

Applying Person-Directed Care Principles to the Care Planning Process for People with Dementia



Introduction

The concept of the Person-Directed/Centered Care Approach for people with dementia was developed by Tom Kitwood and his organization The Bradford Dementia Group in England. This approach has since been embraced world wide as a preferred way of working with people who have dementia, in contrast to the strict medical model of care.

There are many benefits of shifting care plans for people with dementia from a strictly medical model to a person-directed care focus. The medical model tends to constrain care planning to measuring and focusing on declines, negative issues and occurrences and physical care, rather than on quality of life issues for the person.

For example, documenting the number of times a person is incontinent offers nothing in comparison to developing a plan and strategy to help a person maintain continence and take pride in it.

A large planning area that can be improved by a person centered approach is care planning for what is perceived to be “problem behavior”. Often people get labeled negatively in a very general way in a medical model care plan as being “aggressive”, “uncooperative”, “wanderer”, etc. These general labels tend to frighten or negatively influence staff into having negative expectations and acting in ways to protect themselves and avoid the person with dementia. Occurrences of negative behavior are then looked for, documented and measured, and the cycle continues.

In contrast, a person-directed approach looks at the whole person with dementia, what his/her feelings may be in specific situations and why, defines the person’s strengths, and attempts to develop an understanding of how to work effectively with that person in ways that empower, reassure and avoid specific negative behavior producing situations. This is very empowering to both staff and the people with dementia that they work with, because it offers positive and well-defined strategies that enhance quality of life.

Guidelines for Person-Directed Care Planning

The goals for the care planning session are to:

1. Apply Person-Directed Care Principles and approaches to the care plan.
2. Update care plans to reflect the person with dementia’s strengths and needs.
3. Change from using vague institutional, disease focused, “labeling” language to clear, easy to understand, specific-to-the person, strengths based information.
4. Fashion the care plan to be a **learning document about the person**, with the best ways to understand, help and provide quality of life experiences for her or him.
5. Incorporate recent input from people who know the person well and work with him or her regularly (preferably in person as part of the team).

Materials Used to Develop the Care Plan:

- The Five Basic Needs of People with Dementia*
- Examples of changing negative behavior “labels” into positives**
- Information from staff who know and work directly with the person with dementia (team and direct care staff working together on the plan)
- Indicators of ill-being and well-being (from the Bradford Dementia Group)
- Person’s current care plan
- MDS (Minimum Data Set) Triggers for the Resident (for nursing homes)
- Quality Indicator Measures Report from the State of Wisconsin (for nursing homes)

Person-Centered/Directed Care Approach to Understanding Behavior

All Behavior should be viewed, primarily as attempts at communication, related to unmet needs. The caregiver needs to seek the meaning of the communication and to address the need.

- Tom Kitwood

Five Basic Needs of People with Dementia:*

- **Need to be useful**
- **Need to still be able to care (for others and self)**
- **Need to have self esteem boosted**
- **Need to give and receive love**
- **Need to experience joy and laughter**

(From Jane Verity “Rekindling the Spark of Life Program”, Dementia Care Australia, as interpreted from working with Tom Kitwood and the Bradford Dementia Group)

From the *Well-Being Profile* developed by Errollyn Bruse and the Bradford Dementia Group*

Indicators of Ill-Being:

- **Depression or Despair** sad, hopeless, helpless
- **Intense Anger or Aggression** outbursts of rage beyond making wishes known
- **Grief** unresolved grief after loss (home, partner)
- **Anxiety** worried, nervous movements
- **Fear** more intense anxiety, panic,
- **Boredom** tired of inactivity, looking for more
- **Physical Discomfort, Pain** real or imagined
- **Bodily Tension** Tense posture and facial
- **Agitation or Restlessness** more activity/intensity
- **Apathy** not alert, no interest in joining in
- **Withdrawal** secludes self, shuts others out
- **Distress** persisting psychological discomfort
- **Feels Like an Outsider** feels “different”
- **Easily Walked Over By Others** hurt, submissive

Indicators of Well-Being:

- **Making Wishes Known** un-aggressively
- **Initiating Social Contact** physical or eye
- **Warmth and/or Affection** or is responsive to
- **Self-Respect** preserve dignity, modesty
- **Being Helpful** volunteers – it’s the intention....
- **Humor** Jokes, does things to bring pleasure to others
- **Bodily Relaxation** relaxed, alert, calm expression
- **Creative Self-Expression** not doing a routine
- **Showing Pleasure or Enjoyment** or happiness
- **Responding Appropriately to Others** sees needs/feelings
- **Expressing Appropriate Emotions** to situation
- **Holding His/Her Own Socially** sticks up for self
- **Alertness, Responsiveness** not vacantly staring
- **Being Active** uses abilities
- **Being Purposeful** shows can make things happen

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Descriptive Language Changes Our Perceptions**

Starting Point (Old Culture)	Destination (New Culture)
<ul style="list-style-type: none"> ■ Control ■ Problem Behavior ■ React ■ Correct ■ Expect ■ “Victim” ■ “Pacer” ■ Anxiety ■ Wandering 	<ul style="list-style-type: none"> ■ Accommodate ■ Personal Characteristic ■ Respond ■ Connect ■ Accept ■ Individual ■ Motivated ■ Eagerness ■ Exploring
<p>(From application of Tom Kitwood’s Person-Centered Care Principles by Luther Manor Adult Day Center, Milwaukee WI)</p>	

Old vs. New Language: How do we Start? **	
Behavior in “old” language	New language for behavior
<ul style="list-style-type: none"> - Agitation - Rummaging or “Shopping” - Wandering - Egress or Elopement - Refusing Personal Care - Repetitive Crying Out 	<ul style="list-style-type: none"> - Energetic/Assertive - Seeking - Exploring - Assertive/Focused/ Showing initiative - Cautious - Assertive
<p>(From application of Tom Kitwood’s Person-Centered Care Principles by Luther Manor Adult Day Center, Milwaukee WI)</p>	

New Words for Old Labels**
<ul style="list-style-type: none"> - Agitation = Focused, Determined - Rummaging = Rearranging security, seeking familiarity - Elopement = On a mission, Focused - Refuses Personal Care = Self-sufficient, Modest, Assertive, Protecting self from perceived threat - Wandering = Seeking, Exploring - Repetitive Crying Out = Assertive, Asserting for resolution of unmet needs.
<p>(From application of Tom Kitwood’s <i>Person-Centered Care Principles</i> by Luther Manor Adult Day Center, Milwaukee WI)</p>

Example of the Old vs. New Care Plan and Process

Step 1. Examine the format of the care plan.

If it is a template, comb the language for things that would set the plan up to focus on either negative or non-productive things. Here are examples from actual care plans.

Old Care Plan Template Language Examples:

Problem Title

Negative Behavior

Problem Behavior

Goals written as “resident will obey/remember” etc. (things out of the staff’s control due to the person’s dementia process; Using “resident” – instead of using the person’s name).

Intervention – this word says “crisis”. The staff assist, engage and use approaches instead.

Re-direct – this has become the “buzz word” to describe nearly anything - with absolutely no specifics or substance behind it. Instead, describe exactly what will be done to engage the person and change what they are focused on.

Other Words to Eliminate:

Total assist (there is no such thing, there are always things people with dementia can do for themselves), **feeder** (animals are fed, people eat), **wanderer, screamer, etc.** These are used as “shorthand”, but also degrade how people think about and generalize each unique person’s needs. (Imagine being called this when someone is talking about you because of a need you have that you cannot control!).

Judgments or labels such as combativeness, uncooperative, lashes out, agitated, resistive, inappropriate, attention seeking, etc. (negative descriptions that label but do not describe exactly what is happening, these depersonalize the individual with dementia and offer fear and “no hope” to staff.)

The team is invited to look at these labels as Indicators of Ill-Being that have an opportunity to be shifted into Indicators of Well-Being. In order to do this one must understand what is being expressed by the person through the Ill-Being behavior.

Step 2: Involve the team in brainstorming about the person being care planned for.

- Ask: “Tell me about (name), who is she, what does she - or did she - like?” “What are her strengths?”
- **Write down the answers on a flip chart or other place where everyone can see them.**
- Then ask “What do you see as this person’s challenges or barriers to having quality of life?”
- **Write these down in a separate column.**

Now look at the MDS triggers and Quality Improvement Measures Report (for nursing homes) and compare them to the person’s challenges/barriers and Indicators of Ill-Being. This will give you an indication of what you will want to address in the care plan, using the person’s strengths and things they enjoy. Goals or Outcomes can focus on the person displaying and experiencing the Indicators of Well-being, and also on viewing behavior from positive angle (See page 2-3), thus giving people ways to “express high energy” rather than trying to quell “agitation”.

(Note: Please see web-cast on care planning for example of this process.)

Section of Care Plan Before: Sample (taken from actual care plans)

Lucille L.

Problem Title: Potential for inappropriate behavior.

1. Potential for inappropriate physical behavior and verbal outbursts.

Debilities of aging

Impaired hearing and vision

Dementia w/intermittent Agitation and un-cooperation

Evidenced by:

Combativeness with cares

Verbally lashing out at staff

Hostility at times with staff and peers

Wheeling wheelchair into inappropriate areas/eloping from unit

Frustration

Uncooperativeness

Goal: Resident will allow staff to assist dressing without conflict

Resident will accept re-direction when having inappropriate outbursts.

Interventions:

Move resident to her room if having outbursts.

Provide simple one-step re-directing attempts with resident.

Questions: How useful is this care plan?

- If staff were to read this on the first day of caring for Lucille before knowing her, how would staff feel about working with her?
- What would staff know about when behavior would occur, what to do if it does, or what to do to prevent behavior?
- Does this tell staff anything about the person Lucille and why she may have this behavior?
- Intervention 1 - We know that using isolation may make it worse! Is this intervention intended to makes things better for the staff or person with dementia?
- Intervention 2 – What does this mean? Could a new staff person understand this?

Note: People with dementia navigate the environment through sensing others around them and reacting to the environment since they have lost the ability to reason through things. Much the way small children do, they pick up on people's fears, moods, etc. and mirror them back – getting anxious or fearful when someone is anxious or fearful around them, for example. This can cause things to escalate if the caregiver and person with dementia are both anxious.

Therefore it is imperative to give staff the information that will instill confidence, warmth, a desire to work with the person and get to know them, starting with the care plan. Staff can be free to use creativity and apply knowledge about the person to develop much more effective and enjoyable outcomes which also make their jobs more enjoyable.

Step 3. New Care Planning Process and Care Plan: Information

Lucille L.

Who Lucille is – Her Past:

- Lucille is an 86 year old woman who used to be a school teacher of young children. She was married to a Veterinarian and they lived on a farm. Her husband, John, went to war and she had to run the business while he was gone. When he returned, he was disabled and she had to care for him. Lucille’s husband died ten years ago, and that was when her two children realized she had dementia and had her diagnosed. Lucille has Alzheimer’s disease, macular degeneration, diminished hearing and sometimes needs a wheelchair to get around.

Lucille L. – Team Brainstorming Information

Likes/Strengths/Characteristics:

- **Loves Animals** (Veterinarian background - was surrounded by them, nurtured them)
- **Being outdoors, gardening** (Farm in the past – had a very green thumb! Still does)
- **Nurturing to students** (early years as school teacher allowed her to mentor, guide)
- **Loves music** (Taught all subjects including music in school, including music, loves to hear Loretta Lynn sing)
- **Plays piano** (her husband loved to hear her play at night and she loved to perform for him and others)
- **Great sense of humor, kind** (loving, grateful towards staff she knows, recognizes)
- **Loves kids** (from schoolteacher days and had a lot of kids on the farm)
- **Loves sitting by window in the sun** (reminds her of home, birds singing)

Challenges/Barriers to Quality of Life:

- **Diminished vision****
- **Diminished hearing (better right ear)****
- **Wheelchair is limiting to her, trauma/ loss of husband** (going down the “inappropriate rehab wing” of the nursing home reminds her of her husband’s death after the war when he was injured and in the hospital.)
- **Strikes out during personal care (ready for bath)****
- **Corrects peers (as students)**

Lucille L.

New Care Plan

It is not needed to replicate the old care plan. In fact, it may cause the process to bog down and become limiting to the team if approached in this manner. Start with the **Challenges/Barriers to Quality of Life** (and any MDS triggers indicated by ** here, and QI indicators that need to be addressed if a nursing home). Note: Keep in mind that the MDS is the **Minimum** data set – person-directed/centered care is about planning for **Quality of Life**, so there will be more substance in the new plan than a previous care plan may have had. Because this training is focusing on the basic **social and emotional needs***(see page 2) that people with dementia often have neglected in long term care settings, this care plan example will not focus on physical care such as ulcer prevention, diet, etc. in the example and for purposes of short, concise care plan framing. The principles illustrated will be applicable to any area of the care plan.

Step 4. New Care Planning Process and Care Plan: Interpreting Behavior and Applying New Information

Lucille L.

MDS/QI Trigger and Barrier to Lucille for Quality of Life #1.

Old Care Plan:

- Potential for inappropriate behavior (combativeness with cares). **

New Information:

- Strikes out during personal care when getting ready for bath. **

Behavior Interpretation Questions:

1. Why does Lucille strike out at her caregiver when she is getting ready for her bath?
 - She feels vulnerable, is communicating this
 - She doesn't want to be undressed by a stranger
 - She thinks she is being undressed suddenly because of her hearing and vision loss, may feel she is being attacked
 - She is defending herself

Applying Lucille's Strengths/Likes/Characteristics Questions:

1. How could Lucille experience enjoyment, relaxation, warmth, affection (Well Being Indicators) when getting ready for her bath?

Possible Approaches:

- Staff she knows and likes greets her and introduces self when they come in
- Staff come in early, put on Loretta Lynn music, tell Lucille her bath is in awhile
- Speak in right ear
- Sit her in sunlight by the window
- Staff approach her from the front, greet her with her name, reminisce about Lucille's favorite things, tell a joke, ask how she is, and listen.
- Ask Lucille/talk her through each step of the care before doing it
- Ask Lucille to help, eliciting her nurturing side

MDS/QI Trigger and Barrier to Lucille for Quality of Life #2.

Old Care Plan:

- Self Care Deficit/Impaired Mobility**

New Information:

- Diminished vision and diminished hearing (hears better right ear) **

Behavior Interpretation/Improving Quality of Life Questions:

1. Would Lucille benefit from stimulation and communication through other senses, which tend to strengthen when others diminish?
2. Could Lucille still participate in activities she used to enjoy using alternate senses, and feel a sense of accomplishment and independence?

Approaches to strengthening and communicating through multiple senses:

Touch

- Engage Lucille in gardening
- Brush her hair
- Give Lucille back and hand massages
- Have pets visit that can be snuggled, stroked and set on her lap

Smell

- Use aromatherapy in the tub room when Lucille is bathing
- Put flowers from the garden in Lucille's room; tell her she helped to grow them.

MDS/QI Trigger and Barrier to Lucille for Quality of Life #3.

Old Care Plan:

Verbally lashes out, hostility at times with staff and peers.

New Information:

Words she uses sound like a teacher correcting her students

Behavior Interpretation/Improving Quality of Life Questions:

1. Why, when and what does Lucille yell out to other residents and staff? (She seems to be correcting people's manners, telling them they haven't been dismissed yet, and scolding when others talk badly about someone.)
2. How could we use Lucille's past experience of being a teacher to help her experience the self-respect (Well-Being Indicator) from that role?

Possible Approach

- Instead of scolding or correcting or isolating Lucille, (old Care Plan) try having staff role model a response of "Thank you for reminding me Miss Jones."

MDS/QI Trigger and Barrier to Lucille for Quality of Life #4.

Old Care Plan:

Wheeling wheelchair into inappropriate areas/eloping from unit

New Information:

Wheelchair is limiting to her, experiences trauma/ loss of husband when on Rehab unit and seems attracted to going there.

Behavior Interpretation/Improving Quality of Life Questions:

1. Why would Lucille be attracted to going to the Rehab unit? (going down the "inappropriate rehab wing" of the nursing home reminds her of her husband's death after the war when he was injured and in the hospital; she cared for and was with him until his death).
2. How can Lucille be able to express appropriate emotions about her husband's loss?
3. How can Lucille have opportunities to nurture, initiate personal contact with others?

Possible Approaches (offer these things to do in area Lucille needs to stay in):

- Encourage Lucille to reminisce about her husband, cry if needs to, also tell stories.
- Find people who need a visitor, could reminisce with Lucille (or volunteer).
- Depending on her stage of dementia, offer dolls, animals to nurture, staff ask her for hugs.

Lucille L. New Care Plan

Need #1: Lucille needs to feel safe and have staff understand her behavior, to avoid her having to protectively strike out when getting ready for her bath.

Outcome #1:

Lucille will experience enjoyment, relaxation, warmth and self-respect when getting ready for her bath.

Approaches:

- Staff she knows and likes greets her and introduces self when they come in
- Staff come in early, put on Loretta Lynn music, tell Lucille her bath is in awhile
- Always speak into Lucille's right ear
- Sit her in sunlight by the window
- Staff approach Lucille from the front, greet her with her name, reminisce about Lucille's favorite things, compliment her, tell a joke, ask how she is, listen
- Ask Lucille/talk her through each step of the care before doing it
- Ask Lucille to help with tasks, eliciting her nurturing, helpful side

Need #2: Lucille needs senses other than sight and hearing stimulated to help strengthen her senses, enhance her experiences and communication.

Outcome #2: Lucille will enjoy pleasurable activities from her past using alternate senses, and be given an opportunity to feel a sense of accomplishment and independence through those activities.

Approaches to strengthening and communicating through multiple senses:

Touch

- Engage Lucille in gardening
- Brush her hair/let her brush other's hair
- Give Lucille back and hand massages
- Have pets visit that can be snuggled, stroked and set on her lap

Smell

- Use aromatherapy in the tub room when Lucille is bathing
- Put flowers from the garden in Lucille's room; tell her she helped to grow them.

Need #3: Lucille needs to be recognized for her desire to help others, as she did as a teacher, when exhibiting corrective behavior to staff and peers.

Outcome #3: Lucille will be listened to and experience respect from others when offering them corrective advice.

Approach

- Staff will role model a response of "Thank you for reminding me Miss Jones" and encourage her peers to do the same.

Lucille L. New Care Plan (Page 2)

Need #4: Lucille needs to express her emotions of loss, caregiving and nurturing, and needs personal contact with others while in her environment.

Outcome #4: Lucille will have outlets for her feelings when needed, and opportunities to express her caring/being of help to others with staff and peers and through activities in her environment.

Approaches:

- Offer things to do in area Lucille needs to stay in to keep her there.
- Encourage Lucille to reminisce about her husband, cry if needs to, also tell stories.
- Find people who need a visitor, could reminisce with Lucille, or a volunteer who can visit with Lucille.
- Depending on her stage of dementia, offer dolls, animals to nurture, have staff ask her for hugs.