



The Dementia Leadership Course  
*Development. Knowledge. Practice. Networking.*

# Welcome to the 2020 Dementia Leadership Course

*You will be a Founding Member of the new  
**Dementia Leadership Network***





The Dementia Leadership Course  
*Development. Knowledge. Practice. Networking.*

## Leadership and Dementia Care

Susan Frick, MSW, LSW

Rush Alzheimer's Disease Center

312-942-5359

Susan\_Frick@rush.edu

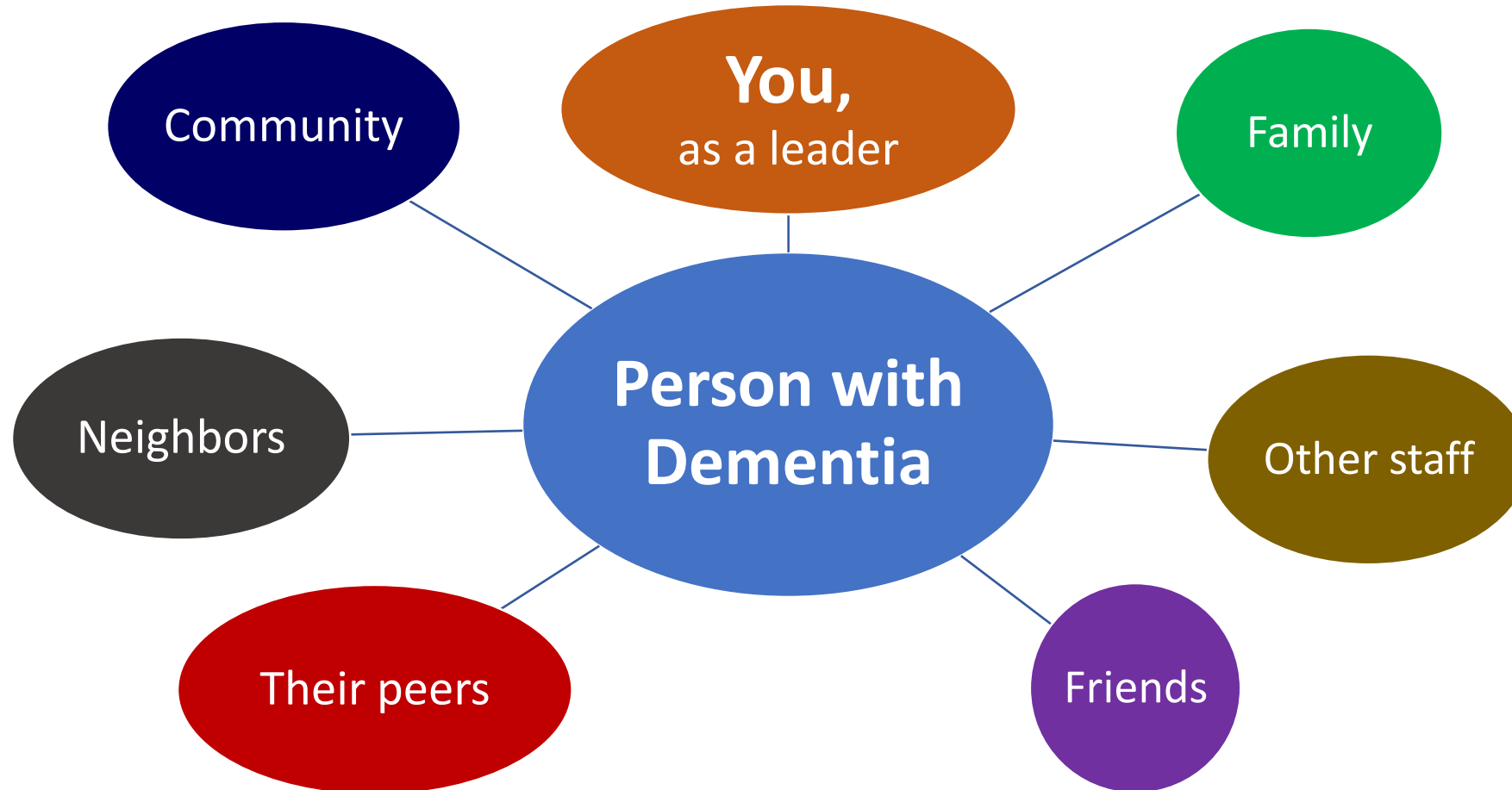


**Rush  
Alzheimer's  
Disease  
Center**





# At The Center of Good Care





# Personhood

- What does it mean to be a person
- How do we define self-worth
- Who is worthy of respect

*As a leader, must recognize the personhood of the people with dementia*

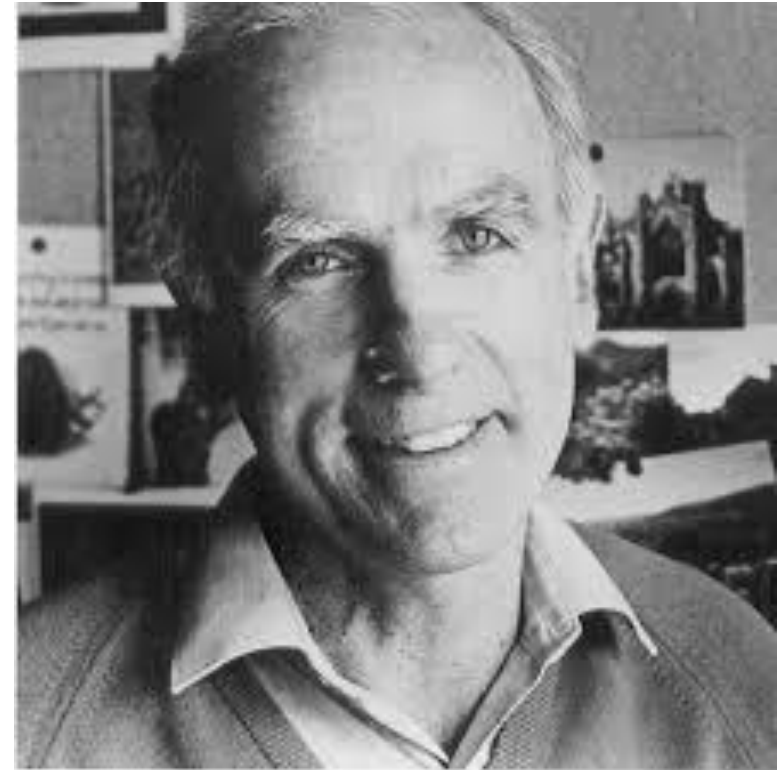


# Leadership and Dementia Care

## Tom Kitwood

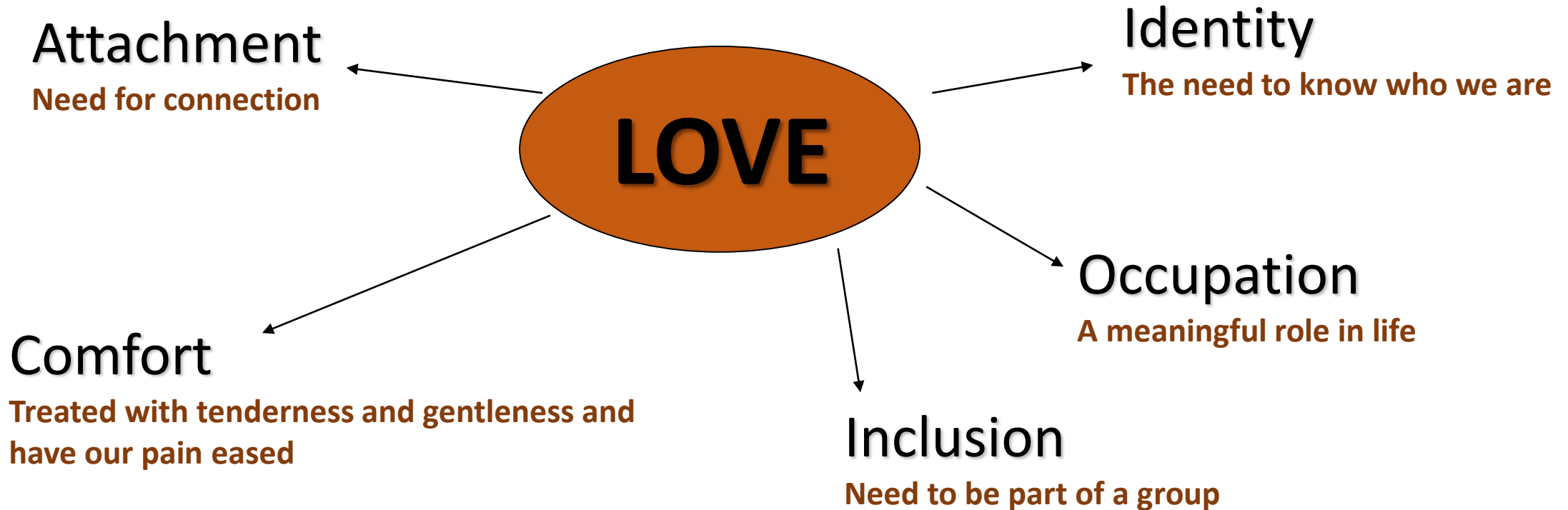
“a pioneer in the field of dementia care. He developed innovative research projects and training courses, challenging the "old culture of care". His aim was to understand, as far as is possible, what care is like from the standpoint of the person with dementia.”

Obituary for Tom Kitwood  
1937-1998





# Maintaining Personhood





## Philosophy of Dementia Care

This shifts the focus from:

- Patients to the person with dementia
- Illness to wellness
- Problems to possibilities
- Inabilities to retained abilities
- Doing “to” and “for”, to “doing with” the person



## Attitudes to Dementia Care

### Old Culture

- Dementia care is the backwater.
- Demands high, challenges are few.
- Suited for those who have low ability, little inspiration, few qualifications.

### New Culture

- Riches area of human work.
- Requires high level of ability, creativity, insight.





# General View of Dementia

## Old Culture

- A devastating disease of the central nervous system, in which personality and identity are progressively destroyed.

## New Culture

- Dementing illness should be seen primarily, as forms of disability. How a person is affected depends crucially on the quality of care.



## Ultimate Source of Knowledge

### **Old Culture**

- Doctors are the people who have the most reliable, valid and relevant knowledge. We should defer to them.

### **New Culture**

- The people who possess the most reliable, valid and relevant knowledge are skilled and insightful practitioners of care.



# Emphasis of Research

## Old Culture

- There is not much we can do positively for a person with dementia until the medical breakthroughs come.

## New Culture

- There is a great deal we can do now, through the amplification of human insight and skill.



# Us and Them

## Old Culture

- Those who have dementia are significantly different from the rest of us because of their condition. We should have different clothing, meals, chairs.

## New Culture

- Those who have dementia are equal members of the human race with the rest of us. We are all persons in the same boat. This should be reflected in our practice.



# What Caring Involves

## Old Culture

- Providing a safe environment and meeting basic needs in a competent way, food, clothing, toileting, warmth, cleanliness, adequate sleep.

## New Culture

- Care is concerned primarily with the maintenance and enhancement of personhood.



## Priorities for Understanding

### **Old Culture**

- Must have a clear and accurate understanding of a person's impairments. The course of dementia moves through stages of decline.

### **New Culture**

- Must have a clear and accurate understanding of a person's abilities, tastes, interests, values, forms of spirituality.



# Problem Behaviors

## Old Culture

- When a person shows problem behaviors, these must be managed skillfully and efficiently.

## New Culture

- Should be viewed as communication, related to need. It is necessary to understand the message, and so to engage with the need that is not being met.



# Cares' feelings

## Old Culture

- The key thing is to set aside our own concerns, feelings, vulnerabilities, and get on with the job in a sensible, effective way.

## New Culture

- The key thing is to get in touch with our concerns, feelings and vulnerabilities, and transform these into positive resources for our work.





# Personhood of Staff

## Old Culture

- Direct care staff are “servants of the organization”. It is not on the agenda of the organization to take them really seriously, or to engage with psychological needs

## New Culture

- Direct care staff are persons. Respecting their personhood is as much on the agenda of the organization as respect for the personhood of those who have dementia.



## Person Centered Care

- Valuing people and those who care for them
- Treating people as individuals
- Looking at the world from the perspective of the person
- Providing a positive social environment in which the person can experience well-being



## Well-Being

- Retains an assertion of desire or will
- Able to express a range of emotions
- Able to initiate social contact
- Displays affection & warmth
- Displays social sensitivity
- Has self-respect
- Shows acceptance of others with dementia
- Uses humor
- Uses creativity and self-expression
- Shows evident pleasure
- Shows helpfulness
- Able to relax



## Ill-Being

- Apathy and withdrawal
- Sustained anger
- Unrelenting sadness or grief
- Physical discomfort or pain
- Anxiety



# Leadership and Dementia Care

## **Brené Brown**

an American professor, lecturer, author, and podcast host. Brown has spent her career studying the concepts of courage, vulnerability, shame, and empathy and has authored seven books including five New York Times best-sellers.





# Who is a Leader?

## **Leader** (noun)

Anyone who takes responsibility for finding the potential in people and the processes and has the courage to develop that potential.

*Leadership is not about titles or the corner office. It's about the willingness to step up, put yourself out there, and lean into courage. The world is desperate for braver leaders. It's time for all of us to step up.*

Brené Brown

[www.daretolead.brenebrown.com](http://www.daretolead.brenebrown.com)



# Being a Leader

# Idea Lab



# Vulnerability

- Uncertainty
- Risk
- Emotional Exposure
- Show up
- Be seen
- Even when no guarantees

**There is no courage without vulnerability**

Brené Brown





# What does it mean to be a Leader?



## **Rumbling with vulnerability**

- Conversation defined by commitment to lean into vulnerability

## **Living into our values**

- Never silent about hard things

## **Braving trust**

- Choosing courage over comfort

## **Learning to rise**

- When we have the courage to walk into our story and own it, we get to write the ending

**Dare to Lead**  
Brené Brown



# Breakout Room Discussion Questions

- What are the main qualities needed to provide good dementia care?
- What are the main qualities needed to be a good leader?

Have one person from the group, email your responses to:

[Susan\\_frick@rush.edu](mailto:Susan_frick@rush.edu)

(mark the email with the number of your breakout room)



# Leadership and Dementia Care

How does the work of Tom Kitwood and Brené Brown Overlap

- Understanding the unique gifts of each person
- The importance of being in relationship
- Understanding the emotional experience of another person
- Creating a culture where all belong
- Taking risks and being vulnerable
- Both Leadership and Dementia Care are skills that can be learned



# The Dementia Leadership Course

*Development. Knowledge. Practice. Networking.*

Thank you for your participation and leadership with those living with dementia.

Join the Dementia Leadership Network at  
[www.DementiaLeaders.net](http://www.DementiaLeaders.net)

