Younger Onset Alzheimer’s Disease

Exploring the Emotional Experience and the Importance of Community

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Part of the National Alzheimer’s and Dementia Resource Center webinar series sponsored by the Administration for Community Living.
Younger Onset Alzheimer’s Disease: Exploring the Emotional Experience and the Importance of Community

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Rush Alzheimer’s Disease Center

• One of 32 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 is 2004.

• Offer groups for person with younger onset, family members, friends, paid caregivers, adult children, and young children.
  • 2 groups for people with younger onset
  • 3-4 groups for family members
  • Separate meetings for children

www.Without-Warning.net
Too Soon to Forget: The Journey of Younger Onset Alzheimer’s Disease

Documentary from the Without Warning Support Groups

• Based of the experiences of 9 families living with younger onset Alzheimer’s

• Narrated by Dan Gasby and B. Smith

• Focuses on the emotional experience – isolation, adjustments and the healing power of community

www.TooSoonToForget.net
What is Younger Onset

• Showing signs and/or diagnosed by the age of 65
• Can be difficult to diagnose because of younger age
• Not sure the number of people with younger onset but estimated that it is 3% of those diagnosed with Alzheimer's disease
• For some families, it can have a genetic cause and seen in multiple generations
What Makes it Different

• Not at an age where dementia is expected
• Often still working
• Often still driving
• Often still raising children
• Often not financially prepared for work to stop

• Other family members not expected to be caregivers
• No peer group
• Within our support group, we have seen an increase in seizures
• Might be more healthy than an older person with Alzheimer’s
Loneliness

“For me, Alzheimer’s feels like I’ve fallen into a pit. I can see everyone but I don’t know how to get back to them.”

Said by Person with Alzheimer’s during a Without Warning meeting

The Pit

Painted by the Rev. Shawna Bowman
Loneliness

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.”
Loneliness

“As the disease progresses, our social circles keep getting smaller until it’s just me and my husband with Alzheimer’s.”

Said by wife of person with Alzheimer’s during a Without Warning meeting

Social Circles
Painted by the Rev. Shawna Bowman
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