahead will be stressful.  
A whole new life awaits me  
But the support of others will sustain me.

In life, valleys give way to hills to be climbed,  
No matter how steep,  
The journey begins  
With one slow step  
A day at a time,  
With a will to succeed  
With hope in my heart  
Anything is possible.

Keeping in mind the beautiful song  
from Carousel:

When you walk through a storm  
Keep your head up high  
And don't be afraid of the dark.  
At the end of the storm is a golden sky  
And the sweet silver song of a lark.  
Walk on through the wind,  
Walk on through the rain,  
Though your dreams be tossed and blown.  
Walk on, walk on with hope in your heart  
And you'll never walk alone,  
You'll never walk alone.

– Nancy



# **Dementia Untangled**

*from the lived experience*

The "Dementia Untangled" podcast aims to offer expert guidance and support for the millions of people living with Alzheimer's or another dementia and their family caregivers. As communities engage in becoming more dementia friendly, it's important to hear directly from those living with a diagnosis and understand their new outlooks on life.

Stream these useful conversations now.



**"Real Talk: Living with Dementia"**  
Arthena Caston & Jay Reinstein



**"A Doctor's Experience: Living with LBD"**  
Dr. Gary Schmidt



**"Keeping Your Purpose while Living with Dementia"**  
Roger Marple



**"A Purposeful Life with FTD"**  
Laurie Scherrer

[BannerHealth.com/DementiaUntangled](https://BannerHealth.com/DementiaUntangled)





# Just Me Support Group

Early Stage/ Mild Cognitive Impairment (MCI) - Person Only



You're invited to a Banner Alzheimer's Institute support group *exclusively for people living with Early Stage Dementia/MCI*. This online group will help you to not feel alone, and connect with others in a safe space while continuing to incorporate good self-care to live successfully with cognitive changes.

If you have any questions, please contact Barbara Klauser, LCSW at 602.839.6510 or via email at [Barbara.Klauser@bannerhealth.com](mailto:Barbara.Klauser@bannerhealth.com)

## DATE

Second Friday of each Month

## TIME

1:00 – 2:30PM

## LOCATION

Online via Zoom

*\*registration is required in advance to obtain Zoom access*

## COST

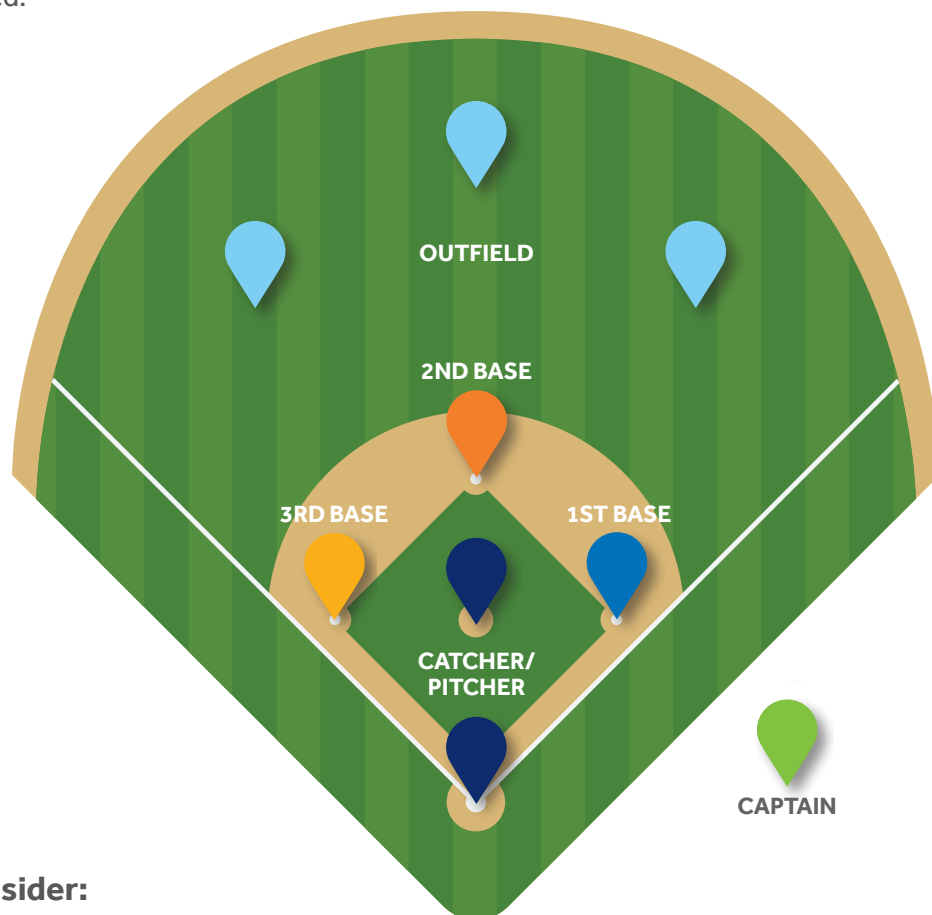
Free

## REGISTRATION

[Barbara.Klauser@bannerhealth.com](mailto:Barbara.Klauser@bannerhealth.com)

## Pick Your Team

Coping with any chronic illness requires love and support from others. Identifying who is on your team is very important especially in the early stages. To win the game, we must create the best team possible. Spending time to select your team members is so important. These are people that have your back and you can trust to help you when you are in need.



### Positions to consider:

**CAPTAIN - You are the captain of your team**  
Your role is to coach your players to play the game the way you want.

### These are your key players who can support you and help with the ups and downs of the game:

**CATCHER/PITCHER - Immediate family and friend relationships**  
Who are those that you are closest with? Significant other family and friends.

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**1ST BASE - Employment**  
Who is your best ally at work? \_\_\_\_\_

**2ND BASE - Community**  
Do you have a spiritual or religious family? Neighbors or a club or gym connection that is important to you?

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**3RD BASE - Healthcare**  
Who is your primary provider? Your Dementia Specialist? Your Social Worker? \_\_\_\_\_

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**OUTFIELD - Any other contacts that are a support to you**  
Education, support or engagement programs through Banner Alzheimer's Institute.

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# Terminology

## Dementia

- Changes in memory, thinking and ability to function severe enough to impact daily living.
- There are over 100 causes of dementia- the most common being Alzheimer's disease.

## Mild Cognitive Impairment - (MCI)

- Notable changes in memory, language, attention, reasoning, judgment, reading and/ or writing.
- Daily activities are still manageable, so MCI does not meet criteria for dementia.
- Not everyone with MCI will progress to dementia, but many do.

## Early Onset

- When symptoms develop under the age of 65

## Late Onset

- When symptoms develop after the age of 65

## Types of Dementia

### Alzheimer's Disease (AD):

- Most common type of dementia.
- Gradual changes in memory followed by decline in other areas of mental and eventually physical functioning.

### Lewy Body Dementia (LBD):

- Second most common type of dementia
- Shares symptoms with Alzheimer's disease and Parkinson's disease
- Gradual onset of fluctuating mental alertness and abilities along with physical symptoms of Parkinson's disease

### Vascular Dementia (VD):

- Deterioration in mental function caused by multiple strokes (infarcts) in the brain
- Can be sudden onset and symptoms vary based on size and location of stroke

### Frontotemporal Degeneration (FTD):

- Group of conditions that affect the front (frontal lobes) and sides (temporal lobes) of the brain
- Initial symptoms typically involve changes to personality, judgment, behavior, planning and social function. Some people will have trouble with language and communication.

## Progression/Stages

- Regardless of the stage, it is possible to live a meaningful, quality life.

Early Stage/Mild Dementia	Middle Stage/Moderate Dementia	Late Stage/Advanced Dementia
<b>Changes:</b> <ul style="list-style-type: none"><li>• Short-term memory</li><li>• Attention/focus</li><li>• Word finding</li></ul>	<b>Changes:</b> <ul style="list-style-type: none"><li>• Short and long-term memory</li><li>• Expressive and receptive language</li></ul>	<b>Changes:</b> <ul style="list-style-type: none"><li>• Impaired memory</li><li>• Reliant on non-verbal communication</li></ul>
<b>Support needed:</b> <ul style="list-style-type: none"><li>• Instrumental Activities of Daily Living (IADLs): cleaning, cooking, handling finances, , driving, etc.</li></ul>	<b>Support needed:</b> <ul style="list-style-type: none"><li>• Activities of daily living (ADLs): grooming, bathing, dressing, etc.</li></ul>	<b>Support needed:</b> <ul style="list-style-type: none"><li>• Completing Instrumental Activities of Daily Living (IADLs) and Activities of Daily Living (ADLs).</li></ul>

**Have additional questions?**

Contact Deidra 602.839.6850 or [baifcs@bannerhealth.com](mailto:baifcs@bannerhealth.com)

