





### TIME REQUIRED:

This two part module discusses:

- 1) the importance of discovering the person behind the disease process
- 2) how families can become partners in care

Together the two (2) topics require one and a half (1.5) hours. If offering this module in smaller components, doing 45 minutes for “individual” concepts and 45 minutes for “family” may be an option.

### SUPPLIES NEEDED:

- Video clip “Featherhead”
- LCD
- Flip chart and markers
- 2-3 copies of the Supportive Pathways Unit Manual 2015

**BEST PRACTICE** - (When preparing to teach this module, the points below are intended to be covered in this module. These notes are repeated at the end of the module so that the trainer can use them to summarize or review the content covered if they wish).

**Best practices related to this module include the following strategies:**

**INDIVIDUAL CARE:**

Staff will be familiar with information regarding the client's care and background

- Information about clients will be treated with respect (e.g. FOIP/HIA and confidentiality principles).
- Staff will provide care in a way that **respects the individuality** of the client.
- Staff will recognize how the client's culture and spiritual beliefs influences care needs.

**FAMILY CARE:**

- **Families will be recognized** as who the client identifies as their family (e.g. guardians, supportive friends, pets etc.).
- Families will be invited to be involved or to be partners in care. **Care conferences**, both formal and informal, will provide opportunities for decision-making to include family.
- Staff will be **aware of family perspectives** and try to meet their expectations for care.
- Staff will have an **understanding of family dynamics**.
- **Family support** will be provided wherever possible or referrals to other resources will be offered.
- **Family rights and responsibilities** will be discussed with families. The appropriate personnel will provide information to families. Informal education will be offered to families.

## Objectives

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

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To understand how culture and spiritual values can impact care

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To discuss how to work with families to create quality partnerships





## OBJECTIVES

The trainer briefly reviews objectives aloud.

### 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."**

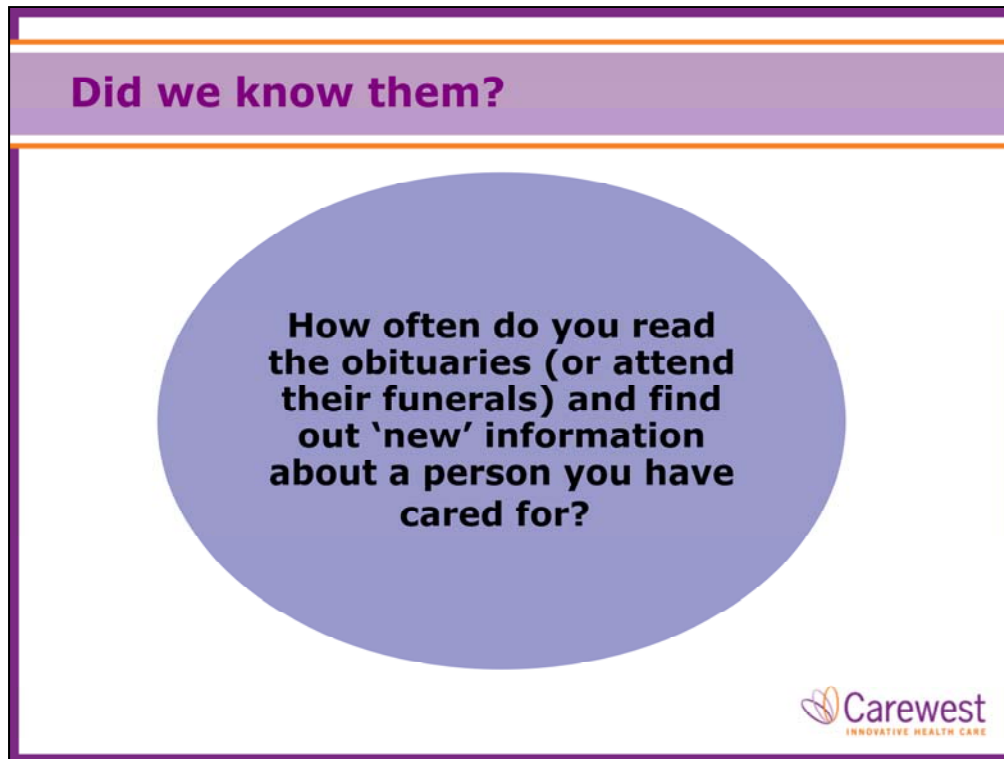


**Key message:** we need to recognize the value of understanding the person behind the disease and how care needs to be individualized. This is important in all care settings.

- A recent study with persons with early dementia found that one thing they feared was a **loss of "personhood"**.
- In the early stages of dementia, the person may worry that who they are will be forgotten as the disease progresses.

### What is the story of the man in the picture?

*His father died when he was young. He was the oldest son (9 years old) so he had to work on the farm helping his mother from an early age. He had a milk route with a horse and wagon before he went to school in the morning. He worked as a carpenter and had six kids. His passion was airplanes and he took his pilots license at age 45. His wife Jean had a major stroke at age 63 so he retired to look after her. At age 70 he was diagnosed with Alzheimer Disease. His cat's name was Shadow and he loved having her sit on his knee. He also loved dogs and would pat any he encountered on his walks around the neighbourhood. His childhood dog's name was "Terry" and he would call all dogs he met by that name.*

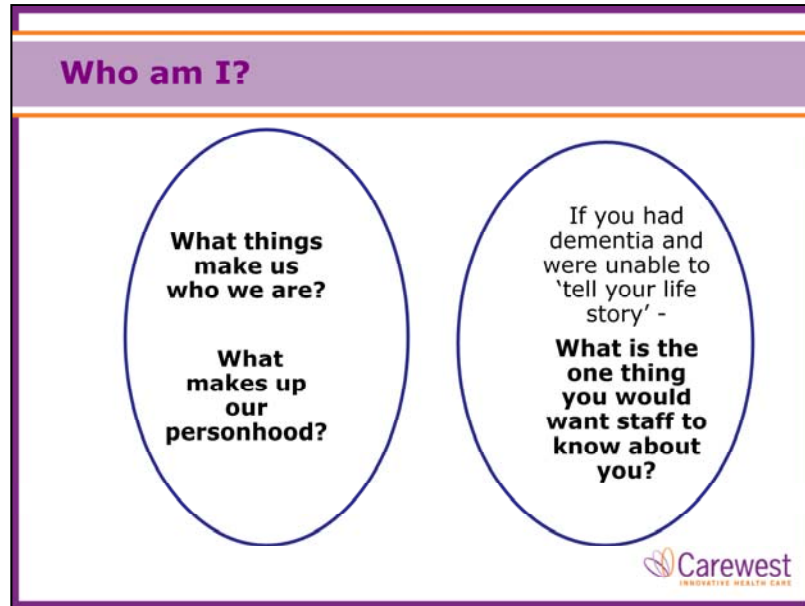


**ASK:** How do we learn their story? What do you use where you work? How do we make sure everyone has read it?

**Think of the two people that you are keeping in mind while you work through these training modules. How well do you know their personal histories?**

*E.g. Post traumatic stress can impact a person for years after the traumatic event (and the traumatic event may be relived when a person has dementia).*

**Carewest uses “Getting to Know You”. Refer them to the Supportive Pathways Unit Manual 2015 (show them a copy and leave the sites each one copy of this manual)**



- **ASK** the group **'What things make us who we are?'**
- Record on the flip chart: (time allocation: about 5 minutes or less)

For example:

- ✓ Life History- parents, siblings, school, work, marriage, kids, pets, significant relationships
- ✓ Significant losses
- ✓ Personality/coping style (are we born with our personalities or do they develop? Look at siblings and how different they are even being raised in the same home)
- ✓ Interests/hobbies/strengths
- ✓ Spiritual beliefs
- ✓ Values/ beliefs- discussed previously in module one
- ✓ Sexuality
- ✓ Culture (**will discuss this in more depth in next section**)

**ASK: If you had dementia and were unable to 'tell your life story', what is one thing you would like staff to know about you?**

(Ask for some volunteers who are willing to share their answer with the group)

## Depersonalizing

Can our words and actions be depersonalizing?

Wanderer

Spitter

Hitter


We "Place them"

She's a "Total care"

"He's a dementia"

Feeder

Can these 'labels' effect our care?

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**Ask:** Do we ever depersonalize older people in the health care setting both by our actions and the words we use without meaning to?

For Example we may say things like:

- We *"place them"* - normally we just place objects
- He is a *"feeder"*; a *"hitter"*; a *"spitter"*, *"wanderer"*
- *"I did up John for you"*
- He is a *"total care"*
- *"He is difficult"* or *"That family is 'difficult'"*
- *"He's a dementia"* rather than *"the person with dementia."*



**Labels – are there more?**

Aggressive

Screamer

Sexually Inappropriate

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

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We want to avoid labels so they don't become who they are e.g. 'he's a spitter'  
Labels are 'judgements' and 'set the next caregiver up' and the person becomes 'vulnerable' to the prejudged label.

E.G. if someone is labelled 'aggressive' we may automatically be afraid of the person or go in with 3 people to give care.

It would be better to include in the care plan – what approach seems to work best.

**ASK:** what should be on care plans instead of 'labels'?

**Answer:** they should describe the behavior and what seems to trigger it.

e.g. becomes upset and has stuck out at staff if approached too quickly – allow time to build rapport before asking the person to let them you help them dress – if becomes upset try again later.

Remind the team leaders of their responsibility to assess, role model and coach in these situations.

## 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**



**Read the Cartoon out loud as they may not be able to see the print**

*"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?"*

**Ask** – what is she teaching us? Next click brings in 'to respect the person and who they are'



**ASK:** What are some ways we can provide reminders of who they are? Use flip chart. (optional)

- *use the name the person prefers*
- *memory boxes*
- *family pictures*
- *items from home in their room*
- *reminisce with them*
- *style of dress, makeup, perfume (Does a woman who always wore make-up feel un-presentable without it?)*
- *individualized activities that connect to the person's previous interests, individualized care. (e.g. Can a gardener could enjoy looking at a seed catalogue if they can't physically plant seeds anymore?)*

Treating the person as an individual goes beyond the Golden Rule; **“Treat others as you would like to be treated” we should: “Treat others as they would like to be treated.”** Find out how they like to be treated - hugs, jokes, more formal? Preferred name?

It requires a great deal of effort on our part to provide this individualized care. Respecting personhood also means that we don't assume that all behaviours stem from dementia.



## SUPPORTIVE PATHWAYS MODEL OF CARE

Think of the Supportive Pathways Model of Care ...

***ASK: Does your unit follow this model of care?***

***How can you change that?***



Culture and religion influences many things about our clients as well as our beliefs and preferences. We will discuss how they both can influence care.

It is important to **emphasize that individuals from a certain culture/religion may not practice all the values, beliefs and practices commonly associated with that group.** *We can't use stereotypes!*

**Group Activity:** divide into groups or partners and give them each a topic from the next 9 slides; asking them to come up with 2-3 examples for their topic. Then have them report back to the large group as you put each slide up. Add examples from each slide's notes if you wish.

**Topics are:**

Mode of Dress

Recreation

Privacy

Spiritual beliefs/practices

End of Life Care

Dietary/Food preferences

Use of Touch

Communication

Health and Healing Practices



## MODE OF DRESS

Are there any special garments required for religious services?

What is their everyday dress preferences?

Do they need to cover parts of the body?

Will some of the cultural dress requirements effect care?

Examples:

Dress for Mosque

Turbans

Hijabs

Hutterite dress

## Cultural Considerations

### Dietary/Food Preferences



### DIETARY /FOOD PREFERENCES

- What is the *meaning* of 'food' for the client?
- Does bringing in food or feeding the client *represent ways of "caring" or "duty"*?
- Are some foods believed to have healing properties or to be bad?
- Are there dietary taboos? e.g. Muslims / Jews - no pork, Hindus - no beef
- Are there dietary preferences ? e.g. rice with every meal
- Are there generational preferences e.g. farmers who ate 'only meat and potatoes' – not pastas, casseroles etc.

#### **Ask participants if anyone would like to share examples such as:**

- *Some cultures have rules about what food you can eat together*
- *Staff offers cold water (believing it is refreshing) and client believes cold water is harmful to their health.*

## Cultural Considerations

### Recreation

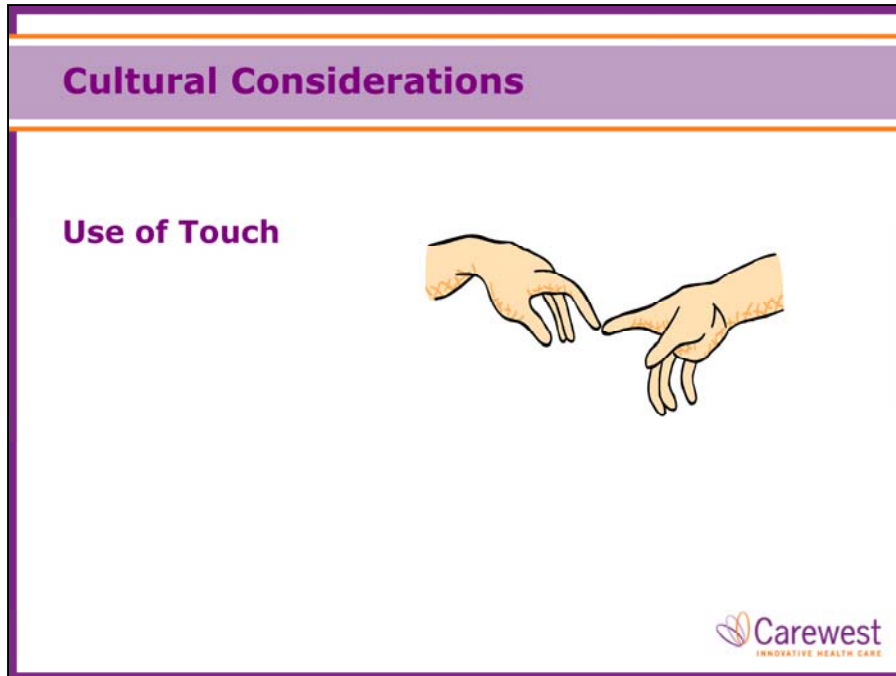


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## RECREATION

Some religions prohibit against dancing, card playing, males and females together, drinking alcohol, playing bingo - so it is important to know if a person has these beliefs and values.





**USE OF TOUCH** - What are the cultural rules around 'touch'?

- French, Italian, Latin American touch lots but in British, Germany, North American cultures there is less. Middle Eastern – no male / female touch (unless married)
- the use of left hand is not respectful in some cultures
- touching on the head may be taboo (\* Many Asian Cultures believe this is disrespectful. Vietnamese believe that the head is seat of life)
- male caregivers may be prohibited to care for female clients. (\*Hispanic caregiver's culture – male cannot touch females.)
- handshaking – it is rare in some cultures –especially between male and female. (Middle Eastern female – not permitted to shake hands with men).

## Cultural Considerations

### Privacy



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### PRIVACY

Some cultures have HUGE issues around exposing the person's body – privacy issues e.g. Muslims wear hijabs

During care procedures, how often do we 'undress someone' and then allow others to see them?

Other concerns may relate to male/ female caregivers

## 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



## COMMUNICATION

- Eye contact (direct eye contact is a sign of honesty in North American culture. "She couldn't even look me in the eye". (Native Americans look at floor, but not necessarily all groups, while paying attention to speaker. In other cultures eye contact is NOT RESPECTFUL for examples amongst the Middle Eastern. Hispanics many show respect when they downcast their eyes - Hispanic Asian.) Source: Andrews & Boyle, 2003

- Dealing with conflict:

Some Asian cultures tend to avoid conflict. A smile and nod may not mean the individual agrees – The nurse may think the plan is agreed to, but the individual disagrees and won't do the action. To avoid conflict, they won't speak up to the nurse and say: "this won't work."

## Spiritual Considerations

### Spiritual Beliefs and Practices



### RELIGIOUS BELIEFS/ PRACTICES

Are there special days/celebrations? Are they still interested?

Are there special considerations?

*(\* Muslims-may wish to bathe in running water (shower may be better).*

Religions may have rituals related to prayer, days of worship, religious holidays

\* Adopted from Source: Andrews & Boyle (2003)



## THEIR HEALTH AND HEALING PRACTICES

- What do they believe helps or causes illness?
- How do they express pain - with silence or loud verbal expressions?
- How is dementia viewed? Is it something to be hidden?
- Who expects to take responsibility to care for the sick?
- Advance Directives / Future choice for Health Care?

Some cultures believe that dementia results from stress or disharmony. Some may think the person is being punished for their sins. Mental illness in any form is highly stigmatized in many cultures so families may resist having their relatives moved to or admitted to a dementia care unit (families might believe this diagnosis is something to hide from others)

Within some cultures herbalists (i.e. Chinese), healing elders – Medicine Man (i.e. Native Americans) may be consulted before a physician.



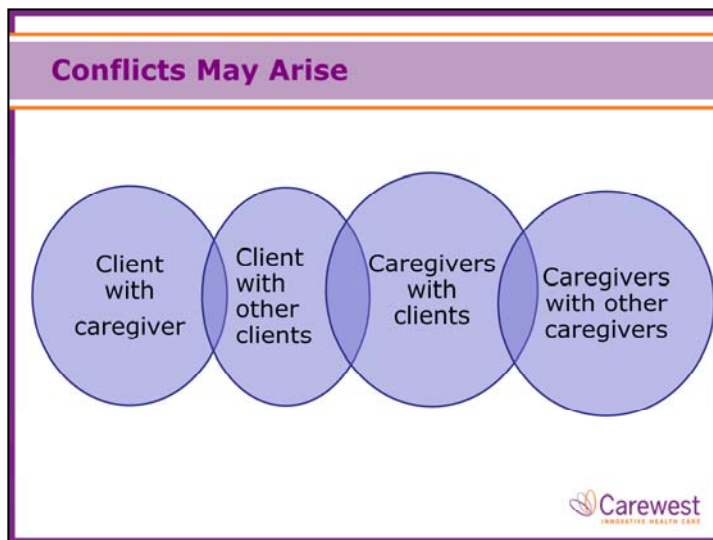
## END OF LIFE CARE

What are the cultural, religious beliefs about the end of life care?

*Some cultures are more accepting of death than other cultures – some might try to extend life at all costs – families from these cultures would want the person to have CPR – Who makes these decisions? The eldest son? The wife?*

Some cultures such as Filipinos and some Muslims may request that the dying person not be told they are palliative

Some cultures based on their religious convictions may request a visit by the clergy – i.e. Catholics may request a sacrament by a priest



### CULTURAL/ SPIRITUAL CONFLICTS

- Many *older people* have had little *exposure to different cultures* and they suddenly find themselves sharing living space, eating with or being bathed by others of a different culture.
- Some clients from the same culture will not automatically be friends-they may be from different backgrounds, education, socio-economic status and feel they have little in common. e.g. In a DAL, a conflict could arise if a support worker introduced two people of similar cultures and 'expected' them to get along.

Resource: Network of Aging – [www.asaging.org](http://www.asaging.org)

**ASK:** Can you think of examples of 'cultural/religious conflict between clients and staff, that you have noticed in your work place?

Examples:

- *Staff may have trouble cooking and serving meat that is taboo in their own religion /culture or working with someone of a different culture or status*
- *Family culture may be in conflict with what the client is expressing. e.g. the JEWISH client who wants to eat pork. What do you do if the daughter says: "Don't give it to her" and the mom says " I want to eat it". What should you do? The daughter is the guardian? NEED TO DISCUSS with the daughter and the client? What would our program goals direct us to do? Living for the moment? Mom enjoys it? Come to some compromise. Early in the disease the person may have expressed a wish that the family help them to maintain their cultural belief. Possible solution – daughter takes Mom out on the days pork is served*

## 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?



Reference – Cross Cultural Profiles (2003) originally prepared by Carrie Bon Benard of the Multicultural Awareness program - Peter Lougheed Hospital, Calgary) See Unit handout

Other Resources:

[Hamilton Health Sciences](#)

<http://www.hhsc.ca/body.cfm?id=1782>

<http://erc.msh.org/mainpage.cfm?file=5.1.0a.htm&module=provider&language=English>



### **Family as Partners in Care**



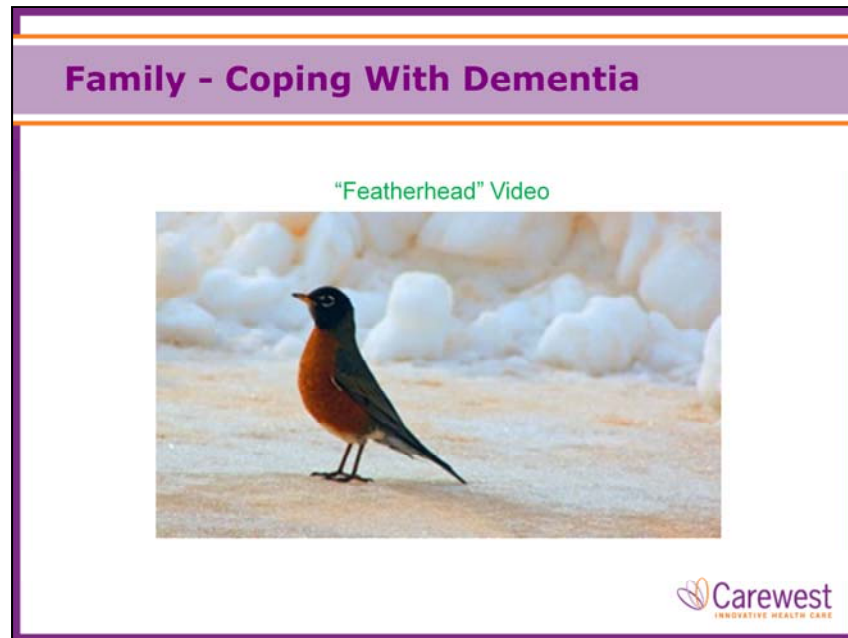
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Remind the participants to think of a family they have worked with in the past.

## Living With Dementia



Common issues encountered throughout the Stages of the disease are discussed in this section.



### Show video

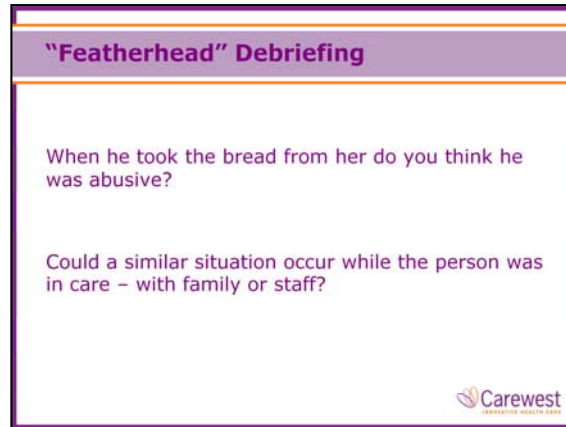
It is important to provide some intro prior to showing the video

- remind participants that they may require 'Kleenex' while watching it

### Intro:

- Video was shared for use in the Supportive Pathways Program by David Sheard ( a person-centred dementia care expert in the UK)
- It helps us understand and gives us a sense of how families struggle and get distressed when a family member has dementia

**Play entire video-Debrief using next slide.**



**Trainers notes for info only: Suggestion: just hi-lite important points for the participants**

#### RISK OF ABUSE


- Affects between 4-10% of older adults
- Staff working in the community or facility need to be alert for signs of abuse or neglect (see slide)
- Being mentally impaired puts the person with dementia at risk.
- Abusers may choose victims they feel would be unable to report or who will be disbelieved.
- In Canada, adult children are the largest category of abusers for all forms of abuse.
- Financial abuse is the most prevalent type of abuse.

#### For persons in care :

- **there is a legal obligation to report any form of abuse to Protection for Person's in Care**

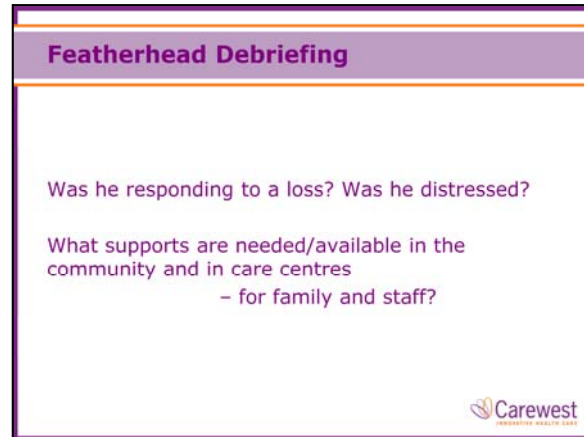
The best predictors of abuse are:

- Mental health issues or substance abuse
- Dependence on the elderly person for financial assistance, housing or other necessities and a history of violence or antisocial behaviour outside the family.
- Often the least capable family member is designated as the caregiver. Elder abuse may be a continuation of previous family violence.

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 or caregiver isolating the person from family or friends	

**Just read these but don't use a lot of time on this slide due to time constraints.**

**Duplicate  
Covered on page 34**



***Trainer's Notes: Again just mention some of the important points on this page and the next note page.***

## **CAREGIVER (Family and Staff) SUPPORT**

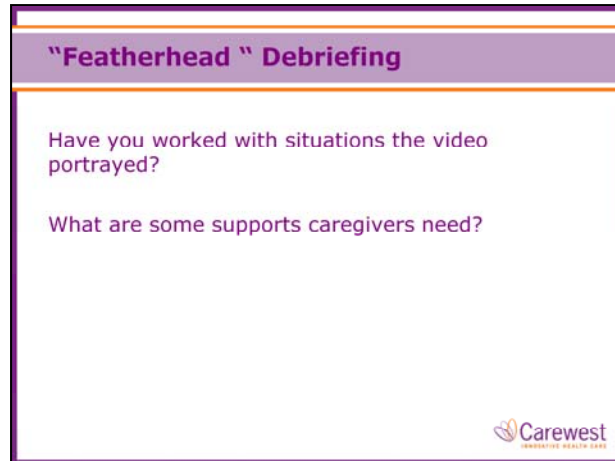
- It is important that caregivers develop support systems early in the caregiving situation.
- Caregivers need education on the physical and psychosocial aspects of caregiving and referrals to other agencies for help and support.
- Acknowledging and praising them for the difficult work they do is important.
- They may need your support and encouragement to take time for themselves if the person with dementia is reluctant to have other caregivers or attend a day program.
- The person and their caregiver are both your clients. You are often their greatest support and source of information.

***Trainer's information only: (many of these tips would work for staff and family)***

**The Alzheimer Society suggests that caregivers:**

- Learn about the disease and share this information with family and friends
- Be realistic about the disease-the person will get worse
- Be realistic about themselves re how much they can do
- Accept their feelings- negative feelings don't mean that they are not a good caregiver, they mean you are human
- Share their feelings with others
- Look for good things
- Take care of themselves- look after their own health, ways to decrease stress
- Look for humour
- Get help - ask for and accept help
- Plan for the future

(Alzheimer Society "Reducing Caregiver Stress: Finding ways to feel better")



## CAREGIVER SUPPORT


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New friend/caregiver is isolating the person from others	
	

**Again, cover these very quickly**



Dementia is a disease that can last for years.

The family and the person with dementia have been dealing with significant losses as the disease progresses.

The words, "longest goodbye" to describe dementia makes us reflect on what the family members go through.

We often join them partway into their journey and may not know what struggles and losses they have faced.

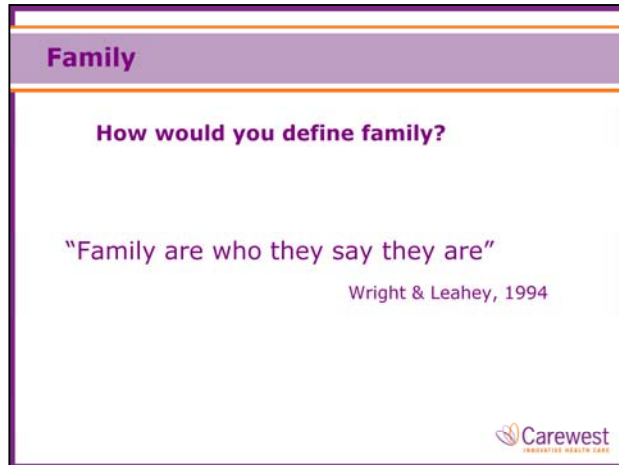
The length of the "caregiver" burden makes it difficult for families.

**The 'Featherhead' video highlights that the caregiver s need to have a plan in place in case of an emergency such as their illness.** Name of emergency contact person should be readily available.

Maintain a notebook for the responsible person who will be assuming caregiving. Such a notebook should contain the following information:

- emergency numbers
- current problem behaviors and possible solutions
- ways to calm the person with AD
- assistance needed with toileting, feeding, or grooming
- favorite activities or food
- medications
- other care services involved e.g. respite, private agencies

(ADEAR- <http://www.alzheimers.org/pubs/homesafety.htm>)

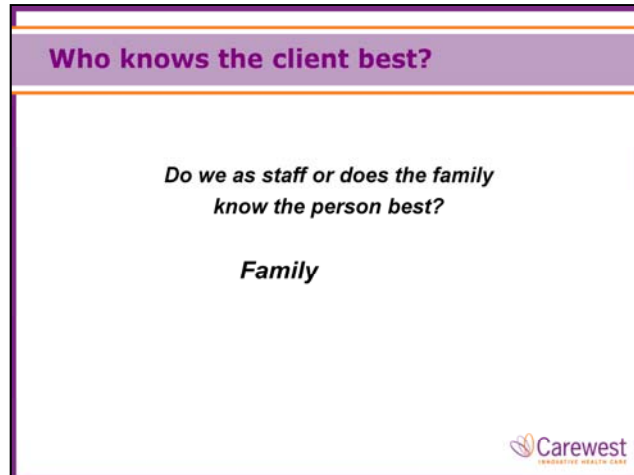


**Trainer Tip-** Discuss first then click to show the definition.

**Prompt Question:**

**Do you have to be related by blood?** No.

Family can often be defined by who the person feels they are close to emotionally. For those living at home maybe their pet or a neighbour is their family.



***Who knows the client the best? Family***

Quote from a daughter. “You know my father with dementia but I know my father.”

*Staff* might know:

- the *CURRENT* day to day routine, preferences – and where they are with their disease

*Family really knows:*

- the client – what is important to them
- their life story – physical, emotional and social

We only know the person with the disease process.

Think of the video “What do you See Nurse?”.



Partnering with families meets this Carewest Program goal

They may wish to be very involved till they gain trust in our care or may be too burned out to be involved in the beginning but later maybe can be more involved.

**PARTNERSHIP - Can we share the care?**

- **How do we include them in the care planning?**
- Do we appear to 'take over' the care decisions?

As in our discussion about individual care, it is also important to understand the family values.

- In some families the husband makes all the major decisions.
- Who in the family is expected to care for ill family members?
- What are the cultural expectations?
- Is there a stigma re: dementia and admitting a family member to long term care?
- How does this family demonstrate their love- e.g. by doing things?
- Is there family history and dynamics we are unaware of?

## 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



Mention that when we refer to families that it includes alternate decision makers such as guardians

Developing a good relationship early will enable positive problem solving should difficult/challenging situations develop in the future

## 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 conditions – may include chronic pain and how they dealt with it



## 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)



Perhaps emphasize:

- that this is **collaboration** – not the health team telling family
- **the importance of documenting** these conversations
- that we should always share information such as the risks and benefits of medications as well as any other care information with the designated decision maker



**Activity:** Ask participants to work with the person beside them to fill in the worksheet found in their handout called Family – friend or foe. After 5 minutes call their attention back and go over the responses – allowing discussion/comments

### **Responses:**

**Clients' families visit out of a sense of guilt or obligation.**

If you ever had a family member cared for at home or in a hospital – did you ever visit out of a sense of obligation – I bet at least sometimes!

***Example:** imagine an involved family who takes the client out every Sunday – client says to you, the caregiver: “I wish I didn’t have to go, there are so many kids – and it takes me so long to get ready”*

*And then the son comes to pick up the father and says to you: “This is really hard to do this every week but I know he looks forward to it.”*

*How can we help them to come to an arrangement that both can manage?*

**Clients (when able) and their families should be involved in developing an individualized care plan.**

- Do we involve families?
- Are we asking or telling?

**Interacting with caregiving staff is stressful for families.**

***Ask the participants: Who has had a family member in care - hospital, home care, LTC?***

- What was stressful?
- What did you learn from being on the other side?
- Families providing care at home may find it difficult to allow formal caregivers into their home – why might this be? *Disrupts routines? Feel judged? Loss of privacy*

**Staff are often defensive in relating to families.**

- We often feel overwhelmed with expectations.
- What is the REAL issue that is going on when a family comes to complain? Rather than becoming defensive, we need to listen carefully for clues that might help us understand the underlying concerns.

**My feelings toward a client's family affect my feelings toward the client.** Of course it impacts us.

- Do we resent the clients whose families complain a lot?
- Do we judge families who don't visit a lot?
- How does it impact the care we give?

**Families who visit a lot usually interfere with nursing procedures in home or facility.**

- Do we explain our routines?
- Do you ask them if they want to help?
- On the other hand, do we sometimes respect the privacy of the visit so much that we don't check on the client at all when the family is present and then leave the family with the impression that the person is being neglected.

**Families are hesitant to “make waves” or complain to staff for fear of reprisal toward their relative.**

- Depends on the person and the relationship they have with staff members.
- How can we keep the lines of communication open with families?
- Some clients fear retribution from staff if the family complains so ask them not to.

**Fear-** Some may feel 'That's me in 20 years'.

**Guilt** – family members may be dealing with their own feelings of guilt

Anger at **other family members - One** daughter is left to deal with this all – “the boys have a hard time visiting”.

**Failure** of the person with dementia **to fulfill** his or her **roles** in the family -  
Caregiver now has to do everything.

**Losses** – trying to cope – “I used to have a husband who washed the car and got the oil changed and now I have to try to rush here and feed him and do all that stuff that he used to do.” Staff think this person is 'demanding' but she is feeling stressed.

**Conflict** amongst family (maybe even with the client) - relationships between family – client impact medical decisions

**Family live far away** – difficult for them to keep informed and this adds to their distress.

## 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'?



**ASK** participants to call out their words that come to mind when thinking about families.

**Trainer Tip: Use Flip Chart.** (optional)

**ASK:** Have we used the words loving, caring, partners, etc.?



### Possible Family concerns:

- Feel staff don't show respect
- Needs are not met – *Client's and/or family's*
- Feelings of **helplessness**
- Feel **staff don't listen**
- Feel their concerns are disregarded – *acknowledging caregiver's effort/background helpful*
- Seeing their **family member suffer**
- Feel clients not being cared for (real or perceived)
- **Notice there are not enough staff** *but don't know how to help*
- *Family see their role not less but changed*

## 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?**



Allow a brief time for discussion

### **Things we can do make it more positive:**

- Make an effort to find the answer to a question or find someone else who can
- Show that you care. Be proactive
- Use a customer service approach  
i.e.– show the same respect you would in the customer service industry  
e.g. tourism





The following are some points that illustrate issues in this slide

**Elevated Expectations:**


- Lack of knowledge about a situation
- May have assumed or have been given inaccurate information about services available.
- Anger at the situation/health care system
- Unrealistic expectations – may have little or no education on disease process and expect the person to improve.
- Unwillingness to accept the situation - *Mom just can't do that anymore. I want the mom back that I used to have.*
- Siblings who disagree with the reality of the care needs.
- Feelings of lack of control
- Lack of experience in loss/death - *Staff have experience – many families have never experienced this.*
- Stressed out with other things in their life – divorce of the family might be the real stress, not the care.

**Examples of those in the community who may not have the knowledge and experience that would support the person with dementia and their family are – police, EMS, friends**

**Distressed Families**

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

***Liken & Collins, 1993***

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Staff need to understand that a family may be grieving the losses they are experiencing.




### How can staff be proactive to help prevent anger and distress?

- Ensure families and staff have a clear idea of who to go to in your care setting to resolve issues. Keep lines of communication open.
- Educate about what to expect as the disease progresses. Educate re what services we provide to meet needs and what we can't provide. Discuss ways of coping with changes associated with the progression of the disease. e.g. Consider the benefits of using a path of least resistance. If in a care centre, explain why the person might not always be shaved when they visit or why another client might be lying on their bed.
- Have a proactive discussion regarding issues such as:  
future care options: admission to facility care/ tube feeding/ falls/  
Advance Care Plan. It is much better to discuss these issues prior to a crisis to avoid 'rush decision making'
- Inclusion e.g. meals, activities
- Thank them and help them share in the care at their desired level to help them feel good about their contribution
- Support them to feel less guilty. E.g. Don't say -"We haven't seen you for a long time." "Your Mom's been looking for you".
- Invite them to Family Support Groups.
- Don't be judgmental. Often we don't know the full story (e.g. client was abusive in the past? family member is overwhelmed with other issues in their life?).

## 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



- Body language and tone of voice are the most important aspects of communication
- Families pick up if we are frustrated or disrespectful even if no words are spoken
- Also if we remember the golden caregiver rule, **“to give care to our clients the way they would like to be treated”**
- We need to recognize how valuable an effective partnership with family can be. Their input is so valuable as they do know the person with dementia the best
- As a family member who was a nurse once said – **“the staff may know my mother with dementia but I know my mother and what would be important to her”**

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- Body language and tone of voice are the largest part of communication even more so than words
- Families pick up if we are frustrated or disrespectful even if no words are spoken
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# Duplicate Covered on page 52



### **Case Study- Jack and Lucy-**

- Use the case study to integrate the knowledge from the prior discussion.
- Discuss how family may perceive staff interaction and how conflict can develop.

This story is told by a wife, Lucy, who has recently admitted her husband from a Lodge setting into care. She is talking about her impressions of the nursing staff...

### **JACK & LUCY CASE STUDY (Read this aloud to the group)**

*Before Jack came to the care home, I was looking after him all the time. I showered him, I shaved him, cleaned his teeth. He wouldn't let anyone else take his teeth out or put them in - but I could do it. I even used to make his bed over there. When he came here the staff said; "No, you put him in here for us to look after him, we're going to do it anyway – so don't worry about it."*

*"Well, it's the same with his clothes really; I know what he likes. I try to get those kinds of clothes for him. One of the nurses said to me last week, "You'll have to buy sweat pants for him because it's easier for the staff to help him to the bathroom"*

*But I know Jack – and he always hated the look of sweat pants. He said they were like wearing pajamas during the day. He always wore dress pants and a belt.*

*And then the nurse said to me that “he won’t know he’s wearing them.”*

*Well she’s right, he won’t know he’s wearing them but I know he’s wearing them and he doesn’t like them.”<sup>13</sup>*

13. Kellett (2000)

The image shows a flip chart with a purple header that reads "Partnering with Lucy". Below the header, there are three questions in colored boxes, each followed by a large white rectangular area for writing. The questions are: "What does Lucy value?" (in a teal box), "Do you think staff were aware of her feelings?" (in a light blue box), and "From our previous discussion what things could we do to partner with Lucy?" (in a dark blue box). The Carewest logo is in the bottom right corner of the chart.

## DISCUSSION QUESTIONS

**What does she value?** Jack's personhood, his past preferences, her role as caregiver. The statement - "He won't know" was not sensitive to his personhood and to Lucy's need to honor his past preferences.

### **Do you think staff were aware of Lucy's feelings?**

*Probably not, but they would sense her anger but not know why.*

We often think families experience 'guilt' as the primary feeling – but one study shows that it is a strong feeling of 'failure' (they were unable to provide the best care they thought they should be able to do). **Do you think Lucy feels this way? Do you think Lucy is being unreasonable/inflexible?**

**What things do you do or could we do to partner with family members like Lucy? Use flip chart.**

*Talk to her.*

*Be flexible.*

*Let the family be involved in the care – to their desired level (check back with them and make certain this is still the involvement they want - it might change as they get more energy after having rested.)*

*Ask her opinion. Listen and value her input.*

*Compromise (that's what partnerships are about).*

*Integrate Lucy's ideas into the care plan.*

*On admission ask for information – refer to the "Getting to Know You" sheet.*



*Honor her knowledge as a caregiver and a wife.*

*Praise her for the good job she did.*

*Discuss what things she would like to continue to do for Jack. Tell her what a help she is when she does them.*

*Keep her informed and involve her in unit activities.*

*Invite her to a Family Support group.*

*Offer her education and information about the disease process.*

*Ask her how she is feeling. Show compassion for her losses.*

## **LUCY AND JACK**

### **Discussion points to thread into the debriefing**

Lucy feels that not all nurses are aware or understand how important it is to her to continue to be involved in Jack's care.

The staff give Lucy the impression that they know her husband better than she does –she feels like an intruder in wanting to stay involved in her husband's care.

Lucy lives with the constant strain of observing care which she perceives to be substandard to what she provided herself – this makes her feel powerless.

Being excluded from participating in care makes Lucy feel useless and worthless. When she believes the situation is serious and would not respect her husband's dignity she will stand up to be heard but, on the whole, she remains aware of her place as a family caregiver. She feels as if she is having to behave continually in a certain way to be accepted within the environment. She is not free to care, but is bound within the limits of what is perceived to be acceptable family caring behaviour.

Kellett (2000)

**BEST PRACTICE** that relate to this module include the following strategies:

### **INDIVIDUAL CARE**

Staff will be familiar with information regarding the client's care and background (e.g. Getting to Know You).

Information about clients will be treated with respect (e.g. FOIP/HIA and confidentiality principles).

Staff will provide care in a way that respects the individuality of the client. Staff will recognize how the client's culture and spiritual beliefs influences care needs.

### **FAMILY CARE:**

**Families will be recognized** as who the client identifies as their family (e.g. guardians, supportive friends, pets etc.).

Families will be invited to be involved or to be partners in care.

**Care conferences**, both formal and informal, will provide opportunities for decision-making to include family.

Staff will be **aware of family perspectives** and try to meet their expectations for care.

Staff will have an **understanding of family dynamics**.

**Family support** will be provided wherever possible or referrals to other resources will be offered.

**Family rights and responsibilities** will be discussed with families. The appropriate personnel will provide information to families. Informal education will be offered to families.

## Questions?



Please refer to your handouts



## References

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- 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.
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