CARE THAT MATTERS: PERSON CENTERED DEMENTIA CARE

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TODAY

- Focus
  - Defining Personhood
  - Recognizing Change
  - Person Centered Care
    - Basic Needs
    - What Works and Does Not Work
    - Well Being
    - Case Studies

PERSONHOOD
Personhood

- Research early 1980's at the University of Bradford UK
- Social psychological perspective of persons with dementia
- Thomas Kitwood PhD, University of Bradford UK, developed the principle of personhood
  Website at: [www.bradford.ac.uk/adad/health/bdg](http://www.bradford.ac.uk/adad/health/bdg)
- Tom Kitwood, PhD was first to document:
  - "Lived experience" of persons with dementia
  - He reintroduced the PERSON

Personhood

- "Me, Myself & I"
- "All that I am,"
- "My connection to the world"
- My life and existence at any moment

Personhood

- Personhood
  - Self
  - Soul
  - Character
  - Spirit
  - Human Nature
  - Personality
  - Life Story
Personhood

• “It is a standing or status that is bestowed upon one human being, by others, in the context of a relationship. It implies recognition, respect and trust.”
  - Bradford Dementia Group

Personhood

• How is your personhood supported?

Personhood

• Personhood is experienced when:
  • A person relates in a positive way to another person
    • It can mediate the disease process
    • It is the opposite of isolation
    • It is the heart of Person Centered Care
    • It emphasizes: THE PERSON, NOT THE disease
The consequences of denying Personhood

Personhood

- Denial
  - Ignoring
  - Outwitting
  - Outpacing
  - Labeling
  - Shunning
  - Isolating
  - Detaching
  - Shaming

EMOTIONAL CARE AND SUPPORT FOR THE PERSON IS NEEDED

Disrupting Denial of Personhood

- Understanding
  - Recognize change

- P.I.E.C.E.S
Recognizing Change

P.I.E.C.E.S.

1. What has changed?

2. What are the RISKS and possible causes (using the PIECES framework)?

3. What is/are the action(s)?

Recognizing Change

P = Physical

- Drugs
  - Anti-cholinergics e.g., benzos,
  - Include OTC, alcohol, herbs, not prescribed drugs

- Disease
  - Atypical presentations, hypoxia, pain, infections
  - Delirium – 30% mortality if undetected
    - Hypoactive and hyperactive

- Undiagnosed Chronic Illness

- Basics
  - Hydration, bowels, bladder, fatigue, sleep
Recognizing Change

• I = Intellectual/Cognitive Change
  • Perceptual difficulties (distances, depth, time elapsed, gaps)
  • Resisting a bath or toileting, running over others.
  • Apathy and “perseveration”
  • May be confused with depression
  • Return of primitive reflexes, perseverative behaviors
  • Grabbing caregiver’s clothing or body part and being unable to let go.

Recognizing Change

• I = Intellectual/Cognitive Change
  • Memory loss/Amnesia:
    • Repetitive questioning.
    • Accusing others of not telling them about upcoming events.
    • Being “uncooperative” with previous requests.
  • Agnosia
    • Accusing family member of being an imposter when cannot quite recognize face...
    • Failing to recognize one’s image in the mirror.
    • Utilizing objects inappropriately.

Recognizing Change

• I = Intellectual/Cognitive Change
  • Anosognosia
    • Not able recognize own deficits and need for help

  • Impaired executive functions:
    • Poor planning/Initiation
    • Unable to appreciate consequences of things said or done before saying/doing them, impulsive behavior

  • Fixed on memories of past
Recognizing Change

- **I** = Intellectual/Cognitive Change
  - **Apraxia**
    - Dressing inappropriately—upset with assistance provided/required
    - Needing assistance to eat
  - **Aphasia**
    - Frustration/anxiety
    - Inappropriate requests/comments
    - Reacting concretely to abstract concept

- **E** = Emotional
  - **Baseline change**
    - Slow
    - Abrupt
  - **Abrupt change**
    - Withdraw
    - Agitation
    - Aggression
    - Hallucinations
    - Delusions
    - Paranoia
    - Acute confusion

- **C** = Capabilities
  - Balance of resources vs demand
  - Support capabilities
  - Support changes
  - Personhood
Recognizing Change

- **E=Environment**
  - **Place**
    - Light, sound and noise, disability supported, familiar, comfortable, food service,
  - **People**
    - Person centered
    - Know history
  - **Clothing**
    - Irritating vs comfortable

Recognizing Change

- **S=Social**
  - Engagement that is positive
  - Stimulation
  - Social Network
  - Needs

Personhood

- Most common emotional response
  - **FEAR**
    - Primitive
    - Amygdala
  - Fight, Flight or Stay
Recognizing Change

**Aggression (related to fear and anger = Most common**

- Physical aggression
- Verbal Aggression
- Aggressive resistance to care

**Apathy**

- Physical aggression
- Verbal Aggression
- Aggressive resistance to care

**Withdrawn**

- Sad
- Tearful
- Hopeless
- Guilty
- Anxious
- Irritable/screams
- Suicidal

**Lacks interest**

- Euphoria
- Pressured speech
- Irritable

**Amotivation**

- Hallucinations
- Delusions
- Misidentification
- Suspicious

**Psychosis**

- Mania
- Psychosis

**Mania**

- Irritability
- Depressed
- Irritable

**Depression**

- Manic
- Depressed
- Irritable

**Personality Dis-inhibition**

- Dis-inhibition
- Suicidal

**Suspicious**

- Agitated
- Paranoid

**Suicidal**

- Suicidal
- Agitated

**Agitation**

- Physical aggression
- Verbal Aggression
- Aggressive resistance to care

**Pacing**

- Repetitive actions
- Dressing/undressing
- Restless

**Hallucinations**

- Voice
- Visual

**Delusions**

- Hallucinations
- Delusions
- Misidentification
- Suspicious

**Misidentification**

- Hallucinations
- Delusions
- Misidentification
- Suspicious

**Suspicious**

- Hallucinations
- Delusions
- Misidentification
- Suspicious

**Sedated**

- Lacks interest
- Amotivation

**Apathy**

- Lacks interest
- Amotivation

**Aggression (related to fear and anger = Most common**

- Apathy 72%
- Aggression 60%
- Anxiety 48%
- Irritability 42%
- Depression 38%
- Dis-inhibition 32%
- Psychosis 32%

**Understanding Change**

Do not ask me to remember.  
Don’t try to make me understand.  
Let me rest and know you’re with me.  
Kiss my cheek and hold my hand.

I’m confused beyond your concept.  
I am sad and sick and lost.  
All I know is that I need you.  
To be with me at all cost.

Do not lose your patience with me.  
Do not scold or curse or cry.  
I can’t help the way I’m acting.  
Can’t be different though I try.

Just remember that I need you.  
That the best of me is gone.  
Please don’t fail to stand beside me.  
Love me till my life is done.

*Author unknown*
• YouTube Video:
MESSAGE Communication in Dementia: Teaching Examples for Care Staff

The Road to,....

• Person Centered Care

Person Centered Care
The Radical Shift

From a sole focus on disease pathology to understanding the personal "lived experience" of dementia.

Recognizing the essential role that social psycholgocial experiences play in dementia care.

“I am more than a disease, more than my brain...I am a person!”
• Social Psychological Experience of Dementia
  • Explores the intimate and personal side of the experience of living with dementia
  • Disputes the mind/body dualism
  • Distinct from individualism
  • Goal is Quality of Life vs. Control and Management
  • Central principal or concept is: Personhood

• Person Centered Care
  1. Applies Psychosocial Basis
  2. Reinforces personhood
  3. Recognizes psychosocial and physical changes
  4. Meets Basic Human Needs
  5. Aware of Detractors and Enhancers
  6. Recognizes the qualities of Well being

• Person Centered Care
  6. Primary principle is personhood
  7. Central behavior is relatedness
  8. Disputes the mind/body split
  9. I, Though Relationship
  10. Acknowledges that persons point of view
• Person Centered Care
  • Relationship Focus
    • Grounded in a moral principal of treating others as they wish to be treated
  • Providing choice:
    • Be knowledgeable
    • Be genuine
    • Respect limitations
    • Identify strengths
    • Be flexible
    • Recognize uniqueness of individual

• Person Centered Care
  • Focus is on “Needs Based” approach to care and treatment.
    • Behavior reflects important needs that the person is attempting to communicate.
  • Not about “challenging behaviors”
  • Not about the “problem resident”
  • Is about UNMET NEEDS
  • Is about treating Excess Disability

• Person Centered Care
  • Concern is for the unique needs of the individual
  • One person may enter into early stage dementia with a steady personality with no recent loss.
  • Another may have chronic depression or “learned helplessness” and recent losses.
Person Centered Care Relationship
- What characteristics or traits do you look for or want in a genuine relationship with someone?

Share your insights w a colleague.

Case Study: Unmet Needs-2 Approaches
- Mr. Ellsworth is a 91 year old farmer in your care who can not sit still, but must walk when ever he has a chance. If you try to interrupt this he pushes you away and looks at you with anger. He says: “I am going home.” His urinary output has increased dramatically in the past few days and he has become increasingly agitated in his interaction with you.
- What will you do?
  - Problem Focus: “He is such a problem and just never learns. It seems that he doesn’t like me and is just getting in the way of me getting my job done on time. He makes me so mad.”
  - Needs Focus: “There must be something either in the environment, the way I am interacting with him...or maybe he is becoming sick again.” Perhaps this is why he is doing this. I need to find out what is going on to help him.”

Person Centered Care = Honoring Basic Needs
Basic Psychosocial Needs

- ATTACHMENT
- OCCUPATION
- LOVE
- INCLUSION
- IDENTITY
- COMFORT

OCCUPATION

LOVE/KINDNESS/COMPASSION
Behaviors: Yours, Mine and Our

Need-Driven Dementia Compromised Behavior/NDCB

• All behavior has meaning
• Physical behaviors may instead be used to communicate unmet needs in persons with dementia

Need Driven Dementia-Compromised Behavior/NDCB

- Background Factors
  - Circadian rhythms
  - Motor ability
  - Memory
  - Language

- Health/Demographics
  - Gender, race, ethnicity
  - Marital status
  - Education, Occupation

- Psychosocial
  - Personality
  - Behavioral response to stress

- Proximal Factors
  - Physiological need state
    - Hunger/thirst
    - Elimination/sleep
    - Pain/discomfort
  - Psychosocial need state
    - Affect
    - Match of assistance to ability
  - Physical Environment
    - Light
    - Sound
    - Heat
  - Social
    - Staff
    - Others

- What works and does not Work
  - Behaviors in the process of caregiving that either
    - Detract or Enhance the 6 basic psycho-social needs of personhood
      - Comfort
      - Identity
      - Attachment
      - Occupation
      - Inclusion
      - Kindness/Love/Compassion

Person Centered Care
- What does not Work? Detractors
Person Centered Care

- Detractors from:
  - Comfort
    - Intimidation
    - Withholding
    - Outpacing
  - Identity
    - Labeling
    - Disparagement
    - Infantilizing

Person Centered Care

- Detractors from:
  - Attachment
    - Accusation
    - Treachery
    - invalidation
  - Occupation
    - Imposition
    - Disruption
    - objectification

Person Centered Care

- Detractors from:
  - Inclusion
    - Stigmatizing
    - Ignoring
    - Banishment
    - Mockery
  - Love/Kindness/Compassion
    - Dispassionate
    - Careless
    - Rude
    - Unkind
Person Centered Care

Think of a time when someone *detracted* from your *personhood.*

- What was it like?
- What did it make you feel?
  - Write your thoughts down
  - Share

**What Works? Enhancers**

- Comfort
  - Relaxed pace
  - Holding
  - Warmth
- Identity
  - Respect
  - Acceptance
  - Celebration
Person Centered Care

- Enhancers for:
  - **Inclusion**
    - Recognition
    - Including
    - Belonging
    - Inviting
  - **Love/Compassion**
    - Kindness
    - Holding
    - Caring
    - Warmth
    - Giving

Person Centered Care

- Enhancers for:
  - **Attachment**
    - Acknowledgement
    - Genuiness
    - Validation
  - **Occupation**
    - Empowerment
    - Facilitation
    - Enabling
    - Collaboration

- The “Possible”
Activity Challenge Participants:
Case Study of Benefits of PCDC

• 19 residents with moderate to severe dementia
• All resident in four specialist ExtraCare Nursing homes in UK
• 10 wheel-chair dependent
• 18 fully dependent for self care activities

Extra Care Charitable Trust Activity Challenge

• Calvert Trust specialist centre activity challenge
  • Canoeing
  • Pony-trap riding
  • Abseiling & zip-wire
  • Heated swimming pool & Jacuzzi
  • Hot-air ballooning
  • Bar & evening entertainment

What happened to people?

• At home, Hugo is usually pushed around in his wheel-chair. He spent most of his time during the Activity Challenge on his feet. In the evening he took to the dance floor, as he did when he used to be a competitive dancer.
What happened to people?

- Bert - after a trip in the hot air balloon - did five lengths of the pool, shunned the steps, athletically pushing himself out the pool. Later, in the bar, he started speaking fluent Italian - a talent no-one knew he had.

What happened to people?

- Maggie, a very frail lady, went down the zip wire and wanted more. She went down a second time. That evening, she sang her heart out with the entertainment - reliving memories of amateur operatics.

What the staff reported

- All residents' general well-being improved
- 3 showed markedly improved sleep
- 3 showed markedly improved continence
- 3 showed markedly improved mobility
- 8 showed markedly improved appetite
- 5 gained weight & 2 lost
Person Centered Care

• Case examples to support Personhood and Person Centered Care
  
  • Jenny
  
  • Emily

What is important to Jenny

Jenny needs to know who she is, to touch her body and have her face to the sun daily.

Jenny needs things that are different, she doesn't like to have the same thing every day.

Jenny gets upset if she is not touched, she enjoys being held.

Jenny enjoys the feel of different textures, she has her own basket with different fabrics in.

Jenny has a great appetite and loves all types of food, in particular puddings and Mars bars.

Jenny loves all types of music, she will sing, dance, clap her hands and tap her feet to the music.

What those who know Jenny appreciate about her

Thoughtful
Care
A real character
Affectionate
Loving

Working

Jenny was involved in a work like activity.

Jenny was engaged with the activity.

Jenny was smiling and laughing.

Jenny was happy and content.

What is important to Jenny

What is important to Jenny to be called.

To talk about her son – in – law Martin.

To eat her meals in the lounge, the dining room doesn't work for her.

She has a great appetite and loves all types of food, in particular puddings and Mars bars.

She has a great appetite and loves all types of food, in particular puddings and Mars bars.

Jenny's bubble bath & toiletries are in her bedroom, these should be kept on the top of the wardrobe.

Jenny has eaten and drunk these products and this causes her to have an allergic reaction.

Working

Jenny was involved in a work like activity.

Jenny was engaged with the activity.

Jenny was smiling and laughing.

Jenny was happy and content.

What is important to Jenny

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NOT WORKING

Jenny was involved in a work like activity.

Jenny was engaged with the activity.

Jenny was smiling and laughing.

Jenny was happy and content.

What is important to Jenny

What is important to Jenny to be called.

To talk about her son – in – law Martin.

To eat her meals in the lounge, the dining room doesn't work for her.

She has a great appetite and loves all types of food, in particular puddings and Mars bars.

She has a great appetite and loves all types of food, in particular puddings and Mars bars.

Jenny's bubble bath & toiletries are in her bedroom, these should be kept on the top of the wardrobe.

Jenny has eaten and drunk these products and this causes her to have an allergic reaction.
Jenny loves music; she will sing, dance, clap her hands and tap her feet. She loves touching different textures and fabrics. Jenny prefers to eat her meals in the lounge. She has a sweet tooth and loves pudding. Her face lights up when she has a hug. To be called by her name ‘Jenny’.

To be given space so she can walk around the home. Keeping the floor clear of any obstacles, she doesn’t wear any footwear. Jenny needs a table to have her meals on in the lounge and verbal prompts to enable her to eat independently. When staff give Jenny a drink they should place it within easy reach and verbally prompt Jenny.

Emily

Emily is 82 and has early stage Alzheimer’s dementia and lives in an assisted living facility. She has chronic osteoarthritis that limits her ADL and IADL activity. She has untreated chronic physical pain and uses a walker. She states that her eye glass prescription is old and has trouble reading. Emily often sits for 2 hours without moving from her comfortable chair and has become increasingly fearful of falling and going outdoors. She also has a dual dx of minor depression and co morbid anxiety. Lately she has become quite agitated and refuses to have help with her ADLs.
Person Centered Care

What is important to Emily?
- Seeing her son John and Sister several times a week
- Loves to bake
- She likes to be with her friend Jenny at the facility
- Early morning black coffee with 2 tsps of sugar. She likes it hot.
- Staying up until 11 pm
- Her physical appearance is very important to her
- She loves nature i.e., outdoors, listening to birds, sitting in parks
- Getting out
- Reading
- Hearing WWII songs
- Going to church
- She loves dogs
- Soft, tactile items
- Warm blankets

What would you do to support Emily’s Personhood?
- Could you use P.I.E.C.E.S?
- Needs-Driven Behavior Compromised Care/NDBC
- Identify any detractors
- Support with enhancers

The Bradford (University) Well-being Profile
- Wellbeing is an estimation of how the person with dementia is doing overall in their life
- Based on behavioral indicators developed by Kitwood and Brendin
- Relies on observation of social and emotional behaviors
- Is an observation monitoring tool
- Used to develop a person centered plan for social and emotional care
- See pg. 14 and 15 (The Bradford Well-being Profile) for detailed description of positive behaviors of well-being
### WHAT WORKS PLAN

<table>
<thead>
<tr>
<th>Needs / basic needs</th>
<th>Who/person</th>
<th>What Works Enhancers</th>
<th>NDBC Dementia Care</th>
<th>Actions</th>
<th>By When</th>
<th>Comments</th>
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<tbody>
<tr>
<td>1. Psychosocial</td>
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### Person Centered Care

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<tr>
<th>Well-being Positive Indicators</th>
<th>Strong</th>
<th>Weak</th>
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<tbody>
<tr>
<td>1. communicates needs and wants</td>
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<td>2. makes contact with others</td>
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<td>3. shows warmth or affection</td>
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<td>4. shows pleasure or enjoyment in daily life</td>
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<td>5. alert and responsive</td>
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<td>6. uses remaining abilities</td>
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<td>7. creative expression (i.e., singing, whistling etc.)</td>
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<td>8. cooperative, helpful</td>
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<td>9. responds appropriately to people and situations</td>
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<td>10. expresses appropriate emotions</td>
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<td>11. relaxed posture or body language</td>
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<td>12. sense of humor</td>
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<td>13. signs of purpose</td>
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### Person Centered Care

- *When Personhood is honored:*
  
  “*We become people living with and not dying from dementia.*”
A person with a spirit

A person with will & personality

A person with a life story
A person who can reminisce and share stories

A person who can be compassionate & concerned

A person with a sense of humor
A person who can be productive

A person who responds to music & and the arts

Person Centered Care

“If you’ve met one person with AD, you’ve just met one person with AD.”