



# What Have We Learned in Dementia Care

Susan Frick, MSW, LSW  
Rush Alzheimer's Disease Center  
1750 W. Harrison, Suite 1000  
Chicago, IL 60612  
[Susan\\_Frick@rush.edu](mailto:Susan_Frick@rush.edu)  
312-942-5359

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## What We Learned in Dementia Care

For 25 years, the Rush Alzheimer's Disease Center and LeadingAge Illinois has held the Dementia Leadership Course.

What is special about the

- Residents
- Family members
- Staff
- Programming
- Environment



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## Does Our Description of Dementia Programs Capture What Makes it Special

*"We have locked doors."*



*"We have special activities."*

*"We train our staff."*



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### Dementia is a Lonely Experience

- For the people living with dementia
- For families
- For the staff
  
- How does the programming and environment work to address that loneliness

Successful programs find ways to address this loneliness for each group

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### Impact of Loneliness on Residents

"For me Alzheimer's feelings like I have fallen into a pit. I can see everyone but don't know how to get back to them."

Person with dementia



The Pit

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### Impact of Loneliness on Residents

We become the keepers of each other's memories.

How do we hold the memories for those living in dementia care units?



Collective Memories

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### Impact of Loneliness on Residents

- Watch for examples of loneliness or distress in each person
- Encourage people to share their stories
- Know important stories for each resident and share them when they are no longer able
- Highlight the meaning and value of each person
- Constantly look for ways to create community

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### Impact of Loneliness on Families

"As the disease progresses, our social circles get smaller until it's just us and the person with dementia."

*Caregiver of person with dementia*



Social Circles

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### Impact of Loneliness on Families




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### Impact of Loneliness on Families

- Recognize that the caregiving experience started long before placement in your facility
- Recognize loneliness and other emotions in the family members
- Encourage staff to be open and supportive to families
- Have staff who are designated to work with families
- Create opportunities for support and education

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### Impact of Loneliness on Staff

"Today I Danced..."  
 I don't dance... at least I try to avoid it.  
 ...But as they live with their disease, they invite us to be singularly present with them in the moment. Whatever happened moments ago is forgotten and what is about to unfold is beyond their control. There is only right now. This beat, this note, this song. I am so deeply thankful to receive their wisdom and to live in this space with them and be invited to dance."

*Rev. Shawna Bowman*



Today I Danced

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### Impact of Loneliness on Staff

- Recognize any loneliness you experience while providing care
- Be comfortable with the uncomfortable
- Follow direction of the person with dementia
- Look for moments of connection
- Work to support each other as staff
- Provide space for staff to talk about the loneliness

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Impact of Loneliness on Staff

"One of the reasons why I was excited about being employed here was because it was family oriented. We came together as one to ensure the safety, the care. It's not like okay, I'm going to work. No, it wasn't like that. It was like a home away from home. That's the feeling that you have here."

Staff Member From Dementia Assisted Living Program

Horizontal lines for handwritten notes.

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Programming and Environment

"We have to do so much behind the scenes to keep our person with dementia center stage."

Child of person with dementia

How do we create space and programming which reduces loneliness?



The Stage

Horizontal lines for handwritten notes.

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Programming and Environment

- Let people with dementia be our guides
- Programming which encourages the strength of each resident
- Programming which encourages community
- Physical environment which is calming while encourages engagement
- Social environment created by staff and residents

Horizontal lines for handwritten notes.

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### New Way to Describe Dementia Care

"We realize that living with dementia can be a lonely experience.

Our trained staff members work as a team to create a space that is supportive for each person living with dementia. We work to recognize the individual needs of each person living with dementia and work to create spaces where they feel connected and valued."

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### What We Have Learned in Dementia Care

I want to live with dementia with grace.

*Bob Hawley, person with dementia*

Dementia Care is the richest area of human work.

*Tom Kitwood, author and researcher*

**By recognizing moments of loneliness,  
we can strive towards these goals**

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### References

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**Dementia Leadership Program**  
[www.dementialeaders.net](http://www.dementialeaders.net)

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*Loneliness and Alzheimer's Disease* by Susan Frick

**Too Soon to Forget** – the documentary  
[www.toosoonforget.net](http://www.toosoonforget.net)

**Without Warning Support Program**  
[www.withoutwarning.net](http://www.withoutwarning.net)

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