



Supportive Pathways Education Program

Module 2

Individual
and
Family Care


A photograph of a person with long dark hair, wearing a dark long-sleeved shirt and dark pants, sitting on a brown couch. They are looking down at their hands, which are resting on their lap. A floor lamp is visible in the background.

Objectives

To understand the value of "seeing" the person behind the disease and how to individualize care


To understand how culture and spiritual values can impact care

To discuss how to work with families to create quality partnerships


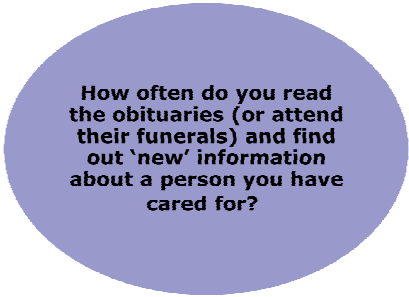
The Carewest logo, featuring a stylized heart shape made of three overlapping loops, followed by the text "Carewest" in a bold, purple font and "INNOVATIVE HEALTH CARE" in a smaller, bold, purple font below it.

Understanding the Person behind the Disease


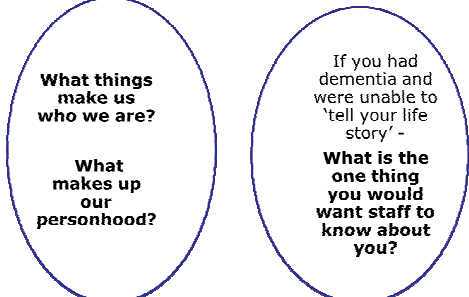
- A person with Alzheimer Disease talking to his wife said:
"Jean, don't forget I'm still in here"
- Staff need to keep in mind that:
"Everybody has a story."

A photograph of a person with long dark hair, wearing a dark long-sleeved shirt and dark pants, sitting on a brown couch. They are looking down at their hands, which are resting on their lap. A floor lamp is visible in the background.

Did we know them?

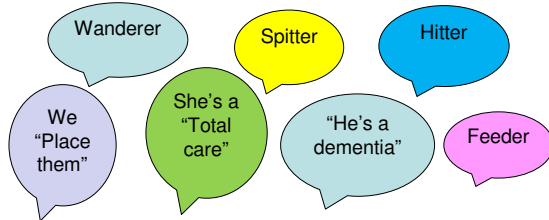
A large blue oval containing the text: "How often do you read the obituaries (or attend their funerals) and find out 'new' information about a person you have cared for?". The Carewest logo, featuring a stylized heart shape made of three overlapping loops, followed by the text "Carewest" in a bold, purple font and "INNOVATIVE HEALTH CARE" in a smaller, bold, purple font below it.

Who am I?

Two blue ovals containing text. The left oval contains: "What things make us who we are?" and "What makes up our personhood?". The right oval contains: "If you had dementia and were unable to 'tell your life story' - What is the one thing you would want staff to know about you?". The Carewest logo, featuring a stylized heart shape made of three overlapping loops, followed by the text "Carewest" in a bold, purple font and "INNOVATIVE HEALTH CARE" in a smaller, bold, purple font below it.

Depersonalizing

Can our words and actions be depersonalizing?



Can these 'labels' effect our care?



Labels – are there more?



Labels don't help us:

- Think of the person and who they are
- Help us understand the meaning behind a behavior
- Think of alternatives to physical restraints
- Think of alternatives to chemical restraints such as antipsychotics



What can we learn?



"Honey, I've been through 2 world wars, the Great Depression, taught 3,297 children, administered 4 elementary schools and outlived every one of the pastors I worked with."

"I'm 89 years old and you're telling me it's bedtime?"

... to respect the person and who they are



Supporting 'Personhood'

- To support 'personhood' we provide individualized care.
- Caregiver Golden Rule: Treat others as they would like to be treated.



Supportive Pathways Model of Care



(Source: M. Woloshchuk, M. Collins, C. Blake 1999)



Cultural/Spiritual Considerations

Cultural and Spiritual beliefs and practices can influence care



Cultural Considerations

Mode of Dress



Cultural Considerations

Dietary/Food Preferences



Cultural Considerations

Recreation



Cultural Considerations

Use of Touch



Cultural Considerations

Privacy



Cultural Considerations

Communication

Staff need to communicate :

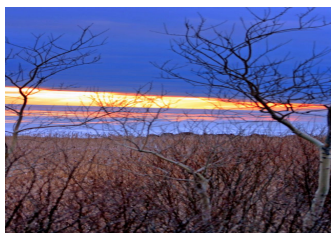


- appropriate to person's cultural etiquette and their language (not speak any foreign language that they can't understand around them)
- to utilize a translator if necessary



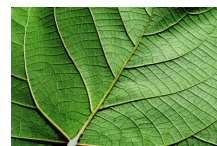
Spiritual Considerations

Spiritual Beliefs and Practices



Cultural Considerations

Health and Healing Practices

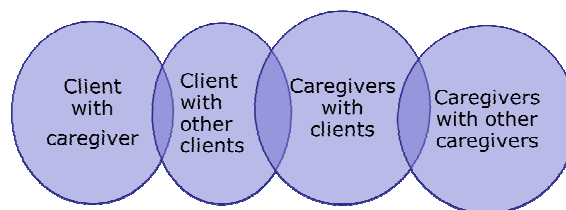


Cultural Considerations

End of Life Care



Conflicts May Arise



Cultural Considerations

- Do you have any additional stories about different cultural beliefs in the clients you care for? Alternative health care practices?
- How are cultural considerations communicated to the staff in your work place?



Family as Partners in Care



Living With Dementia



Family - Coping With Dementia

"Featherhead" Video



"Featherhead" Debriefing

When he took the bread from her do you think he was abusive?

Could a similar situation occur while the person was in care – with family or staff?



Featherhead Debriefing

Was he responding to a loss? Was he distressed?

What supports are needed/available in the community and in care centres
– for family and staff?



"Featherhead " Debriefing

Have you worked with situations the video portrayed?

What are some supports caregivers need?



Risk of Abuse - Warning Signs

Suspicious injuries

Poor physical appearance or signs of neglect

Fearful of the caregiver

Discrepancy between known income/standard of living

Worrying about documents they have signed

Caregiver concerned more about the financial status of the person not their health status

New friend/caregiver is isolating the person from others



Why Families Need to Seek Support

Some caregivers have described dementia as the "longest goodbye".

(Bourgeois 2002)



Family

How would you define family?

"Family are who they say they are"

Wright & Leahey, 1994



Who knows the client best?

*Do we as staff or does the family
know the person best?*

Family



Program Goals

**Family will
be encouraged to be
involved to their desired
level**



Why should we Partner with Families?



- To help us provide **individualized care**
- To **share** in the care and care decisions
- To exchange **information** with each other
- To **build trust** and an **understanding** of expectations between family and staff



What Families can Share

- the person's life story – **who they are**
e.g. important people, events, routines and activities
- their likes and dislikes
– **'what makes them smile'** 
- changes that seem to be due to their dementia and any other conditions they have
- what they were like before these changes occurred
- the person's cultural and spiritual beliefs/practices



Other Helpful Information

- tips or strategies that have helped the person with dementia
 - what family feels is important in regards to the person's care
 - any questions and concerns the family have
- (Family Input is so Valuable)



Effective Partners in Care - An Example

If an antipsychotic is being considered /reduced/stopped

- the **health team and family** will discuss:

- Reason for the medication change
- Risks and benefits related to the change
- How it will be monitored and how family can help
- Care strategies (Brainstorming together)



Family: Friend or Foe?



See handout for this activity



Our Relationship with Families

- How many of us think of 'partners' when we think of families?
- *What do we think of when we think of families?*
Helpful? Loving? Dedicated? Uninvolved? Dysfunctional?
Demanding? Having unrealistic expectations? In denial?
- Will it help us to be more understanding when we realize that family members may be 'distressed'?



Things We Say That Distresses Families?

- NOT my job!
- NOT my shift!
- I'm on my break!
- I'm just back today
- We're short staffed today
- We have lots of clients



Marlene Collins 2009



Things We Do That Distresses Families?

- Appear to ignore family when they visit
- Not include clients in conversations
- Not follow through when we say we will
- Seem to be chatting with co-workers
(non-work related)
- Talking on our cell phone in a client area
- Appear to ignore call bells



How do we turn these actions into positives?



Understanding Distressed Families

Some families already have:

- Elevated expectations
- Wishes for the person to be back to normal
- Different Beliefs/Values
- Experienced lack of community support due to the community at large having limited knowledge and experience with dementia

Marlene Collins 2009



Distressed Families

"Grief is a constant part of the process of caring for a loved one with Alzheimer disease."

Liken & Collins, 1993



Distressed Family Strategies

Include in activities, care planning, care to their desired level

Be Proactive



Support them to not feel guilty. Invite to Family Support groups.

Have empathy for their losses

Don't judge them

Educate on normal progression of the disease

Marlene Collins 2009



Distressed Family Strategies

Staff need to greet family in a friendly manner

Provide care which is in line with the Care Plan



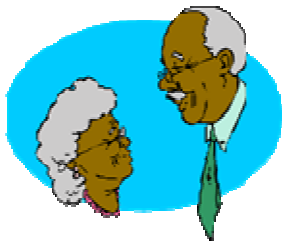
If there is disagreement over the Care Plan, then set up a meeting with the family

Be careful of your tone of voice

Marlene Collins 2009



Jack and Lucy's Story



Partnering with Lucy

What does Lucy value?

Do you think staff were aware of her feelings?

From our previous discussion what things could we do to partner with Lucy?



Questions?



Please refer to your handouts



References

- Andrews, M.M., &Boyle, J.S. (2003). Transcultural Concepts in nursing care (4th ed.).Philadelphia: Lippincott, Williams & Wilkins.
- Kellett, U. (2000). Bound within the limits: Facing constraints to family caring in nursing homes. *International journal of Nursing Practice* 6, 317-323.
- Kitwood, T (1997). Dementia Reconsidered-the person comes first. Buckingham, UK: Open University Press.
- Lustbader, W. (1996). Tales from individualized care. *Journal of Gerontological Nursing*, March, 43-46.





Families: Friend or Foe?

GROUP EXERCISE

	Agree	Disagree
1. Residents' families visit out of a sense of guilt or obligation,	_____	_____
2. There should be no restrictions on visiting hours.	_____	_____
3. Residents (when able) and their families should be involved in developing individualized care plans.	_____	_____
4. Interacting with caregiving staff is stressful for families.	_____	_____
5. Staff are often defensive in relating to families.	_____	_____
6. Families should take on the role of resident advocate.	_____	_____
7. My feelings toward a residents' family affect my feelings toward the resident.	_____	_____
8. Families who visit a lot usually interfere with nursing procedures.	_____	_____
9. Relatives have a responsibility to provide some care – e.g., help with feeding, transportation to appointments.	_____	_____
10. Families are hesitant to “make waves” or complain to staff for fear of reprisal toward their relative.	_____	_____

INDIVIDUAL REFLECTION

- a. What have you noticed about families in your facility / center / community?

- b. What would make staff / client / family relationships better?

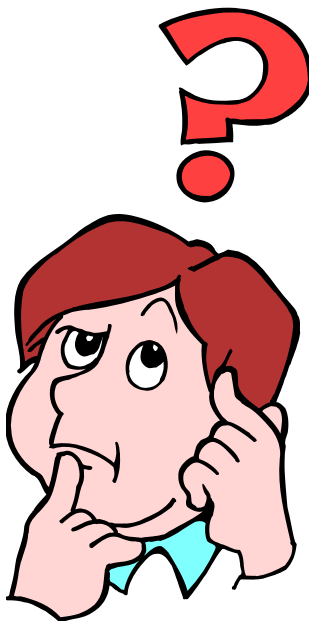
Source: Baycrest, Toronto

Enhancing Family Visits

Families may find visiting their impaired relative more and more difficult as their relative becomes more impaired, less communicative, and less like the person they once knew. Families may believe that their visits no longer matter to the relative, since the relative does not recognize them. Some may feel frustrated by the fact that their relative does not remember previous visits.¹

Questions that families and friends often ask about visiting:

- What should I talk about with my cognitively impaired relative?
- How do I deal with my relative who claims I never visited before, or have not visited for a long time?
- How do I deal with the relative who no longer recognizes me?
- What should I do with my relative during the visit?
- How do I communicate with someone who no longer is able to verbally respond?
- What do I do if my relative becomes aggressive during a visit and hits someone?



1. O.W. Malott, ed., Alzheimer Resource Manual (Waterloo, ON: University of Waterloo, 2000)

Tips to Enhancing Family Visiting

- Time visits to maximize resident responsiveness
- Mealtime schedules and procedures, special events, down times, and gaps in activity programming are good times to visit
- Determine if the family would like to have visits scheduled so they can participate in care (example – mealtime)
- Some families may appreciate visiting when they can help reassure the resident (example – bedtime)
- Encourage visiting when families can observe activities, or during a time when things are not so hectic
- Encourage and support family members' desire to help out by asking them to contribute their special talents to the activities program
- Have materials available to promote visiting
- If possible, providing a visiting room
- Help families leave without difficulty
- Encourage family members to volunteer
- Encourage the creation of a memory box

