

**Rush
Alzheimer's
Disease
Center**



Long-term Services and Supports Challenges Unique to Younger Onset

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Financial Disclosure/Conflict of Interest

Susan Frick, MSW, LSW

Social Worker

Recruitment-Education Coordinator

Rush Alzheimer's Disease Center

Chicago, IL

I have nothing to disclose and no conflict of interest

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Without Warning


Support program for those with younger onset Alzheimer's disease offered through the Rush Alzheimer's Disease Center since 2004

www.withoutwarning.net

with Younger Onset Alzheimer's Disease of the Rush Alzheimer's Disease Center



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From the Perspective of the Person

- Difficulty recognizing symptoms and receiving diagnosis
- Loss of job
- Change in sense of purpose
- Loss of independence
- Loss of medical insurance
- Changes in communication
- Changes in ability to perform everyday tasks
- Change in judgement

"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."

Person with younger onset Alzheimer's Disease

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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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Challenges for the Person

- Diagnosis can take a long time
- Exit from work can be difficult
- Difficulty navigating disability insurance and other benefits
- Difficulty finding purpose and roles in family and groups
- Difficult finding others living with younger onset

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From the Perspective of the Family

- Isolation
- Changes in Communication
- Change in mood and personality

“As the disease progresses, our social circles get smaller.”

Spouse of someone with younger onset Alzheimer’s



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From the Perspective of the Family

- Financial burden
- Having to assist with everyday tasks
- Adjusting to change in role in family and larger community
- Having to find appropriate resources

“You always have to do so much behind the scene to keep your person with dementia center stage.”

Children of people with younger onset Alzheimer’s disease



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Challenges for the Family

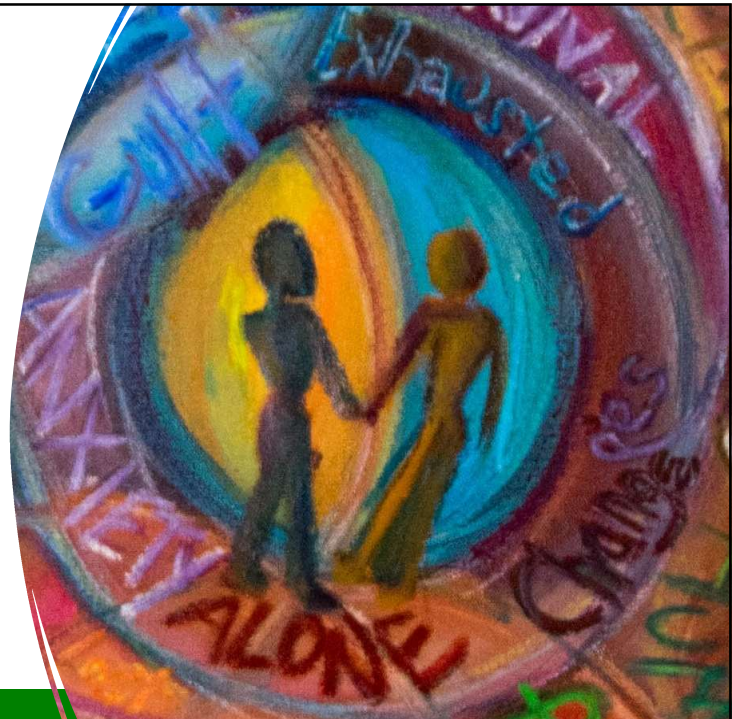
- Recognizing the problem
- Learning to balance safety and autonomy
- Finding appropriate support for legal and financial matters
- Finding resources which support a younger person with dementia
- Balancing work and caregiving roles
- Finding support programs



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Common Resources

- Home Care
- Day Care
- Respite
- Residential Care
 - Assisted living
 - Skilled Care
- Palliative Care
- Hospice



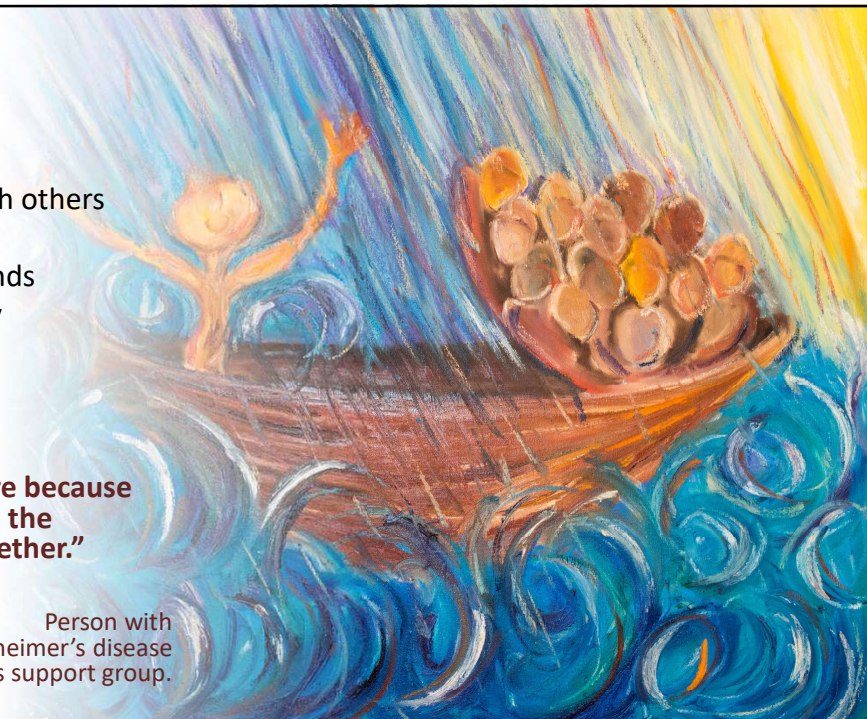
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Importance of Community

- Finding connection with others
 - Family
 - Neighbors and Friends
 - Greater Community
 - Faith Community
 - Groups and clubs
 - Support Groups

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

Person with younger onset Alzheimer’s disease about his support group.



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Find Ways to Make a Difference



Community Effort

www.dfamerica.org

Over 400 communities and growing.

People in a community coming together to find ways to provide support and education.

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Find Ways to Make a Difference



Individual Effort

www.dementiafriendsusa.org

Become a Dementia Friend online.
Only takes 10 minutes but can make a world of difference for people living with dementia.

160,000 Dementia Friends in the USA

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Resources from Without Warning

Support Group Meetings

- Without Warning offers a free support program for families living with younger onset Alzheimer's disease. Currently, meetings are being held virtually.
- For more information, contact Susan Frick at 312-942-5359 or withoutwarning@rush.edu



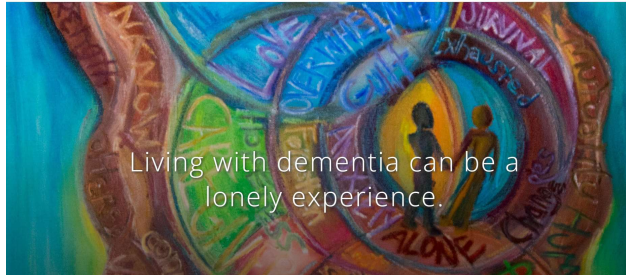
without warning[®]

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

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Resources from Without Warning

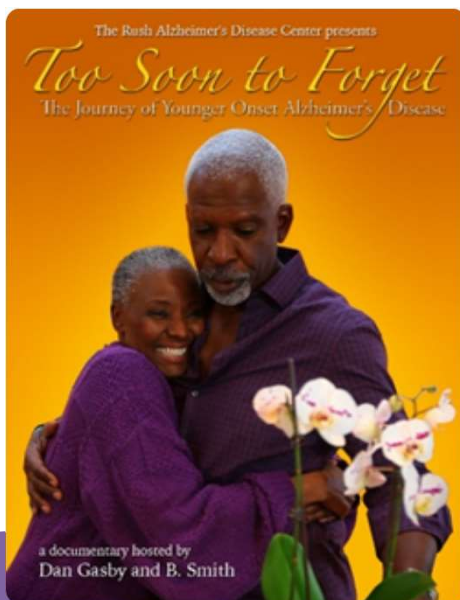
The Without Warning Website



This website shares the experience of group members with a wider audience. Through video clips, personal writings, drawings, and pictures, Without Warning members share their stories and experiences.

www.withoutwarning.net

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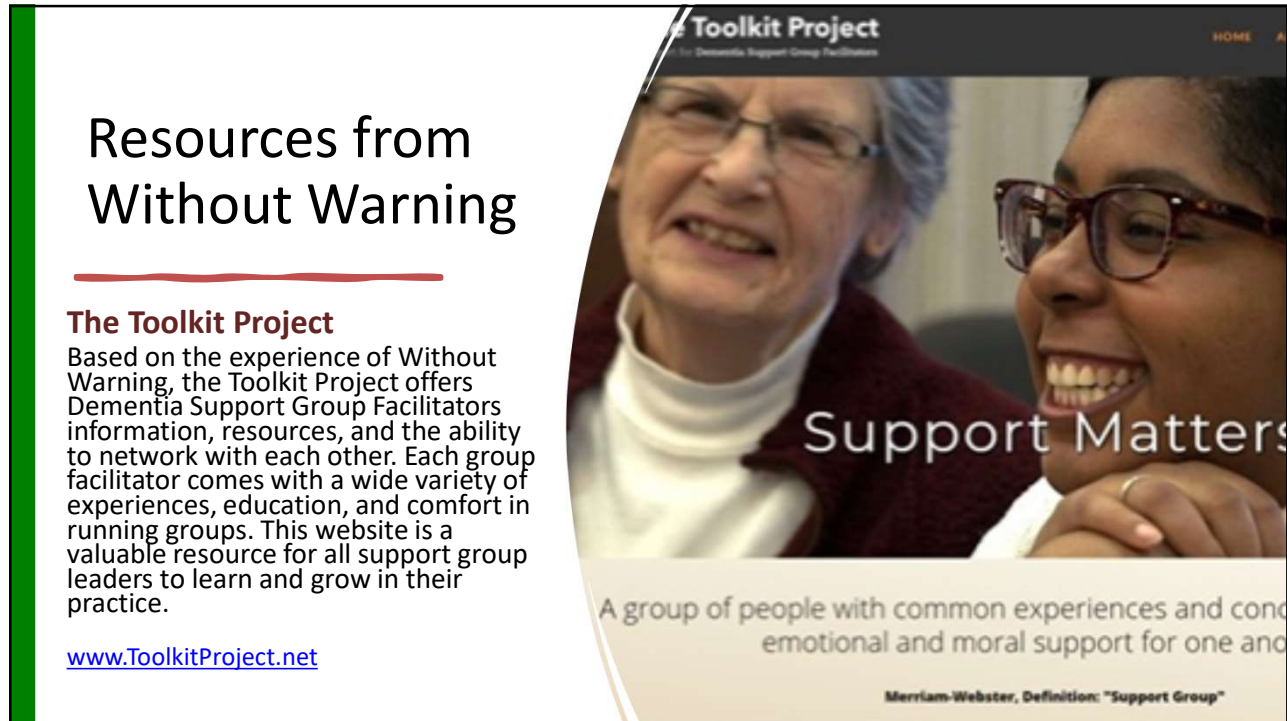
Resources from Without Warning

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

A documentary which shares the experiences of those living with younger onset Alzheimer's disease and highlights the communities of support which should surround the families throughout the journey. No one should have to face this journey alone. Too Soon to Forget is available as a DVD with Spanish subtitles and on Amazon Prime, PBS, and PBS Passport.

www.TooSoonToForget.net

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Resources from Without Warning

The Toolkit Project

Based on the experience of Without Warning, the Toolkit Project offers Dementia Support Group Facilitators information, resources, and the ability to network with each other. Each group facilitator comes with a wide variety of experiences, education, and comfort in running groups. This website is a valuable resource for all support group leaders to learn and grow in their practice.

www.ToolkitProject.net

Support Matters

A group of people with common experiences and conditions providing emotional and moral support for one another.

Merriam-Webster, Definition: "Support Group"