



Trainer Notes:

TIME REQUIRED: 4 hours with a 15 minute break or could be divided into 2 or more sessions

1st part – 1 hour 45 min

- Introduction
- Distressed Families
- Effective Communication
- Respect

2nd Part – 2 hours

- Altered Behaviours/Use of Appropriate Medications
- Safety
- Sexuality/Intimacy
- Positive Social Interactions
- Questions/Evaluation

The History of Supportive Pathways



Trainer Notes:

Welcome everyone and do **introductions** – needs to be brief due to time constraints.

Share an overview of the history related to Supportive Pathways:

- Originally developed as an education program by the Program Managers for Carewest staff who cared for residents who had dementia
- Based on the Carewest Philosophy of Care and Guiding Principles
- After reviewing dementia care education programs both nationally and internationally, Alberta Health chose to promote the Carewest Supportive Pathways Education Program as the provincial education program for front line staff in the province of Alberta
- As of 2015 approximately 30,000 Supportive Pathway Certificates have been issued and the program has been taught in AB, BC, SK and NWT
- Continues to be a two day training session that includes 7 modules
- Listed as best practice on the Accreditation Canada website
- Recognized by the Alzheimer's Society



Trainer's notes: Briefly remind participants of the key messages for each module

Mod 1:

- To recognize how personal and organizational beliefs/ values can affect care
- To recognize stereotypes related to 'ageism' and 'dementiaism'

Mod 2

- To understand the importance of individualizing care that considers 'the way the person would like to be cared for' (includes cultural and religious values)
- To work with families to create quality partnerships

Mod 3

- Normal Changes of Aging/Types of Dementia – disease process and stages

Mod 4

- To understand the importance of non-verbal communication
- To know how disease process can effect the person's communication skills
- To develop effective strategies for communication

Mod 5

- To develop an understanding, effective problem solving and strategies related to behavior

Mod 6

- To understand the importance of providing quality of life – both physical and social
- To consider safety concerns e.g. use of restraints
- To be aware of the person's needs related to intimacy

Mod 7

- To recognize the importance of providing meaning to each person's day (for all stages)
- To be creative in our efforts to develop opportunities for individualized meaningful activities

Refresher Topics to be Covered

- Distressed Families
- Effective Communication
- Respect
- Altered Behaviours/Use of related Medications
- Safety
- Sexuality/Intimacy
- Positive Social Interactions



Carewest's Philosophy of Care

In support of the Carewest Frame of Reference,
our Philosophy of Care is:

**“To provide our residents and clients with quality care
in safe, comfortable and supportive environments.”**



Philosophy of Care - Guiding Principles

The Guiding Principles to the Philosophy include working together to:

Preserve and promote **dignity through respectful**, individualized approaches to care;

Provide **kind and compassionate care and service**;

Foster supportive **relationships between all staff, clients, families and communities**;

Foster an environment of **learning to promote excellence** in care and service.

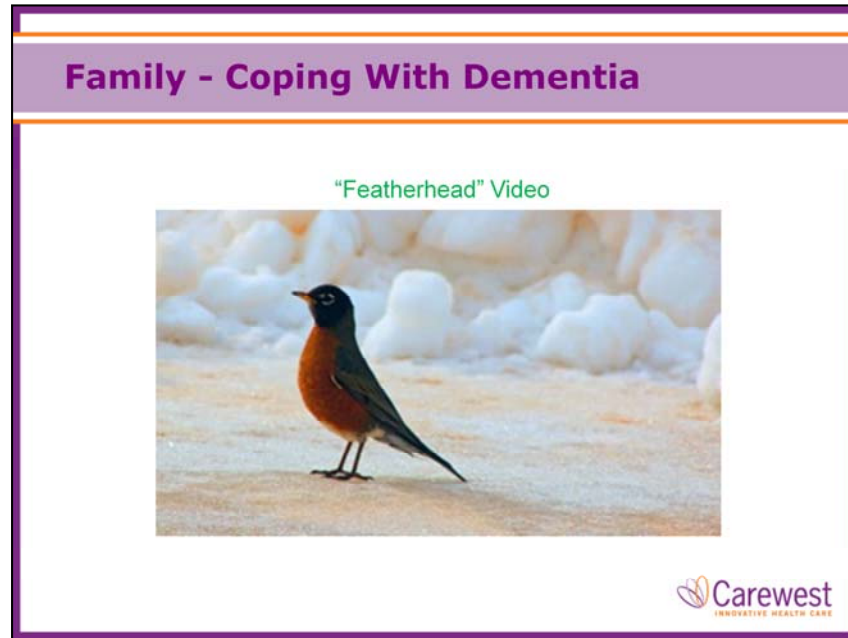




Trainer's Note:

Ask:

- Does this model support the Carewest Philosophy of Care and the guiding principles?
- **Does your place of work support this model?**
- How can you make it happen?



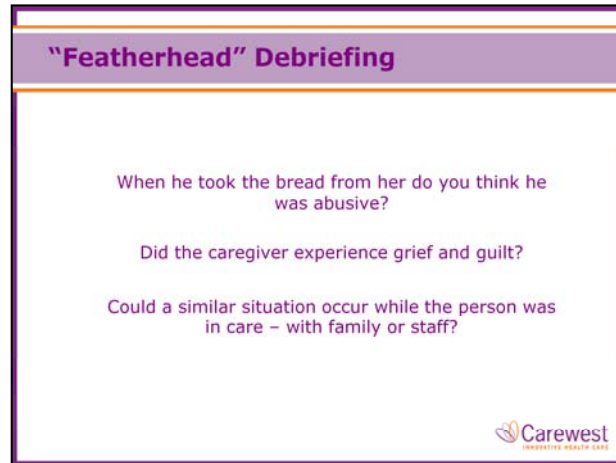
Trainer's Notes:

*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 with 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 :

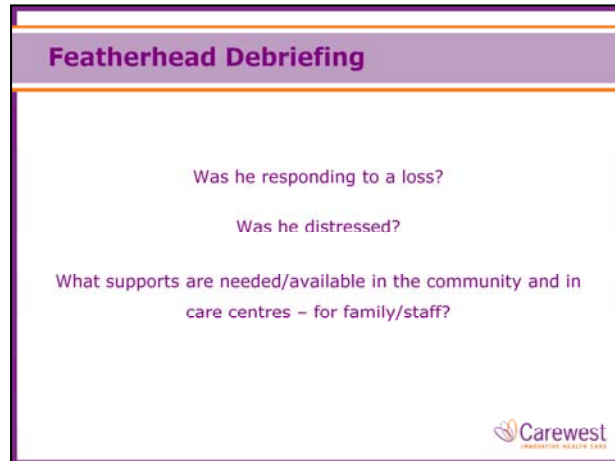
- **there is a legal obligation to report any form of abuse to Protection for Person's in Care**

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	

Trainer's suggestion: just read these and not spend a lot of time on this slide due to time constraints.



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, having empathy for grief/feelings of guilt and praising family 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")



Trainer's Notes : *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
- Worry about the care based on negative media coverage

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

We need to be reminded to not judge families



Trainers Notes:

Most clients come with families. We need to have empathy for what they are going through and find ways to work together.

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 may impact medical decisions

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

Distressed Families

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

Liken & Collins, 1993

 **Carewest**
INNOVATIVE HEALTH CARE

Trainer's Note: Staff need to understand that a family may be grieving the losses they are experiencing.

They may also be experiencing guilt even if they have done their very best.

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'?*



Trainer's note: Have participants respond

Share that this may be a great slide to use at a team meeting when discussing a family.

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

 Carewest
INDEPENDENT HEALTH CARE

When we say – we're short staffed we have added a sack of burden on them when they leave – knowing that there aren't 'enough' staff to take care of their family member

Things We Do That Distresses Families?

- Appear to ignore family or be judgmental
- Not include clients in conversations
- Talk on our cell phone in a client area
- Appear to be having non-work related chats with co-workers
- Appear to ignore call bells
- Not follow through when we say we will do something



How do we turn these actions into positives?



Allow a brief time for discussion

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
- See their role not less but changed

Things we can do:

- Make an effort to find the answer to a question or find someone else who can.
- Show that you care.
- Use a customer service approach.
i.e.– show the same respect you would in the customer service industry e.g. tourism
- At Carewest – remind staff to review the Positive Talk booklet on how to answer family questions




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.
- Consider all avenues to connect with families e.g. technology

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



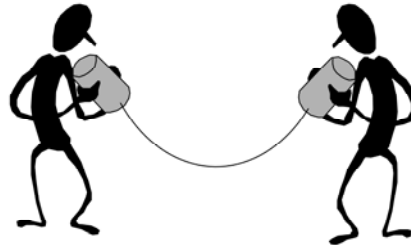
Trainer's Note:

- Remember in the communication module we talked about body language and tone of voice being the largest part 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”**

Effective Communication

Good Communication is Key with Clients and Families

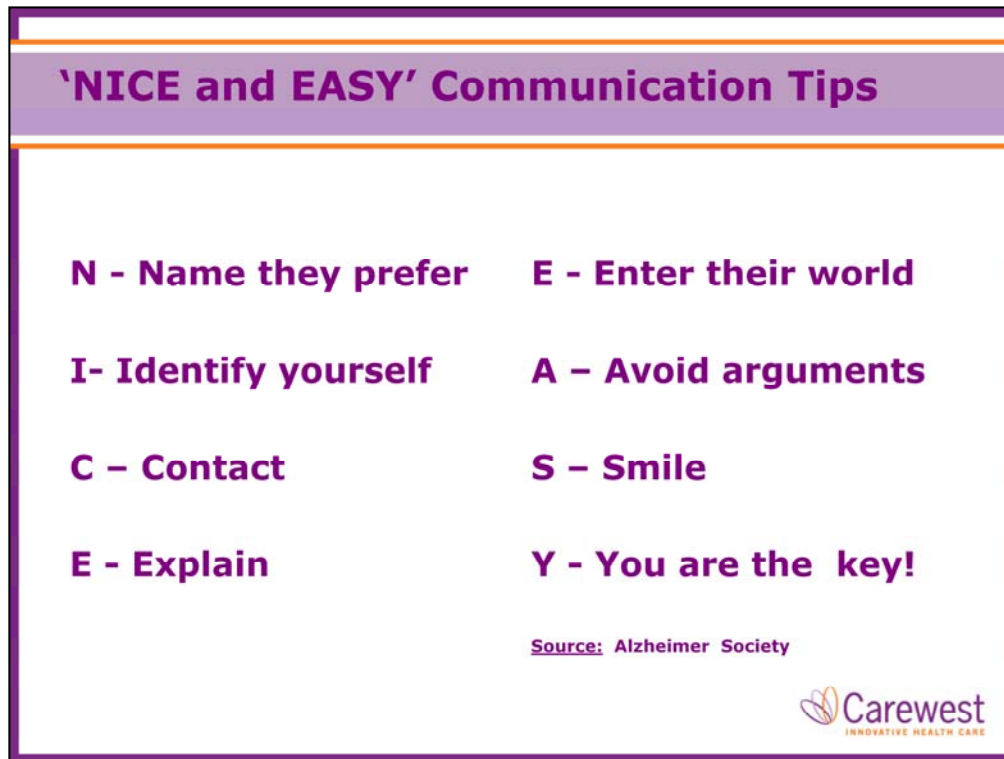
- to create positive trusting relationships
- to help avoid distressful situations and behaviors



Trainer's Note:

Encourage the participants to **share their expertise** with new staff and families

- i.e. - role model and let others know what seems to work best when communicating with the person who has dementia



Trainer's Notes: *Tips to help us communicate with clients who have dementia – could be posted as a teaching tool in staff rooms etc*

- **Name**
 - ✓ Use their preferred name.
- **Identify Yourself**
 - ✓ Introduce yourself each time if the person has memory problems (but don't over-do it! Watch for their reactions).
 - ✓ Avoid: "Do you remember me?" – It may embarrass the person if they don't remember you and think they should.
- **Contact** - eye contact, gentle touch.
 - ✓ Get their attention. Ensure you have them engaged before proceeding in the conversation.
 - ✓ Avoid competing distractions - turn off music, TV with permission
 - ✓ Be aware of vision and hearing problems that may prevent the message from getting through.

- **Explain** - What you are going to do.
 - ✓ Give them extra time to process.
 - ✓ If not responding, repeat using the same words so they don't have to start over before you change your words.
 - ✓ Show objects, use gestures to assist your communication.
 - ✓ Use short sentences - one topic. (5 word rule - no more than 5 words at a time).
 - ✓ Be sensitive-"let's get cleaned up" rather than "we need to change your diaper".
 - ✓ **State what you want them to do, not what you don't want them to do** ("come with me" vs. "don't go in there").
 - ✓ **Use language that is inviting and inclusive: "Let's go over here and see what Ethel is doing" not "Go over there..."**
- **Enter** their world
 - ✓ Find out where they are. Their reality may be different.
 - ✓ Use Validation.
- **Avoid arguments** - Does it matter?
 - ✓ ***"They are right- We are wrong". It is unlikely that you will change their mind by arguing.***
 - ✓ The part of the brain that allows us to consider that we might be wrong may be damaged.
 - ✓ Use diversion and distraction.
 - ✓ Don't give orders.
 - ✓ This is especially important to tell families that are dealing with a person at home.
 - ✓ Ensure that the intent is good.
 - ✓ This is used cautiously as it may make the person more agitated.
 - ✓ Keep in mind - **"It is better to be kind than right"**
- **Smile**
 - ✓ A smile or a hug speak volumes.
 - ✓ Your body language and tone of voice will be understood better than your words.
- **You** are the key!
 - ✓ We can change-they can't.
 - ✓ You can make or break a person's day.

How do we communicate non-verbally?

- body language (posture; space)
- gestures or props
- touch/eye contact / facial expressions
- use of social rules e.g. handshake
- tone of voice
- pictures / signs / symbols / orientation boards
- environmental clues e.g. smells can ↑ appetite



Trainer's Notes:

Research tells us body language and tone are significant:

- 55% is body language - the message we give by facial expression, posture, gestures
- 38% tone and pitch of voice
- 7% words we use
- **Negative body language like sighs and raised eyebrows are easily picked up by persons with dementia.**
- **Also they retain their feelings and emotions even though they may not understand what is being said.**

Source: www.betterhealth.vic.gov.au



Trainer's Notes: Briefly review each strategy
(can be posted as a teaching tool in staff rooms etc.)

Validation

Respects the individual's sense of reality.

Validates what they may be feeling

We need to

'Join their journey'— go to their reality

Naomi Feil, a gerontological social worker and originator of Validation Therapy, describes it as:

"the process of communicating with a disoriented elderly person by validating and respecting their feelings in whatever time or place is real to them at the time, even though this may not correspond with our 'here and now' reality" (Vanderslott, 1994, p. 151). *Journal of Gerontological Nursing*, April 1997

Reality Orientation

Orientates to person, place, time

Is more useful in early stages

Can provide cues, e.g. calendars, updated orientation boards

Should not be used if it creates distress


How could we respond?

" Can I go home now?"

"I need to go to work!"

" Where is my mother?"

" Can you call my wife?
(Asks over and over again.)"



Trainer's Notes:

Invite responses from the group at large or if time allows break into small groups or pairs and have each group discuss one of the quotes on this slide using the tools in their tool-kit. Then have them report back. The slide is animated so each quote will come in when you click the mouse.

The notes below and on the next slide offer suggestions you can use to add to their feedback.

"Can I go home now?"

Validation: "You are thinking about your home - can you tell me about it?"

Try distraction: "The ladies are having tea do you want to go?"
"Let's go over here and talk about it."

Tell them what they need to hear: " For tonight you are going to stay here with us in this nice room. Tomorrow we can look into it again."

Ask family to bring in pictures so you can reminisce with them about their home and related memories.

Often when families take them to their home they ask to go home while they are there. Perhaps they are wanting to return to good memories instead of the actual place.

Wrong Approach? Reality Orientation: " You are in Calgary at the Signal Pointe Care Centre and we are going to look after you." **(If this is upsetting to the client avoid this approach and document on care plan).**

“Where is my mother?”

Validation – “You are thinking about your mother. She must have been very special to you. What do you remember about your mother?”

Distraction etc. as above

Wrong Approach? Reality orientation – “Your mother is dead” - could cause unneeded stress and grief. (Also never assume mother is dead).

“I need to go to work!”

Validation – “You must be thinking about work today”. Staff should be aware of the type of work they did and talk to them about it. E.g. “farming sure must have kept you busy – what type of animals did you keep?” etc. or, “As an accountant tax time sure must have been busy. You must like working with numbers.....”

Tell them what they need to hear - Could say that it is a holiday and there is no work today then ask him to join you for coffee.

Distraction - offer an activity – perhaps one related to the type of work they did, (suggest they go back to the room to get ready – on the way reminisce about the person’s work – may be able to distract the person from ‘leaving’).

Wrong Approach?: Reality Orientation - Staff tells him he is in a nursing home and doesn’t have to go to work. (Wrong Approach? - as he may react badly to this and angrily call the staff member a liar and head for the door.)

“Can you call my wife?” CLIENT IS USING REPETITIVE QUESTIONS.

Validation – “you are thinking about your wife – will she be at work today?” Ask him about his wife and the things they like to do together.

Distraction - Call the wife if appropriate to do so. If he has photos of her ask to see them. Invite him to come to an activity

Tell them what they need to hear - Give a reason why you can’t call right now. Let him know she is okay. If you know when she will visit reassure him that she will be coming.

Partner with the family - Discuss situation with wife to see if there is a time that is okay to call so it can be arranged. Then you may have tell the client, “Your wife isn’t home right now but she said you could call at 5 PM as she plans to be there then”..

Be prepared to answer the same question over and over again with patience and understanding.

Wrong Approach? - Staff member ignores his question and uses a hand gesture and tells him “go sit over there - that’s a good boy”. *Not dealing with him will likely cause his behavior to escalate. Never treat our adults like a child.*

Key Message

We need to watch for the person's
reaction to our body
language/communication to
ensure we are not causing
them more distress...

This is how we learn



Trainer's Note

Staff can 'mirror the client's emotions' to help communicate 'understanding' even if they don't understand the content of the words the client is using.

Key Message

When two people are required to provide care together it is essential that:

- ✓ Only one of the two people provides any instructions
- ✓ All conversation includes the client (observe for body language)
- ✓ Staff speak English or in the client's native tongue
- ✓ Always give the client time to respond/understand



Trainer's Note:

It is very confusing for the person with communication difficulties to respond to more than one set of instructions.

For 2 person care – staff must decide if it is necessary to have two people assist and who is doing the talking prior to going in to provide the care. The other staff member should be assessing the person/situation or be the one doing the care if that is the plan.

The decision that someone requires two person care should be made by the team – including the professional staff (RN/LPN). They can observe, assess and suggest strategies.

Key Message

**Persons with dementia may be
cognitively impaired
but remain
emotionally sensitive**

- they feel our kindness,
- they know if we care,
- they know if we are upset



Trainer's Note:

Talk about whether their clients seem to know when the shift or the Home support visit isn't going well

Read: A Message to Family Members & Friends – and staff

(written on behalf of someone with dementia)

- Please don't correct me. I know better – the information just isn't available to me at the moment.
- Remember, my feelings are intact and I get hurt easily.
- I usually know when the wrong word comes out, and I'm as surprised as you are.
- I need people to speak a little slower on the telephone.
- Try to ignore off-hand remarks that I wouldn't have made in the past. If you focus on it, it won't prevent it from happening again. It just makes me feel worse.
- If I put my clothes on the chair or the floor, it may be because I can't find them in the closet.
- If you can anticipate that I am getting into difficulty, please don't draw attention to it, but try to carefully help me through it so nobody else will be aware of the problem.
- At a large gathering, please keep an eye on me because I can get lost easily! But please don't shadow my every move. Use gentle respect to guide me.



Trainer's Notes: Read these aloud or have the participants take turns reading them from their handouts.

Best practices include the following strategies:

Ensure you have the **person's attention**, approach within their **field of vision**

Obtain and use **direct eye contact at client's at eye level** e.g. if in a wheelchair, squat down

Eliminate **background noise**; remove **distractions**

Use cueing (verbal or physical), **gestures** e.g. washing face, **props** e.g. hair brush, photos, pictures

Use **short simple sentences**; use **one-step directions**

Label the door with written labels or diagram

Be **aware of tone of voice**, **put the client at ease** with a calm manner Be **aware of body language**

Use an **open gentle approach** e.g. offer your hands palm up

Use **appropriate gestures/expressions** e. g. nodding, beckoning, smiles

Attend completely when listening, **be patient** - give the client time to respond

Listen for what the person is not saying- **watch body language** for signs of **frustration**

Do not argue or criticize

Limit questions to yes/no answers and then validate what the person is saying.

Utilize concepts of **Validation Therapy** (Feil, 1982) and Reality Orientation, as appropriate.

Empathize with the person and validate feelings - join the person where they are **in their reality** (joining their journey):

Look past the behavior to the person within and connect.

Respond creatively to help them find comfort in a situation

Tell them what they need to hear to help them cope (e.g. if someone wants to catch a bus to leave, encourage them to have a cup of coffee while you check on the bus schedule – then to return to let them know the bus won't come until tomorrow) . This may not always be the exact truth but may help them find comfort and cope for the present time.



Remind participants: this includes clients/staff/visitors/families

Respect for the Person's Home

How do you show respect for the person's home?

- Knocking
- Wait to be invited in
- Obtain permission
- Ensure they have control
- Offer suggestions not orders
- Take care with their possessions
- Avoid calling their possessions 'clutter'



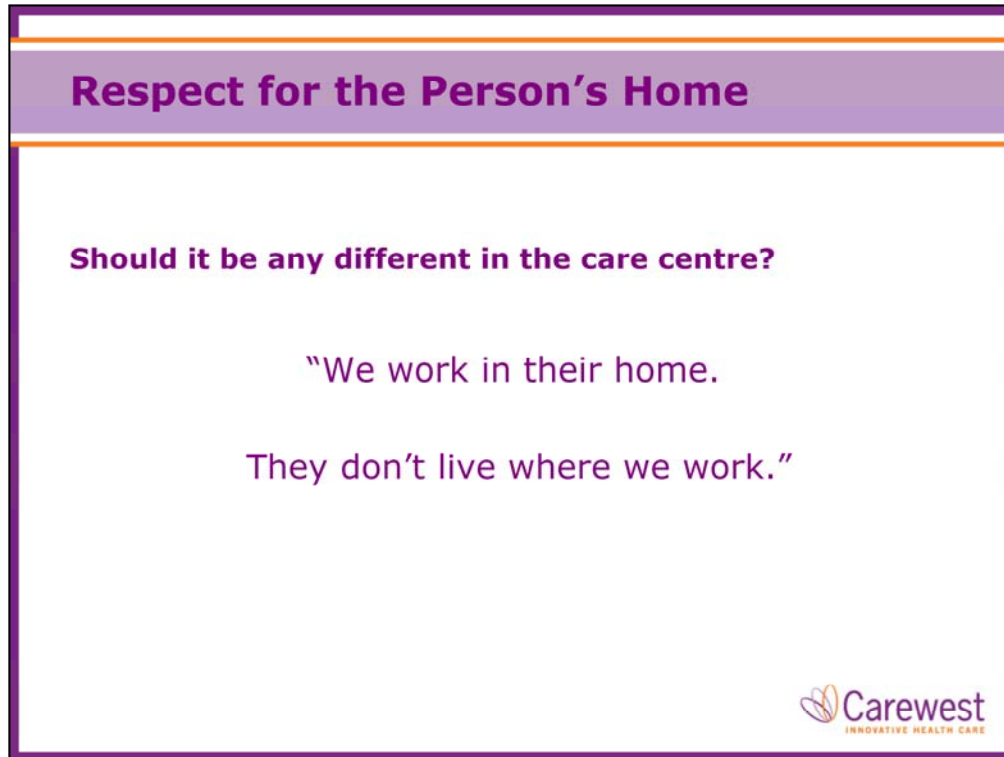
Trainer Note:

Ask staff: **How do/would we respect a person's home when working in the community?**

The next slide talks about facility.

The answers will come in after the discussion.

- Knocking
- Waiting to be invited to enter unless previous agreement to just walk in
- Asking permission to throw away or move items
- Allowing them control
- Giving suggestions not orders - involving them in care decisions
- Show care for their possessions
- Avoid calling their possessions 'clutter'



Trainer's Note:

Ask the facility staff: **Should it be any different in the care centre?**

Would you go into someone's home and demand they clean up all their “clutter”? What looks like clutter to you may have meaning for them.

‘We work in their home they don't live where we work’. In other words we need to fit with their concept of home whenever we can.

Responding to Altered Behaviors



Trainer's Note: *this next section is a brief review of Mod 5*

If doing a 4 hour session – this would be a good place to break for 15 min



Trainer's Notes: Just a reminder that we need to understand the meaning behind their behavior but also to be aware that our behavior will portray meaning to our clients.

All behaviour has meaning – it's our job to try to figure out the meaning!

These behaviours are often referred to as...

Responsive Behaviours (they are responding to something)

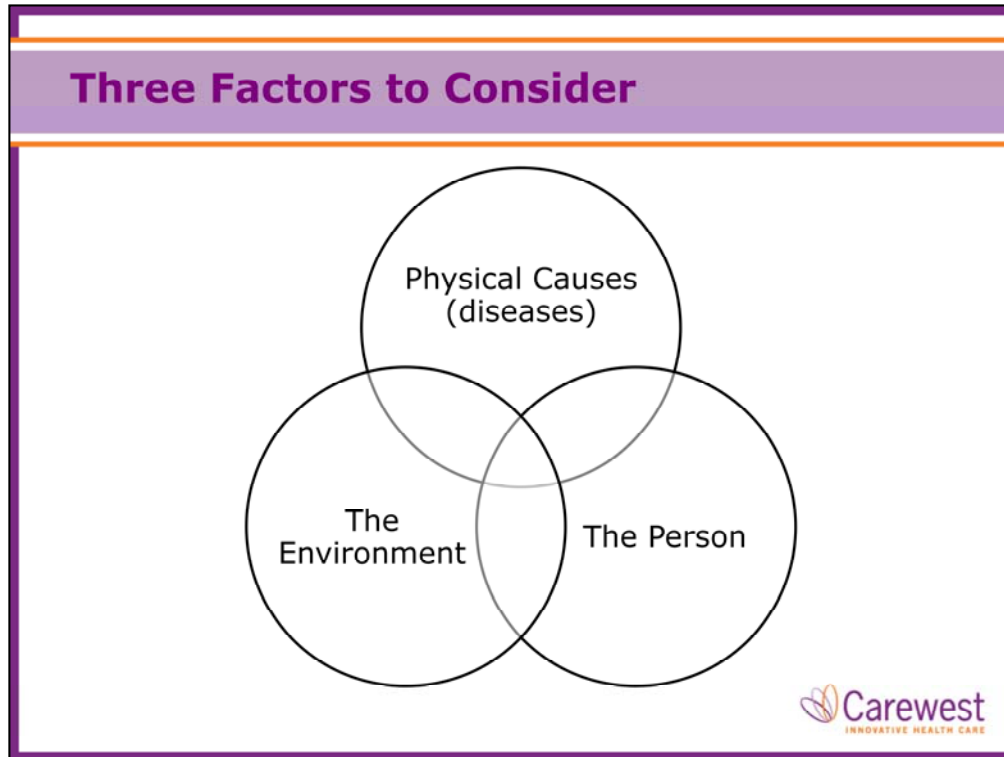
Expressive Behaviors (they are trying to tell us something) – David Sheard

This is helpful because it causes us all

- to focus on the person
 - to look for the meaning behind the behaviour
 - to consider, 'what might they be responding to or expressing?'
-
- Persons with dementia sometimes lose their ability to express themselves through the spoken word
 - Non-verbal behavior becomes an important communication mechanism for the person with dementia
 - Sometimes physical illness is the message being conveyed (**delirium**)
 - It is very important that all caregivers report behavioral changes to someone who can help look for the cause and possible interventions

Think about who this would be in your situation – Care Team Members? RN?

Case Manager? Team Leader? Mental Health Team?



To discover the meaning of behaviour the situation needs to be assessed from four different perspectives.

Read the first three:


- physical causes (diseases)
- the person
- the environment

Trainer: these are described on the next slides

Physical Causes

Is the behavior related to:

- medical history, chronic pain, psychiatric illness?
- depression or delirium?
- UTI, pneumonia, constipation, dehydration, acute pain?
- medications such as antipsychotics?
- changes related to the type of dementia they have?
- what the disease has taken away?



Trainer's notes:

A medication review should be considered - Side effects? Appropriate dose? Interactions?
A physical assessment is required

The Person

Is the behavior related to:

- fears (e.g. post traumatic stress)?
- hunger, thirst, other unmet needs such as intimacy?
- things that upset them (triggers)?
- boredom – nothing meaningful to do?
- their personality, family relationships, culture or religion?
- abilities/disabilities to understand, communicate or function?
- past routines/lifestyle (e.g. went for a daily walk outside)?



Trainer: This was discussed in detail in previous modules so do just a quick review. If you have examples from your practice add them in.

Trigger - Something that causes a **person to react** in a certain way.

ASK the participants:

What would cause you to react?

e.g. fear of water, fear of heights (lift) being told what to do, noise,
someone looks like your mother-in-law?

Another example: the person may recall something they don't like about 'dark haired people' and react to staff who have dark hair.


Are they bored?

Quote by Marlene Collins – If the person has nothing to do – we may not like what they find to do.

The Environment

Is the behavior related to:

- a rushed, noisy, hospital-like environment?
- unfamiliar caregivers/surroundings?
- no opportunity for choices or to do something?
- task focused versus resident focused care culture?
- minimal social interaction with staff?



Trainer Notes:

Share: When their surroundings are too **unfamiliar**, it won't trigger the memories required to recognize the new situation as safe and acceptable.

What is the Fourth factor?



Trainer Note:

ASK: What is the fourth factor to consider? Answer on next slide.



Trainer: provide a few brief examples from experiences.

Do we have a need to be 'in control' ?

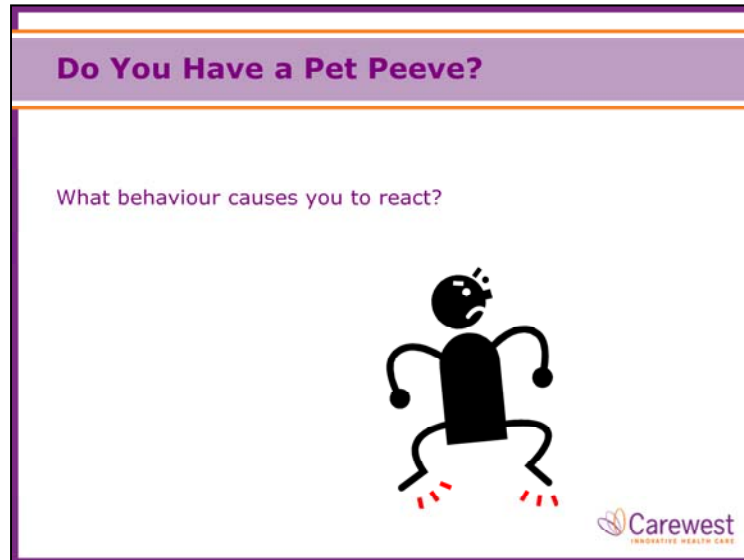
Do we 'force' the person to do things that lead to behaviours?

Do we anticipate needs?

- thirst
- hunger
- tired
- constipation
- pain relief
- something to do
- loneliness
- need for toileting
- need for reassurance
- need for touch

Are we reinforcing the behaviour? E.g. Does the person only have human contact when they yell or call out?

Are we willing to share and try our creative ideas?



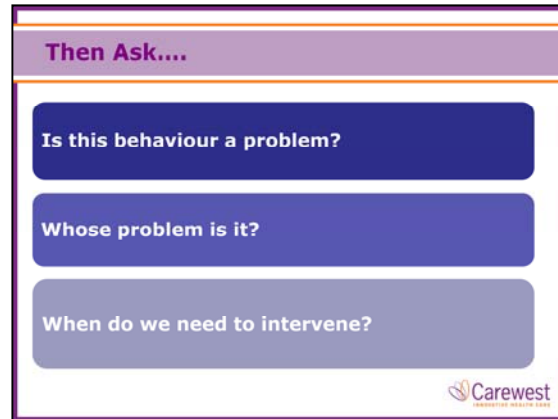
Trainer Notes:

Ask: Are there some behaviours that you are less tolerant of - while other staff aren't so bothered?

Ask the group if anyone has any pet peeves – e.g. spitting, messing things up, noise? These are our triggers.

If working with **Caregivers including Family**

- Encourage them to consider why some behaviours bother them more than others
- Help them to realize the person is not knowingly acting that way
- Encourage them to schedule breaks from caregiving



Trainer's Notes:

When we are considering altered behaviors, we must ask ourselves the above questions.

Sometimes we do not need to intervene.

E.g. Rummaging in their closet may not be a problem but going through another residents things may put them at risk

In an adapted environment, some of the behaviors may be tolerated:

- the client is safe
- their dignity is being preserved
- there is not the potential for injury to themselves or others

We must not assume that altered behavior is unacceptable.

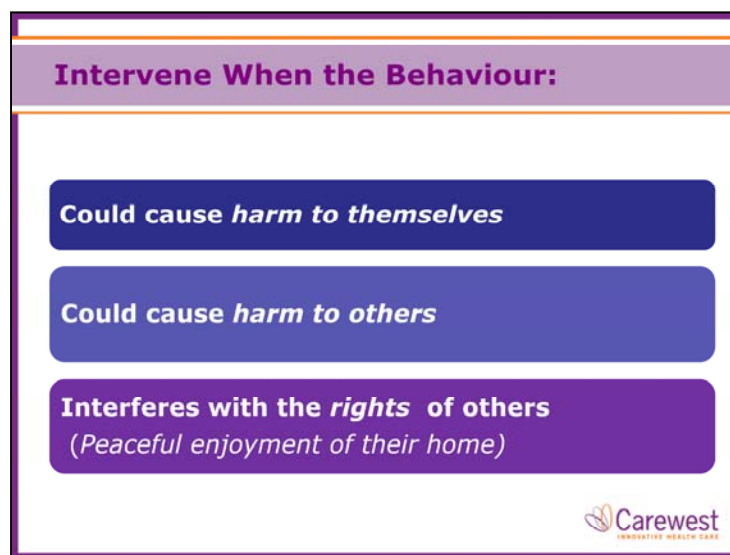
E.g. Think about someone pacing.....**Is this a problem? When does it become a problem?**

- if they are so exhausted that they may fall or if they are pushing their way through a group of clients.

Do we need to intervene?

- **Yes, when it is a problem but only after team planning and discussion to come up with a strategy**

Trainer: Move to the next slide to discuss when we need to intervene.



Trainer Note:

Discuss the rights of others. '*Peaceful enjoyment of their home*'

Examples: not having others interrupt your meal, sleep etc.



Trainer Note:

Ask: **‘SO WHAT’** – meaning - **Will there be a negative consequences if we don’t do something?**

What are the consequences of NOT doing something? e.g. changing an incontinent product

- How likely is their skin to breakdown if they are moving around?
- Is it bothering anyone?
- Can we try again later or with a different person?

Act only if the consequences would put the person or others at risk if the intervention did not occur at that time

- Communicate with the staff/family why you didn’t do something e.g. change dirty clothing (chart your actions and rationale).
- If the intervention is **REALLY** necessary, you might need to involve other staff (e.g. bowel movement might need to be cleaned up as it impacts others) – but there are some ways to approach even this in a way that helps reduce the client’s stress

Ask staff to share how this can be done

- Try to take the **”path of least resistance” (pick your battles)**. This is an important concept for staff and the family member caring for someone at home. This can decrease their stress and battles with the person.

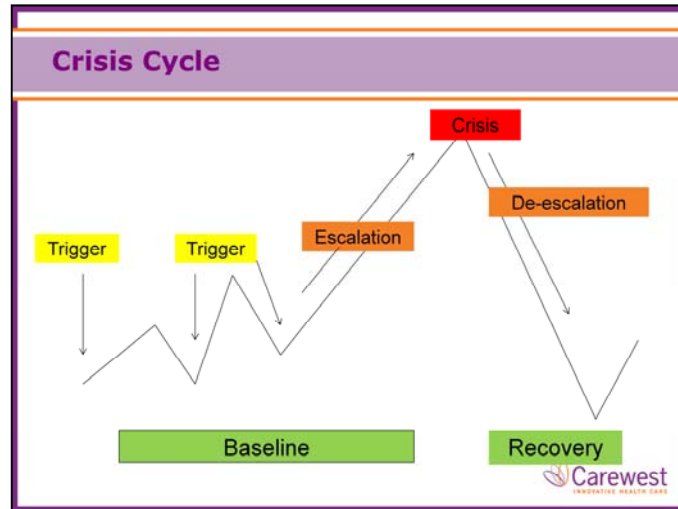


Trainer Notes:

Stress the importance of early intervention to prevent the behaviour from becoming a crisis situation. Deal with it now or it may take twice the amount of time to deal with the crisis later.

ASK: What are some interventions we can do at this stage?

- recognize and deal with what is happening
- take to quieter area – (not a punishment, but a way to help the client feel calmer– you might ask if you might sit with them)
- validate their feelings (You look really upset, can I help you?)
- reassure
- consider the need for pain medication, food, water
- distract with food or activity (calm activity)
- there is LOTS we can do without giving medication
- remove other clients from the area if you are unable to move the agitated person



Trainer's Notes:

The **CRISIS CYCLE** helps to explain what happens when beginning behaviors are not "checked" by interventions and a crisis ensues. Stress the importance of knowing your client and their baseline data (normal pattern of behaviour).

TRIGGER

This is the precipitating factor(s) – what are the things that build up to lead to the crisis (catastrophic reactions)? Communicate the triggers to others to help everyone avoid the crisis.

- It is a situation or event that creates/causes stress
- This is what makes someone change their behavior i.e. deviate from their baseline behaviour

ESCALATION

This is when the behaviors start increasing in severity and become more challenging. The client is trying to communicate to us. What is the message?

CRISIS: ALSO KNOWN AS CATASTROPHIC REACTION

- an over-reaction to situation
- often unpredictable (usually lasts less than 2 minutes e.g. client may be crying hysterically)
- our goal at this stage is to prevent injury to client or others

Trainer: see next hidden note page for more notes

WHAT BEHAVIORS DO WE SEE IN A CRISIS SITUATION?

PHYSICAL ABUSE: kicking, choking, punching, hair pulling, grabbing, biting, spitting, pushing other clients, wrecking things

VERBAL ABUSE: *swearing, yelling*

EMOTIONAL OUTBURSTS: *crying*

INTERVENTION

If the caregiver is at home alone they may need to remove themselves from the situation to prevent injury.

Remove other clients from the area. Only intervene physically if danger to themselves or others.

DE-ESCALATION STAGE

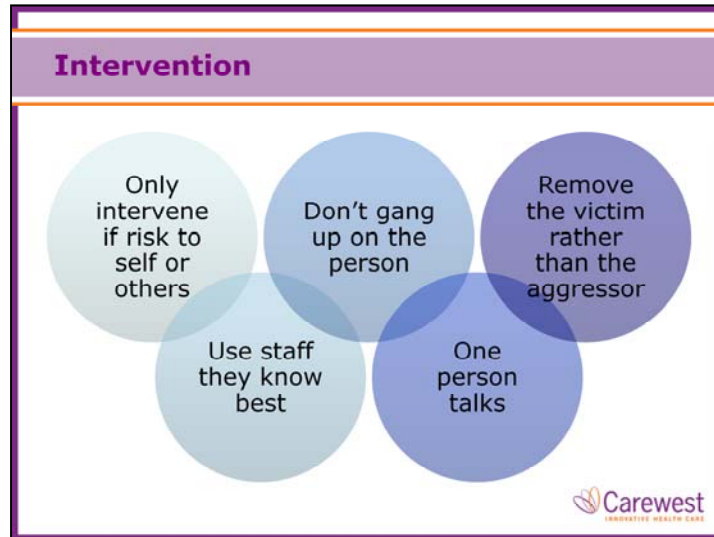
Decreased emotion, exhaustion, collapse, slowing down

INTERVENTIONS

Reassure, rest, quiet, decreased stimuli, comfort: food, water, sweater, analgesic

RECOVERY PHASE

Back to baseline behavior. It will depend on degree of catastrophe. In earlier dementias, you may see increased depression following a crisis. This will be very individual.



Trainer Notes:

If client is out of control and at risk to injure self or others - respond quickly and calmly. Have staff who know the client well or have a good relationship intervene.

If the client is being aggressive with other clients, try and remove the other clients not the aggressor as they will be more willing to go.

No more than 2 staff are needed to approach client – remember only 1 should be doing the talking.

The team leader (e.g. RN/LPN) should always be present and the key leader in the situation – an opportunity to be a role model.

Try to diffuse the situation first.

Speak in gentle, matter of fact manner, one person provide explanation. Staff should offer a hand and ask “ Can I hold your arm”?

Only if necessary due to continued risk of harm, staff would gently each take hold of an arm. There is no need for any other physical contact. Disengage the person from the victim and gently lead the person away. If escorting them, put your arm through theirs and then hold their hand. Ensure that the client does not lose his balance.

If you ‘must’ move someone to another location, and they are very agitated, you might ask another staff to bring a wheelchair to put behind them, lower them into the chair to move them.

Debriefing

- Help to realize that the situation was not personally directed
- Empathize
- Should be about learning and problem solving not blaming



Trainer's Notes:

DEBRIEFING FOR STAFF AND FAMILY CAREGIVERS

- Staff and family must be supported and be able to realize that the situation was not personally directed at themselves.
- Empathize that the experience may have been very scary for them.
- Debriefing should be a learning experience not blaming.
- Discuss at an appropriate time what happened and encourage problem solving towards solution.
- Aggression in the community may be more difficult to deal with as the caregiver may not be able to get help.
- Caregivers may need to leave the house for their own safety.
- This is a common reason for institutionalization.

Can We Support the Client with Dementia?

Behavior can be an indication
that the person with dementia
is **distressed** and
needs our support.

Do we have tools?



Trainer: Proceed to next slide for tools

What is in the Caregiver's Toolbox?

- Knowledge
- Personal Strengths
- Caring
- Patience
- Sense of humor
- Communication skills
- Supportive environment
- Creativity
- Team Support



Trainer Note:

Add and discuss: The ability not to take it personally.



Trainer: This slide and the next two give examples of common support strategies.

Give examples of when these strategies were effective from your experience

Support Strategies

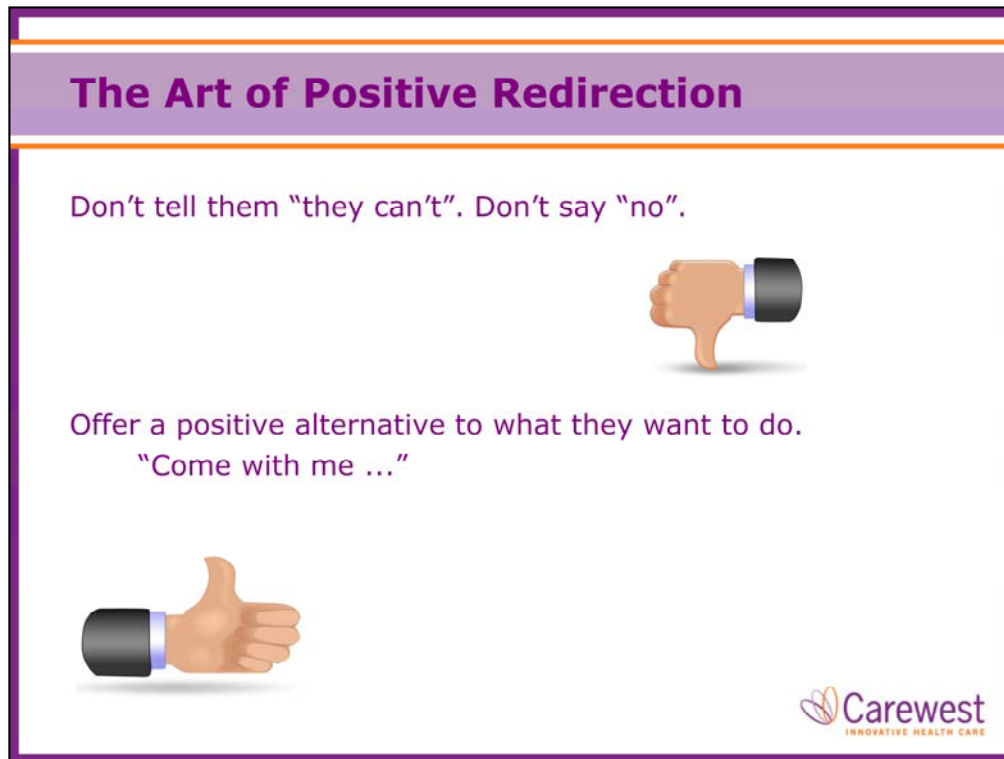


Marlene Collins 2009





Suggest that these slides on support strategies could be posted in staff rooms



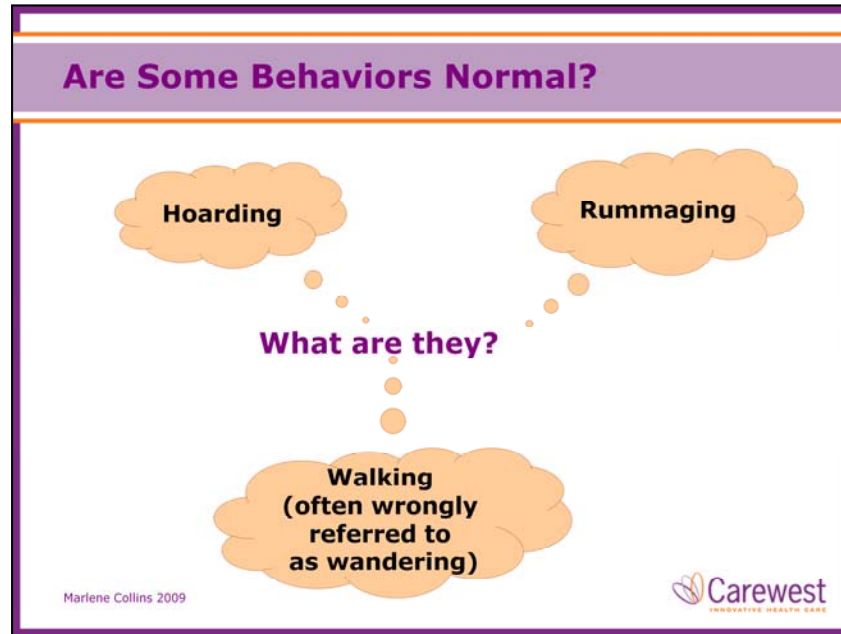
Trainer:

Explain that distraction is a very effective tool providing it is done in a positive way.

This includes recognizing and acknowledging the person's feelings and **their topic of concern and then suggesting something else.**

E.G. a person upset about a locked door:

"I don't like that door either – let's go look for a different one",
and then try find something to do or see on the way that could be a good distraction.



Trainer's Notes:

'Hoarding' can be 'collecting'

'Rummaging' can be 'sorting', 'organizing', 'packing'

'Walking' or 'wandering' can be 'exercising', 'going somewhere', 'looking for something'

Behaviors are often 'labeled' and we need to avoid this when we can – because then we could miss the meaning behind the behavior

These behaviors can become a 'problem' though if they start to:



- interfere with the rights of others, or
- cause potential harm to themselves and others

For example:

- if they were to 'hoard' items that were potentially dangerous
- if they 'rummage' in other people's belongings with the potential that that person may harm them
- if they pace until they are exhausted and start to fall

Support Strategies


You cannot medicate for these, nor should you want to!



Instead ...

we need to find ways to support their needs

Marlene Collins 2009



Trainer's note:

Examples include – having things that they can 'rummage' through, ensuring there is opportunity to walk

Medications as a Last Resort

Did you notice that ...
medication was not listed as a strategy for
altered behaviors in our tool kits?

Why would that be?

Medication has to be used appropriately
– right reason/right dose



Trainer's Note:

Ask participants to comment on the question

Answers should include:

- other strategies should always be tried first
- all medications have side effects and often interact with other medications that our residents are on
- older adults, especially those with dementia do not do well on medications
- usually they can't tell us how the medication is effecting them and it could result in 'altered behaviors' that are medication induced
- new research has shown that lots of these medications, especially antipsychotics cause individuals to be at risk (refer to the next slides)

Appropriate Use of Antipsychotics (AUA)

What is all the fuss?



In the past antipsychotics have been used to help manage behaviours for persons with dementia but with more evidence and research this is now being reconsidered



Are Antipsychotics Effective For...?

- Interfering with other residents - NO
- Inappropriate dressing/undressing - NO
- Perseveration, doing something over/over - NO
- Repetitive screaming/calling out - NO
- Eating items unsafe to eat - NO
- Trouble sleeping - NO
- Voiding, etc. in inappropriate places - NO
- Elopement (trying to leave) - NO
- Poor social skills - NO

That's why we need other strategies



Trainer's Note:

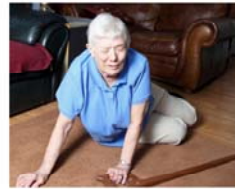
This slide is animated so that each behavior will appear and on the next click they will disappear because they are not effective. The bottom line will appear and stay at the end.

Antipsychotics - Possible Hazards

- Decrease in cognitive function/ability to engage
- Mobility impaired - increase in falls
- Metabolic implications - diabetes
- Strokes/Aspiration Pneumonia/Cardiac problems
- Mortality (death)

Therefore....

**Health Canada issued Warnings
about the use of Antipsychotics**



 **Carewest**
INNOVATIVE HEALTH CARE

The Appropriate Use of Antipsychotics

Antipsychotics should only be considered when:

- the person has a mental illness or a psychosis (e.g. delirium)
- the person is at risk of harming self or others
(and everything else has been tried)

Antipsychotic use must be:

- reviewed frequently
- at the lowest dose possible
- for the shortest time possible then gradually reduced/discontinued



Trainer's Notes:

Remind staff that:

Long term use of antipsychotics are appropriate for many mental illnesses such as schizophrenia

Antipsychotics should not be substituted with benzoids such as: Ativan, sedatives or use of physical restraints



Trainer's Notes

FAST FACT:

40% of all Nursing Home admissions are the result of a fall.

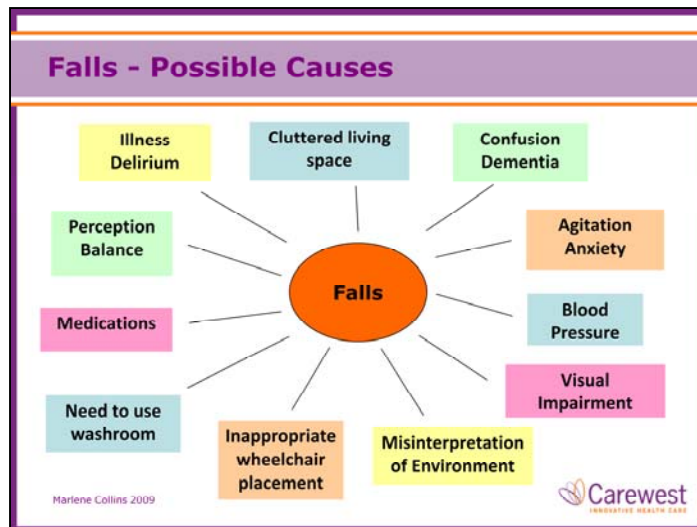
1 in 3 seniors living in the community and 40-50% of those living in institutions will experience a fall each year.

10% of LTC falls result in serious injury.

Those elderly with cognitive impairment or dementia are twice as likely to fall as those without.

In a population-based cohort study, which used health care databases from Ontario, **the use of cholinesterase inhibitors was associated with increased rates of syncope, bradycardia, pacemaker insertion, and hip fracture in older adults with dementia.**¹⁸ These findings highlight this class of medications as a potential risk factor for falls; these risks should be weighed carefully and discussed with patients and caregivers."

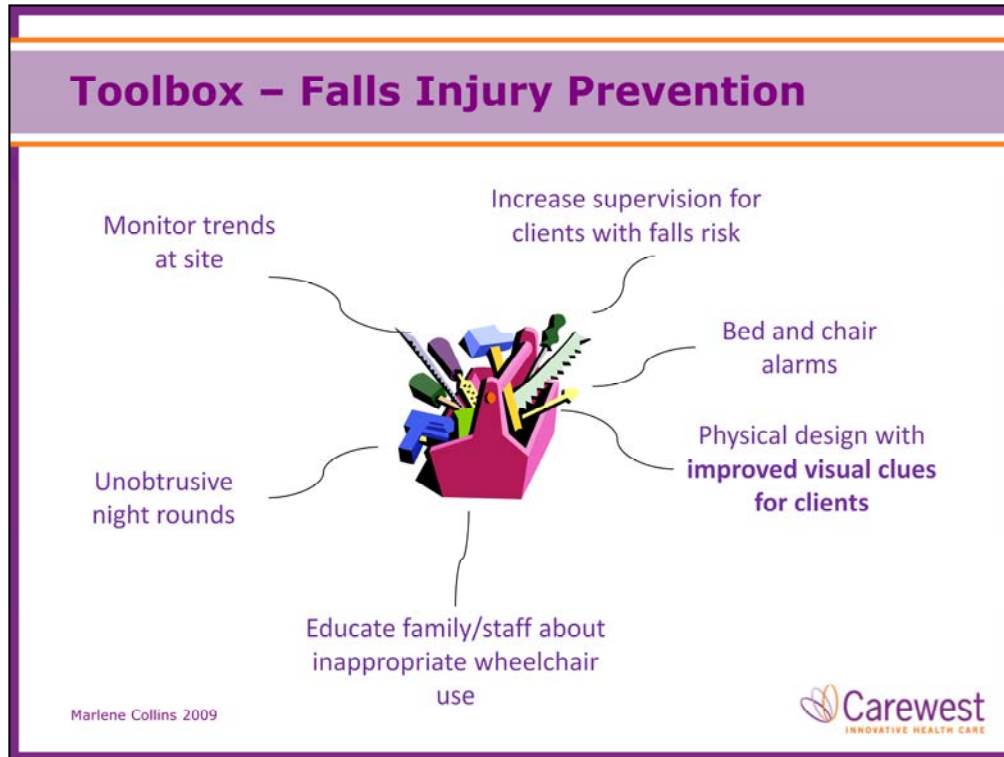
Medications like antipsychotics and sedatives can also increase the risk of falls.



Trainer's Note:

Ask: Are there other causes?

Remember to avoid calling possessions 'clutter' when talking to clients.



Also – review medications regularly to ensure they are not causing falls

Physical Design Features

More Visible



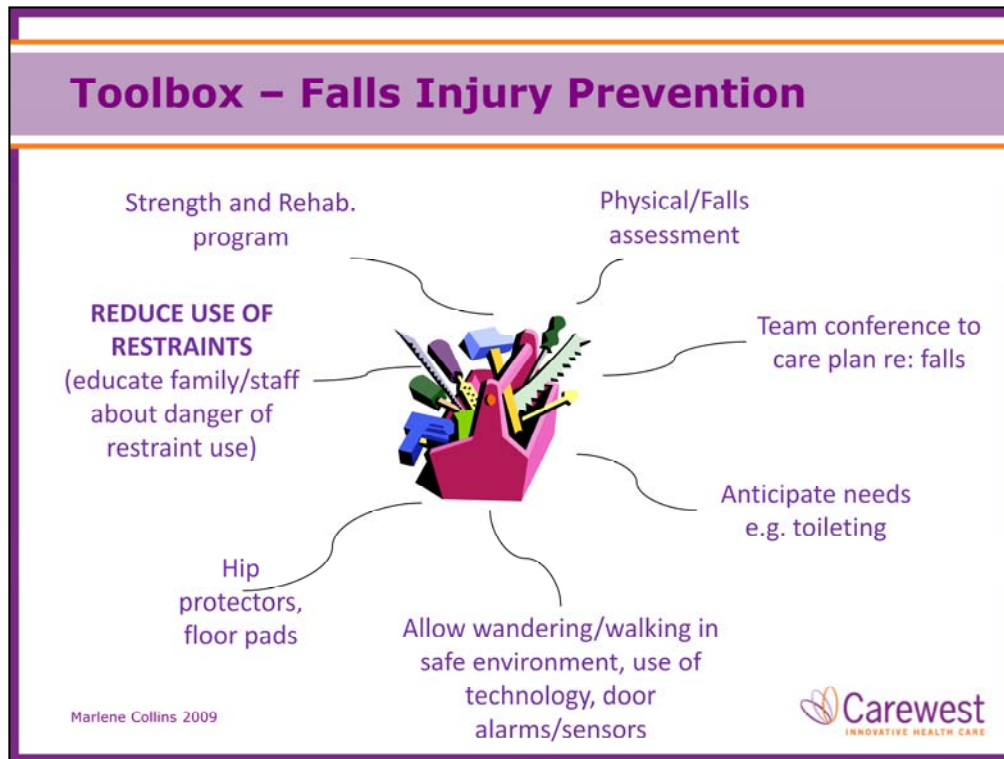
Less Visible



Trainer's Note:

An example of how design can aid vision and reduce falls:

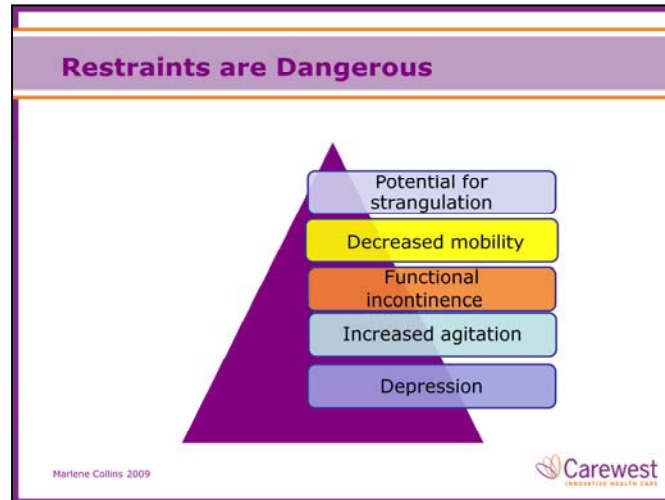
Also making the toilet visible from the bedroom can help the person find it independently.



Trainer's Note:

IN ORDER TO ELIMINATE RESTRAINTS CAREGIVERS NEED TO:

- provide individualized care- anticipate needs
- optimize individual function and mobility
- consider alternatives such as: chair/bed alarms - hip protectors, floor pads
- we may need to educate families about the risks of restraints
- allow 'wandering' (anxious) clients to walk freely in a safe environment
- utilize expertise of architects and therapists to change the environment to meet needs of clients
- increase the ability to observe the client



Trainer's Notes:

Restraint use is more expensive than alternatives if frequency of checking is maintained.

Many studies have documented negative responses for those who are restrained - incontinence, contractures, loss of bone and muscle mass, increased agitation, more behavioural symptoms, injuries and death. Consider the person who is restrained all day and then tries to walk to the bathroom at night – high risk of falls!

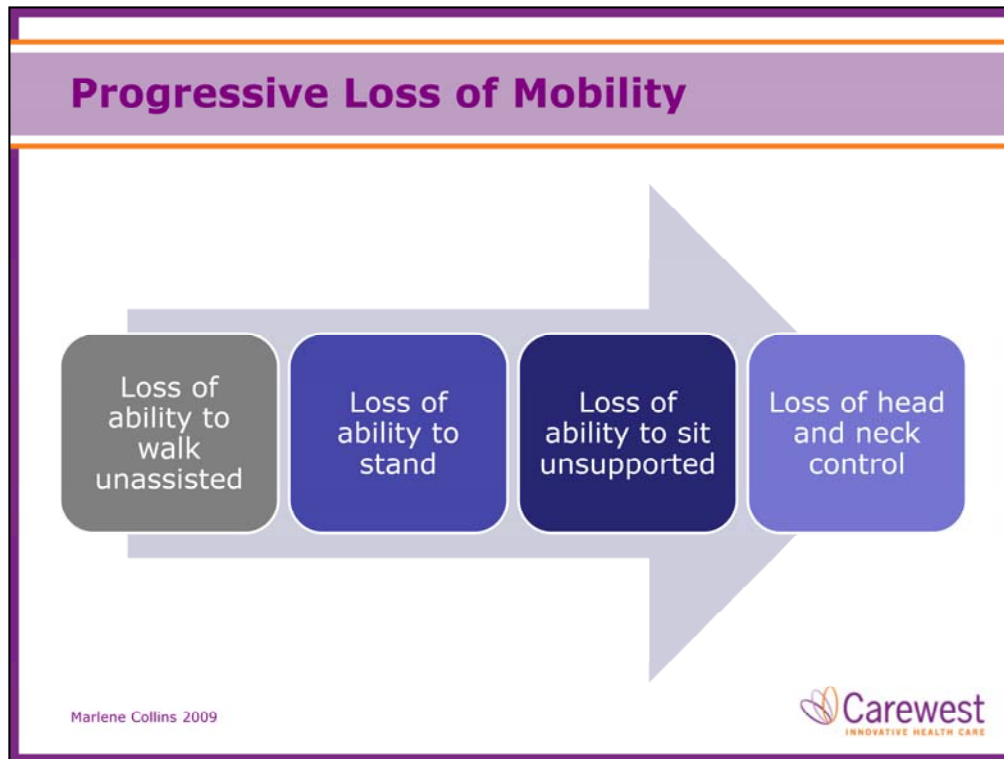
Under the Protection of Persons in Care Act (PPIC) we know that abuse to clients also includes inappropriate use of restraints both **physically** and medically with **chemical restraints**. Therefore, it is important to be mindful of the legal implications re: inappropriate use of restraints.

"It is the position of CARNA that policies of least restraint will be implemented in all client care settings. 'Least restraint practice' means that a registered nurse will exhaust all possible alternative interventions before deciding to use a restraint."

Caregivers must set a program in place to assess, monitor, and evaluate the use of restraints. We cannot continue to use restraints just because we believe we might be preventing injury – **they cause injury**. An Alberta case that received wide publicity found that strangulation from a back fastening seat belt had occurred. We need to learn from this and other tragedies.

There are documented cases of strangulation related to restraints.

At Carewest – only the Director can approve restraints – that is how important it is to ever consider restraints – they are dangerous.



Trainer's Notes:

LOSS OF MOBILITY

Loss of mobility will be progressive-loss of ability to walk, ability to stand, ability to sit unsupported and eventually loss of head and neck control. Maintaining the ability to ambulate for as long as possible is an important goal - prevent medical complications and outlet for physical energy.

How do we achieve this- no restraints and staff keeping them walking as long as possible. Use hip protectors around the clock to increase safety. Use it or lose it!

Quality of Life – Intimacy/Sexuality Needs

Video: 'Bringing Sexy Back'

As you watch the video think about people you care for ...



How can we support the need for intimacy/sexuality?



Trainer Tip: Show video “Bringing sexy back”

Encourage participation to answer the question.

Ask: *what has changed from the era of our clients relative to intimacy and sexuality*

Possible answers:

– lots!

Examples:

- privacy
- non-judgmental staff
- relationships i.e. same gender

What is Intimacy?

- The experience of being known, understood and loved
- Includes talking loving words, kissing, hugging, and body contact
- A sense of connection or relationship



Source: Bradford Dementia Group, University of Bradford 2005



The Issue of Consent



Are people with dementia able to give consent?

YES NO MAYBE

When are people vulnerable?

What does 'yes' look like?

Why is it important to involve families?



Trainer's notes:

Yes/maybe but we need to protect those who are vulnerable.

Ask participants to respond to the questions *for discussion*

Answers:

When are they vulnerable?

- when they can't make decisions or communicate
- vulnerable to staff judgement and values

What does consent look like?

- *see next slide*

Why involve families?

- they need to know that a situation is occurring as early as possible so we can offer education and include them in any problem solving/care planning

Consent

- A person with dementia can agree (has the capacity to decide) to participate in sexual activity
- They are capable of expressing a full range of emotions, both 'positive' and 'negative'
- They are able to show mutual affection
- Agreement to participate is indicated by their verbal and non verbal communication



Reference: Bradford Dementia Group, University of Bradford 2005

Privacy, Intimacy & Sexuality Policy

It is important to know any related policies in place where you work

At Carewest:

The Carewest's Privacy, Intimacy and Sexuality Policy is located in the Care & Services Manual, Policy #CS-03-02-01)



Trainer's note:

If other sites are interested in reading this policy they can contact:
Carewest – Clinical Standards and Nursing Practice Dept.

Positive Social Interaction

Confessions of an Old Cowboy



Trainer's note: Show the video clip

Positive Social Interactions



What is everyone
thinking?

What did the old cowboy say about positive social interactions?

Are positive social interactions important to you? Why?



Trainer: ask for a response from the participants



Trainer's notes: Give examples and ask the questions noted in these notes

David Sheard advocates that staff need to know how to increase positive social interactions.

The idea is to be like a butterfly flitting from person to person initiating brief meaningful interactions throughout the day.

Butterfly Moment Example:

Jean is paralyzed on one side and can no longer quilt but is still interested in it. The homemaker worker comments on the quilt on her bed and asks the name of the pattern, what type of material she used, compliments the colors, asks when she made it.

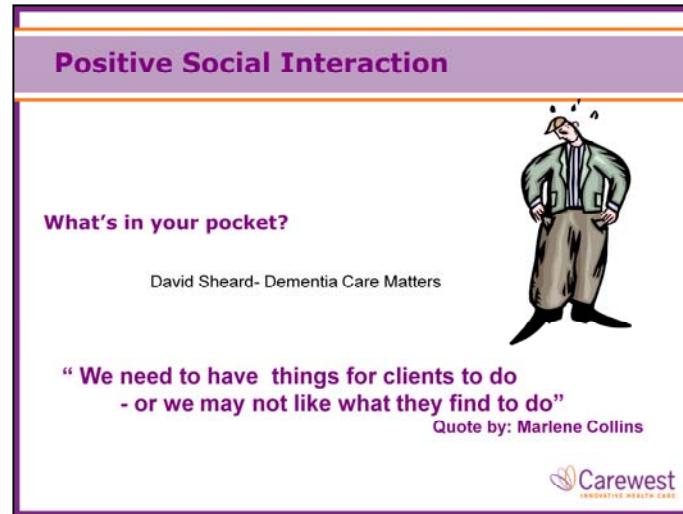
Did this take a lot of time? Did she make the client feel good?

Pick a flower, smell it, engage them in something that makes them 'smile'

Marlene Collins shared a story about one of her residents:

A resident came to her one day and appeared very concerned because he couldn't remember his birthday. After confirming the date, Marlene went back to him and said 'James – I found out your birthday was on June 5th, 1918 and you were born in Edmonton – wow that must have been a great day! Then she would continue to reminisce with him. He smiled and became fully engaged.. After that on different days whenever she ran into him she would remind him enthusiastically – "Hi James – I think you are that lucky person who was born on June 5th, 1918" in Edmonton. Again he would smile. (Butterfly Moments for James).

Ask participants to share some of their butterfly moments



Trainer's Notes: What's in your pocket?

David Sheard also advocates that:

- **staff need “stuff” in the environment to use and staff need to “fill up their pockets” with stuff to talk about or do.**
- staff may need training to do this. This will come naturally to some, others will need to observe and practice how to do it.

“Practice how to keep the conversation going using touch, taste, smell, sounds, reminiscence, life history, staff's own lives, things people including what staff are wearing, colours - the list is endless

“What's in your pocket?” can include:

- a physical item e.g. a checker, a ribbon, photo, seed catalog etc
- knowledge of their personal history (a conversation topic they will enjoy- e.g. where they lived, their birthday)
- something they enjoy doing – e.g. cards

Could recreation staff mentor/assist others to do this and have items available?

Quote was from Marlene Collins noted on slide. (So true isn't it?)

Marlene also tells the story about how she would sit down with a residents when he was alone, sitting at a table and not engaged – she'd pull out the checker in her pocket and push it across the table to the resident who would then send it back to her. They would engage in this for a few minutes – result - lots of smiles!

Meaningful Life Roles

- 'Everyone needs to feel needed'
- Our clients need meaning/purpose in their life
 - a job, activity or role



- Differs from basic need and leisure activities
- May connect to past interests/roles
- May be a new opportunity



Meaningful Life Roles refers to an activity, job or role that a client takes part in as an individual or group. It may connect to a past interest, responsibility or be a new opportunity

This is different from activities the person normally performs to meet their basic needs (getting dressed, eating meals,) and from recreation therapy, which is focused on an enjoyable way to spend time in a leisure pursuit (playing a game, practicing a hobby.)

Think of those tasks that could normally be filled by someone as an occupation, in a volunteer or paid role - care of animals, providing a service like working in a store, cleaning an area, doing yard work, or delivering mail/papers/supplies. These roles have a value to others, and therefore have more satisfaction for the person completing them.

It is most important that this is voluntary, and provides engagement and satisfaction to the client

It may be something that allows them to use past interests, skills or training or can be in a completely new area. This is often linked to our sense of identity as an adult; "I am a groundskeeper/cleaner/dog walker," or "I deliver the supplies/I work in the store."

Meaningful Life Roles

The role must:

- be flexible and match the person's comfort level
- be set up for success
- have a clear agreement on the reward
- meet legal or regulatory restrictions
- have full team support/understanding (all departments)



Meaningful Life Roles – keep in mind:

- a person can have good days and bad days, so the role must be flexible
- It should be set up for success, which may mean there is a gradual shift from dependence on a staff member to complete the role to increasing independence
- the level of social interaction must match the individual's comfort level
- there must be clear agreement on the reward for filling this role (small item, thank you card, recognition, pay) or trust can be lost when resident's or family's expectations are not met
- the team must have understanding of legal or regulatory restrictions (ie. health and safety, IP&C, handling of money) before you begin the activity. If you are willing to problem solve through the process, you may be able to find a creative way to allow a resident to fill a role not previously thought possible
- there must be full team support, including those of other departments (Food Services, Physical Plant Services) to provide a variety of roles and ensure there is understanding and support of the person in the role

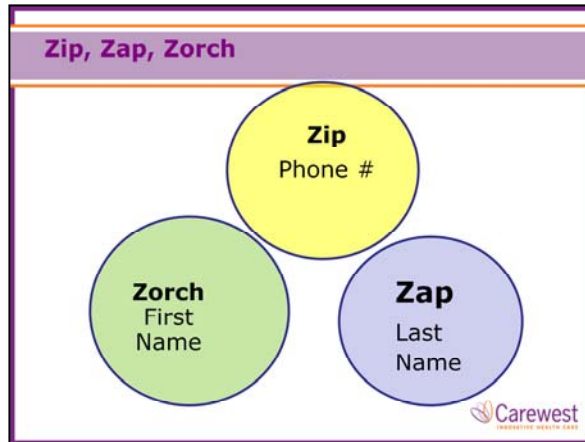
Meaningful Life Roles

**How can we help our clients who have
dementia find a meaningful life role at our
work place?**

Please share your ideas/examples



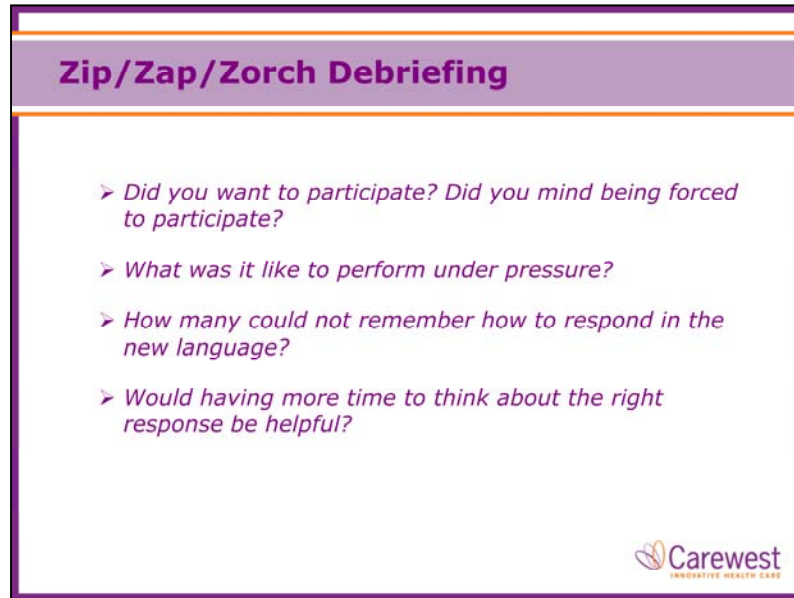
Ask for a response from the whole group or ask them to talk about it with the participant beside them and then report back.



Trainer's notes:

Optional Exercise if time: but explain the exercise even if you don't do it. Can be done as a group or just by quickly approaching someone and asking them to respond to 'zip' (phone #), someone else to 'zap' (last name) and a third person 'zorch' (first name) - without this slide up

- The trainer announces all participants will be playing a game.
- Also tell them, "These are the rules and it's really fun!!"
- No real lead in... debrief purpose at the end of the session)
- Have everyone sit or stand in a circle (depending on the room).
- The trainer act as the leader.
- Explain to the participants that we are creating a new form of communication and they will be learning a new language.
- Read aloud: "In our new language if someone says to you:
 - ❖ "Zip" - **you state your** phone number.
 - ❖ "Zap" - **you state your** last name.
 - ❖ "Zorch" - **you state your** first name
- Tell them "If you do not **reply properly within the count of three** you will be asked to sit down. The last person standing is the winner."
- **Remove the slide after explaining the 'rules' so staff do NOT have the visual reference**
- After explaining the 'new language' the leader stands in front of a staff (in their space) or points and randomly says one of the words
- Wait only three seconds for the person to respond then either exclude them (if they get the answer wrong) or quickly move on to the next person.
- The game is fast and intended to make the staff feel pressured and tested.
- How this makes the staff feel or would have made them feel will be included in the debriefing of the game.



Trainer's Notes: Ask the participants for their feedback related to these questions even if they didn't do the zip/zap/zorch exercise but have a sense of what it would have been like

Share the following:

- That our clients may experience some of the same difficulties we did during the game to process and respond appropriately when we don't give them time to process it.

Ask: How do you think our clients must feel when they can't understand or communicate with language/ feel pressured etc.

Trainer note – if the group of participants are not interacting you may want to introduce this exercise early as it seems to break the 'ice'



Trainer's Note:

An "enjoyable now" would include "Butterfly moments" and "What's in your pocket?"

Remind the group that one of the goals for care stresses how important it is to find opportunities to engage our clients in 'enjoyable nows'.

Show the **video clip from "One Thousand Tomorrows"** of Everett and his wife.

It shows how they experience "enjoyable nows".

E.g. folding clothes, swinging, smelling flowers

Remind staff that not everyone has an Everett in their lives. We need to do this for our clients.

Speak to the **IMPORTANCE OF ACTIVITIES THAT GIVE ENJOYMENT** to life.

As we discussed in Module Two (2) what gives each person interest and pleasure is highly individual.

Learning

Please write down:

- At least one thing you learned today that will change how you provide person-centred care
- At least one way you can ensure that you will continue to follow best dementia care practices

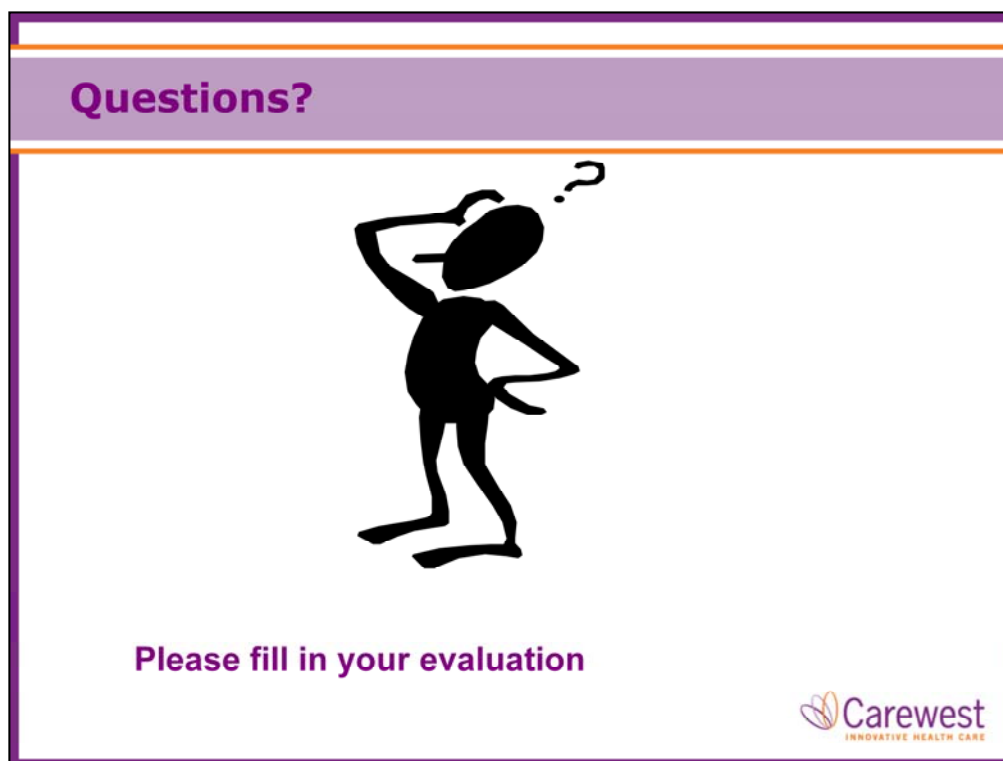
(refer to handouts)



Trainer's Notes:

Ask participants to jot down these items on their notes and to take them with them

Ask a few participants to share what they have written down



Trainer : click on slide if there are no further questions and the note about evaluations will appear.