



The Experience of Alzheimer's Disease:

Walking the Journey Together

Susan Frick, MSW, LSW

Rush Alzheimer's Disease Center

1750 W. Harrison, Suite 1000

Chicago IL 60612

312.942.5359

Susan_Frick@rush.edu



Rush Alzheimer's Disease Center

- One of 29 federally funded Alzheimer's Centers

The RADC Mission:

Research

- Epidemiological Studies
- Clinical Trial

Education

Family Care

- Memory Clinic
 - Without Warning
-





The Without Warning Program

- A support program for families living with younger onset Alzheimer's disease which began in 2004.
- Offer groups for person with younger onset, family members, friends, paid caregivers, adult children, and young children.
- At main meeting, offer 2 groups for people with younger onset and 4 groups for family members. Meetings for children are occur separately.

without warning®

*Supporting Those with Younger Onset Alzheimer's Disease
A Program of the Rush Alzheimer's Disease Center*



Too Soon to Forget: The Journey of Younger Onset Alzheimer's Disease

- Based on the experiences of 9 families living with younger onset Alzheimer's disease
- Narrated by Dan Gasby and B. Smith
- Show the emotional experience – isolation, adjustments and the healing power of community
- Airing nationally on PBS
- Plans for streaming channels and on DVD



Why is it important to hear another's story?

Understanding the
experience of another
increases our empathy
and empathy opens
space for connection



Without Warning Members on Loneliness

"Feels like I'm fading."

"Alzheimer's is still a whispered disease..."

"I would love to be able to connect the dots."

"They treat you like you have the plague."

"My thoughts just snips out."



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



Alzheimer's Disease is Isolating

Our job -

make the world around
them a
supportive community



Isolation – change in power

- Increases isolation
- Increases depression
- Changes relationships
- Feel invisible
- Opinion no longer of value
- Role no longer of value
- One person with Alzheimer's said, "I'm now just the person who pushes the cart. I don't make the decisions anymore."



CAN YOU SEE ME?

How Do We Reduce the Feel of Isolation?

- Listen to their story
- Create value
- Create a role for the person
- Let their opinion matter
- Let them know they are seen
- Encourage community



Isolation – changes in relationship

- Sadness
- Grief
- Anger
- Change in roles
- Miss companionship
- “Miss being loved.”
- One husband said, “We’ve lost the little nicknames we called each other.”



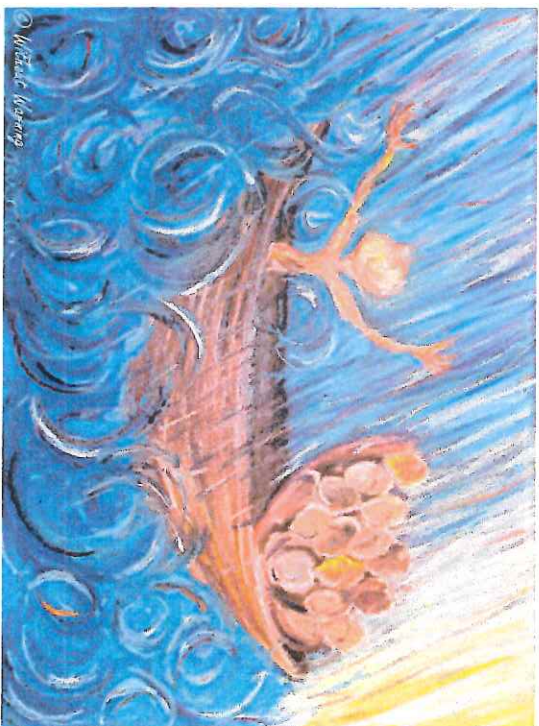
Adjustments for People and Families Living with Alzheimer's

- Learning to find good in what is now
- Separating the disease from the person
- Finding ways to connect
- Creating new routines
- Flexibility
- Patience





The Healing Power of Community



Without Warning Members on the Benefits of Community

"For us to be able to have a sense of **belonging** and not be judged and just accepted how we are is huge."

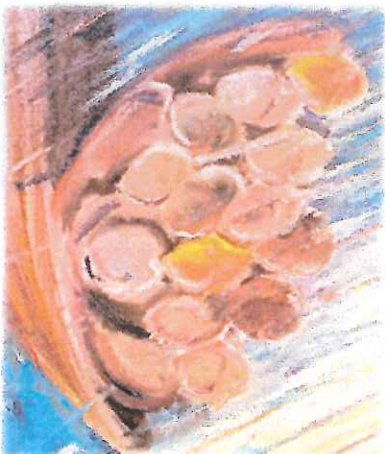
"I think, for me, it's the **validation**, the sense of **unity**, a sense of **belonging**. Not a fun club to belong to, but nonetheless..."

"This group makes you feel **relevant**. This disease with all the devastation it gives, you feel **relevant**."

"Some days it's not so good and other days are better. I think that when we're **together** we can **easily talk** and **give** these things out..."

Benefits of Community

- Connection to one another
- Has a role
- Feels part of a group
- Has a purpose
- Decreases depression



How Do We Build Community: Move from Person Centered to Community Centered

- Encourage people with dementia to interact with each other
- Able to share story without judgment
- Individuals are recognized and valued for what they bring to the community
- Purposely consider community in all interactions with people
- Encourage love, laughter, and support





Putting the Community Spirit Into Action

How do we create neighborhoods where people feel supported?

Join two grassroots initiative that have come to Illinois

- Dementia Friends
- Dementia Friendly Illinois



The Individual Level

Sign up online at:

www.dementiafriendsusa.org



Interested in helping spread the word about Dementia Friends? Contact Susan Frick, at the Rush Alzheimer's Disease Center, to become a Dementia Champion.

Susan_frick@rush.edu



Dementia Friends – Five Key Messages

- Dementia is not a normal part of aging. Not everyone who grows old will develop dementia.
 - Dementia is caused by diseases of the brain. The most common is Alzheimer's.
 - Dementia is not just about having memory problems. It can affect thinking, communication and doing everyday tasks.
 - It is possible to have a good quality of life with dementia.
 - There's more to the person than the dementia. People with dementia are a valuable part of the community.
-



Turn your understanding into Action

As a Dementia Friend, I will....

- Keep in touch with someone living with dementia.
 - Start or support Dementia Friendly efforts in my community.
 - Volunteer for an organization that helps people with dementia.
 - Campaign for change-participate in local advocacy efforts.
 - Carry out a personal action-be more patient out in my community.
 - Adopt one or more dementia friendly practice in personal/professional life.
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The Community Level

making our neighborhoods
supportive for all



www.ilbrainhealth.org/dementia-friendly-illinois



Thank you
for your support of
people living with Alzheimer's disease

Your efforts and compassion mean so much

The Rush Alzheimer's Disease Center
and their
Without Warning® Support Program
presents

The Toolkit Project:

Support for Dementia Support Group Facilitators

With a generous grant from the Rush Woman's Board, we are creating an interactive website, in both English and Spanish, to offer information, resources and ability to network for people facilitating dementia support groups.



Leading a dementia support group is both a rewarding and challenging experience. The Toolkit Project wants to be an important resource for those providing these valuable groups.

To join The Toolkit Project distribution list,
send your email and contact information to

Susan_Frick@rush.edu

We will be reaching out to everyone on the list
to ask for their input as we develop this site.

Watch for the launch of The Toolkit Project early in 2019

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Mary Sue's Top Ten Sing Along Favorites

- 1 My Bonnie Lies Over the Ocean**

The words to this song are very repetitive and everyone seems to know it. It's a long song that lets people with memory loss settle in and feel secure singing something they know really well. You can learn how to add some simple movements on my Singing Heart to Heart YouTube channel.
- 2 I've Been Working on the Railroad**

This song has a strong and steady beat. And everyone knows it. Use it to encourage marching in place while seated and clapping along. Or bring rhythm sticks to tap out the beat.
- 3 You are My Sunshine**

This is a proverbial favorite. Many people have relationships tied to this song. Take a minute to ask about that. It can spark a discussion amongst the folks singing together. Did they sing this with their sweetheart or their children? Did their mother sing it to them?
- 4 Swing Low Sweet Chariot**

This African American spiritual tends to have a calming effect. It invites gentle swaying back and forth. But it can also be lively and energetic. Try starting out with a slow gentle rhythm and then for fun pick up the pace the last time you sing the chorus.
- 5 The Old Gray Mare**

This funny song is always a hit. The words are very simple and they repeat. I always start by asking "Do you ever feel like an old gray mare?" Then I point to my gray hair and tell them "I sure do!" Go for the laugh!
- 6 Let Me Call You Sweetheart**

This is a very old song and one that most folks learned from their parents. Short and sweet and very familiar. Sing it twice.
- 7 The Irish Lullaby**

This is a gentle, peaceful song. It creates a calm mood and would be a good song to end the day with. Don't worry about the verses. Just sing the chorus several times. "Too-ra-loo-ra-loo-ra."
- 8 I'm Looking Over a Four Leaf Clover**

Keep things lively with this upbeat song. Cue folks by saying "I'm looking over a" They will fill in the blank and tell you "Four Leaf Clover!" Or you might start by asking if anyone has ever found a four leaf clover. Or "When was the last time you looked for a four leaf clover?"
- 9 Take Me Out to the Ball Game**

"Play ball!" "Batter up!" Sometimes I pretend to bat a ball and see if folks can guess what song we are going to sing. Sing it twice and insert the name of a local or favorite ball team. "For it's root, root, root for the" If they don't win it's a shame."
- 10 God Bless America**

Even reluctant singers can't resist this patriotic song. It's easier than the national anthem and it works great to get people started.

Champion's Name

Susan Frank

Date Presented

I am a Dementia Friend

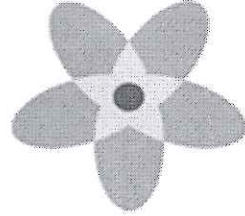
Dementia Friends Information Session

Name

Certificate of Participation

A Dementia Friendly America Initiative

**Dementia
Friends
Illinois**



Too Soon to Forget: *The Journey of Younger Onset Alzheimer's Disease* Two DVD Collection



The first DVD contains the Documentary, as seen on PBS, an 8 page Information Booklet, and two Supplemental Features. Each feature explores a specific topic in greater detail, offers discussion questions, and averages 10 minutes in length.

The second DVD, not pictured, contains 11 Supplemental Features with discussion questions.

The two DVDs are sold separately and together contain almost 3 hours of material.

The Too Soon to Forget: DVD Collection will soon be available subtitled in Spanish.

Too Soon to Forget: Documentary with

Two Supplemental Features \$35

The DVD contains the documentary plus two supplemental features, in all almost 80 minutes of content.

The Supplemental Features include:
The Experience of Isolation
Noticing the problem
The Healing Power of Community
Advice from other

Too Soon to Forget: Supplementa Features \$25

This DVD contains 11 Supplemental Features which explore in greater detail

topics raised in the documentary. These feature average 10 minutes in length and contain questions for discussion.

The Supplemental Features include:
The Experience of Isolation
Receiving the diagnosis
Sharing the news with others
How this experience changes you -Part One
How this experience changes you - Part Two
The Experience of Adjustments
Employment
Handling Each Day
Planning for the Future
Hospitalizations
End of Life
The Healing Power of Community
Accepting help
Participating in clinical trials

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Too Soon to Forget: The Journey of Younger Onset Alzheimer's Disease

Now airing on PBS

An award winning documentary from the
Rush Alzheimer's Disease Center
and the Without Warning program
withoutwarning@rush.edu
[#TooSoonToForgetTheDocumentary](https://www.facebook.com/TooSoonToForgetTheDocumentary)
[#CreatingCommunityNow](https://www.instagram.com/CreatingCommunityNow)



The Message

Living with Alzheimer's disease is a challenge – changing life for all. Imagine, though, the challenges of living with Alzheimer's in midlife.

Too Soon to Forget shares the emotional experience of younger onset Alzheimer's disease, from the loneliness and isolation, to common adjustments, and finally, to the healing power of community. Nine families along with people who support them share a common message – this difficult journey is made easier with the help of others.

The Hosts

Dan Gasby and B. Smith

Entrepreneur and Supermodel B Smith was diagnosed with younger onset at the age of 62. With her husband Dan Gasby, they have become ambassadors for younger onset Alzheimer's disease.



"I remember from getting that diagnosis, when we left the hospital. We walked eight or nine blocks, and she looked at me and she said we're going to tell people, because the one thing we understood from being in front of the camera and public eye is that people make things up, and people connect dots that are not there, and the only way to have any sense of your own serenity, and confidence in what's going on is for you to tell people exactly what you're dealing with, so you ultimately define yourself."

Dan Gasby from *Too Soon to Forget*

DVDS can be purchased at
www.toosoonforget.net
shipping and handling added to online purchases

