

**Rush  
Alzheimer's  
Disease  
Center**



# Dementia and Loneliness: Our Role in Making a Difference

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## Objectives

- Discuss the common reasons for loneliness in people with dementia
- Explore how each of us can work to support those with dementia
- Review the Dementia Friendly and Dementia Friends movement in Illinois

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## Effects of Loneliness

- Increase in depression
- Poor sleep quality
- Impaired executive function
- Accelerated cognitive decline
- Poor cardiovascular function
- Impaired immunity

Louise C Hawkey  
John P Capitanio  
[Article from 2015](#)

- Risk for premature death

Kassandra Alcaraz, PhD, MPH  
[Article from 2019](#)

- Increased risk of stroke

Nicole Valtorta, PhD  
[Article from 2016](#)

- Increase risk of dementia

Angelina Sutin, PhD  
The Journals of Gerontology: Series B, online 2018

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## *Brendan Behan* *- Irish Poet*

“At the innermost core of all loneliness is a deep and powerful yearning for union with one’s lost self.”



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# From the Perspective of the Person

- Isolation
- Change in roles
- Change in mood and personality
- Increase in anxiety
- Increase in depression

***"I don't know where I am.  
Not just in this spot but  
in the whole world."***

*Person with younger onset Alzheimer's*



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# Alzheimer's Disease is Isolating

People with Alzheimer's talk about feeling alone and different -

- because of the disease
- because of the world around them



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## Changes Adding to Isolation

### Memory

- Often trouble with short term memory

### Processing

- Difficulty understanding steps involved in a task, confusion with time and place

### Attention

- Trouble following through on a task

### Communication

- Problems following conversation or joining in

### Visual

- Trouble with balance, reading judging distance, determining color and contrast, or issues with driving

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# Emotional Changes Adding to Isolation

## Decreased self-esteem

- Many with dementia make negative comments about themselves

## Depression

- Families often report seeing signs of depression before signs of dementia

## Fear

- A feeling that something is wrong

## Apathy

- Lack of interest

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# Do We Add to the Changes

- Memory
- Processing
- Attention
- Communication
- Visual

- Decreased self-esteem
- Depression
- Fear
- Apathy

**What expectations to do we set? Are they supportive of their changes?**

**How do we make the person feel about themselves?**

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# Loneliness for the Caregivers

## Social Circles

"As the disease progresses, our social circles get smaller until it's just the two of us."

*Spouse of person with Alzheimer's disease*

- Stress
- Embarrassment
- Family and Friends not as engaged
- Fatigue



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## Alzheimer's Disease is Isolating

### Our job -

make the world around people  
with dementia  
and their family members a  
*supportive community*



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## Jiddu Krishnamurti - Indian Philosopher

“Life is relationship, living is relationship. We cannot live if you and I have built a wall around ourselves and just peep over that wall occasionally. Unconsciously, deeply, under the wall, we are related.”



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## Creating Community

“I love coming here because we are all in the same boat together.”

*Person with Alzheimer's disease*

*Wherever you work,  
whatever your role, how do  
you create that community  
for people with dementia?*



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# Move from Person Centered to Community Centered

- **Move from Person Centered to Community Centered**
- Encourage people with dementia to interact with others
- Able to share story without judgment
- Recognized and valued for what they bring to the community
- Purposely consider community in all interactions with people
- Encourage love, laughter, and support



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## Creating Community Across Illinois Join the Dementia Friendly Illinois Efforts

### Dementia Friendly Communities



A national network of communities, organizations and individuals seeking to ensure that communities across the U.S. are equipped to support people living with dementia and their caregivers

[www.dfamerica.org](http://www.dfamerica.org)

### Dementia Friends

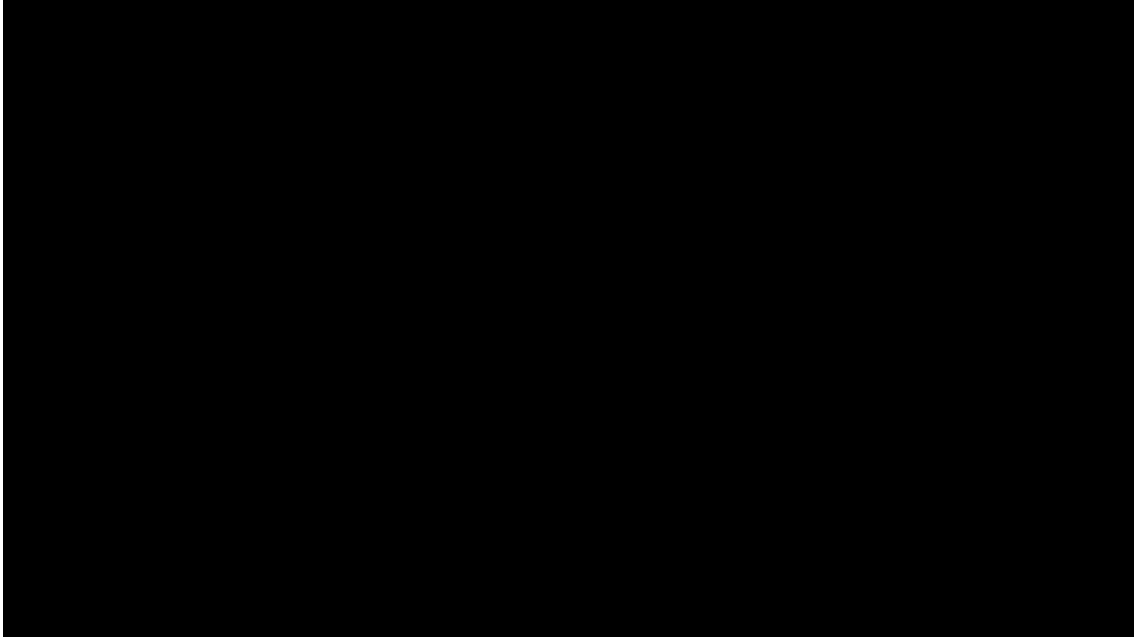


Join other friends in a movement that is changing the way people think, act, and talk about dementia.

[www.dementiafriendsusa.org](http://www.dementiafriendsusa.org)

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## DFA Communities in Illinois

### State Lead



Austin – Chicago  
 Barrington  
 Belleville  
 Bronzeville - Chicago  
 Carbondale  
 Carterville  
 Chinatown-Chicago  
 Decatur  
 Effingham  
 Elgin  
 Englewood - Chicago

Eureka  
 Evanston  
 Galesburg  
 Geneseo  
 Glencoe  
 Grayslake  
 Highland Park  
 Hyde Park – Chicago  
 Kankakee County  
 Marion  
 Mendota  
 Moultrie County  
 Naperville  
 North Chicago/Lake County  
 Oak Park  
 O'Fallon/Shiloh  
 Orland Park

Oswego  
 Princeton  
 River Forest  
 Rockford  
 Salem  
 South Loop - Chicago  
 Springfield  
 Tinley Park  
 Tri-Cities (Batavia, Geneva, St. Charles)  
 Vandalia  
 Washington  
 Washington Heights - Chicago  
 West Deerfield Township  
 West Pullman/Roseland - Chicago  
 Westmont

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# Dementia Friendly Illinois Progress and Goals

## Progress - 44 recognized communities

- 8 Chicago neighborhoods
- 18 suburbs and counties around Chicago
- 18 communities in central and southern Illinois
  - Population from 149,936 to 5,800



**Goal** – at least one Dementia Champion and a Dementia Friendly Community in each Planning Service Areas of the state.



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## Dementia Friends Efforts

- **13,124** - total Friends in Illinois
- **10,309** – Friends from in-person talks
- **2,815** – Friends from online sign-ups
- **333** - Dementia Champions who can give Dementia Friends talks



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Sign up online at:

[www.dementiafriendsusa.org](http://www.dementiafriendsusa.org)



Let us know if you have a group that might be interested in a Dementia Friends presentation.

Interested in helping spread the word about Dementia Friends?  
Become a Dementia Champion.

[Susan\\_Frick@rush.edu](mailto:Susan_Frick@rush.edu)

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*Tom Swenson*  
*Person with Alzheimer's Disease*

"We are only our true self when we are in a community of people who completely understand."



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# Thank you

For everything you do so support  
people and their families  
who are living with dementia

