



Champlain Dementia Network

Réseau de la démence de la région Champlain

What you need to know to work with people with dementia:

**... A primer for those
starting to work in
dementia care.**

Introduction

All staff working with elders and especially those with dementia should have specialized knowledge and skill.

This guide "*What you need to know to work with people with dementia: A primer for those starting to work in dementia care*" was developed as a pilot project sponsored by the Education Committee of the Champlain Dementia Network (CDN). A CDN Forum was held on Nov. 2005 that involved multiple stakeholders. Identified was the need for shared specialized education for clients with dementia and a sharing of resources.

The objectives for the development of the Dementia Primer were:

1. Provide a *brief* resource that could be adapted to any setting
2. Incorporate selected mandatory orientation topics: fire, dining, restraints
3. Develop a pre-post quiz
4. Include multiple teaching formats

The guide is not meant to be comprehensive; however, we hope it will give staff members who are new to an organization some information and skills to help them interact with residents who have dementia. The three suggested formats below incorporate showing parts of the DVD "*Brain and Behaviour*". This may be purchased from the Alzheimer Society of Canada. Please check their website for more information: www.alzheimer.ca.

In order to provide a general overview for staff, you may try the following teaching suggestions:

1. 30 minutes: DVD & brief discussion on the Dementia Primer
2. 60 minutes: DVD & discussion of Review Questions in the Dementia Primer, or
3. 90 minutes: Follow suggestions for 60 minute session and add video: *Hello in There* which is available from the Canadian Learning Company.

If you have used the Dementia Primer we would appreciate your evaluation.

Please take the time to fill out the feedback form provided and fax to:

Alzheimer Society of Ottawa and Renfrew County: Fax: 613-523-8522

Thanks for your help!

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... about dementia

- Dementia affects each person differently.
- **Dementia:**
 - describes a group of symptoms
 - is not the name of a specific disease
 - symptoms include loss of memory, understanding and judgment
 - can be either reversible or irreversible
 - affects a person's **daily functioning**.
- **Alzheimer's disease** is the most common form of irreversible dementia, accounting for over 60% of dementia cases.
- Not everyone who is confused has dementia and not everyone who has dementia has Alzheimer Disease.
- **Types of irreversible dementias** include: Alzheimer's disease, vascular dementia, mixed dementia, frontotemporal dementia, Lewy body dementia.
- Reversible dementias are those medical conditions which cause symptoms of dementia which are reversed if treated.
- Delirium is not a dementia but causes a **sudden change** in thinking and behaviour and may be improved with treatment. e.g. infection

Review questions

1. Not everyone who is confused has _____ and not everyone who has dementia has _____.

2. Dementia is a set of symptoms that includes loss of:

- _____
- _____
- _____

..... symptoms of dementia

Dementia has many symptoms that can at times be confusing. Understanding the symptoms that cause a person to behave in a certain way can make it easier to respond and provide appropriate support. The 8 A's of dementia are another way to look at the changes in abilities, remembering that symptoms may present differently in each person.

Amnesia– loss of memory (sensory memory, long-term memory, short-term memory, habitual memory)

- The person may forget and not remember later, especially things that happened more recently
- Last thing learned is first thing lost
- Will ask/repeat same questions/ comments

Example: Mr. Jessup accuses his roommate of stealing his glasses when Joe himself had placed the glasses in the drawer of his night table the day before.

Agnosia - loss of recognition

- Loss of recognition crosses all senses (smell, taste, vision, touch and hearing) - the person has trouble understanding the meaning of what is seen, heard, smelled, touched, and tasted
- The person may not recognize familiar faces – the person loses recognition of people in the order that they last came into his/her life

Example: Mrs. Agnew becomes frightened when she sees her reflection in the mirror, thinking an old lady is staring back at her.

Apraxia – loss of purposeful movement

- The person loses the ability to plan, sequence and carry out the steps of particular tasks even though the person is physically capable of performing the activity
- Every task has an order and the person loses the ability to organize the sequence
- Often a combination of not recognizing items and how to use them

Example: Miss Rogers is seen wearing her blouse over her pajama top at breakfast.

Apathy – loss of initiation

- The person has lost the ability to begin an activity on his/her own; however will engage in conversation or activity if someone else begins.
- It is sometimes interpreted as a symptom of depression – the difference is that the person will participate if engaged by someone else – it is not because they do not want to but rather because the person lost the ability to initiate.

Example: Mrs. Agnes will agree to go to an activity, but remains in her chair unless accompanied – once at the activity she participates and enjoys herself.

Anosognosia - no knowledge of the disease - meaning the person is unaware of the changes caused by the disease process.

- The person does not recognize the effects of the disease on his/her daily functioning. He or she may be unaware of problems with insight, judgment, planning, controlling impulses, concentration and attention.

Example: Mrs. Smith does not accept help with care because her brain is telling her she is still performing her own care

Aphasia - loss of language

- The person may have difficulty both expressing his/herself and understanding what is said. These losses are unique to that person. Do not assume that the person understands what you are saying because they can speak and do not assume the person does not understand if they cannot express themselves.

Example: Mrs. Brown often repeats “I need that thing over there to help me do that.” Using ‘**creative reasoning**’ and observing her behavior, staff understand she is referring to the Kleenex she uses.

Altered perceptions - loss of perceptual acuteness

- The person with dementia often misperceives what they see or hear to be something it is not.
- Some persons may see or hear things that do not exist.

Example: Mr. Deacon remarks “See those worms there. Pick them up.” He is referring to colored flecks in the carpet which he perceives to be worms.

Attentional deficits - difficulty in sustaining concentration on one thing.

- The person with dementia often has difficulty maintaining attention and is easily distracted.

Example: Miss Reid wanders away from the dining table even though she was enjoying her meal and is not finished. With redirection she returns to her chair and finishes eating.

References:

Putting the P.I.E.C.E.S....Together, P.I.E.C.E.S. Resource Manual, edition 6, 2006

Bell, Virginia and Troxel, David. The Best Friends Staff: Building a Culture of Care in Alzheimer's Program. Health Professions Press, Inc. 2001

Gentle Persuasive Approaches in Dementia Care: Responding to Persons with Challenging Behaviours. Continuing Gerontological Education Cooperative, 2005

Review questions

3. The person with dementia often misperceives what they see or hear to be something it is not. This is an example of: _____.
4. The person has lost the ability to begin an activity on his/her own; however will engage in conversation or activity if someone else begins. This is an example of: _____.

... stages of Alzheimer's disease

Progression of Alzheimer's disease:


- varies from person-to-person, but there are similarities.
- can span from 3 - 20 years, with an average of 8-12 years.

Stages of Alzheimer's disease are a guide to the pattern of how the disease progresses, which can help when making care decisions. However, it is important to note that the disease affects each person differently.

	Early stage	Middle stage
Description	<ul style="list-style-type: none"> • May be aware of changes • Short-term memory loss • Communication difficulties 	<ul style="list-style-type: none"> • Continued memory problems • Personality & behaviour changes • Assistance needed for daily tasks
Cognitive changes	<ul style="list-style-type: none"> • Short-term memory loss • Difficulty concentrating • Trouble following directions • Unable to find right words 	Loss of abilities include: <ul style="list-style-type: none"> • Memory and retention of new information • Recall, calculations, • Decision-making, planning • Memory of personal history • Thinking abilities
Personality changes	<ul style="list-style-type: none"> • Less sparkle, spontaneity, ambition • Appears indifferent, decreased interest • Withdrawal from usual activities 	<ul style="list-style-type: none"> • Appearance of self-interest • Increased confusion, anxiety, mood changes, suspiciousness
Functional changes	<ul style="list-style-type: none"> • What is happening to me? • Getting lost • Appears vague, uncertain, hesitant to initiate activities • Forgetfulness disruptive to formal routines 	<ul style="list-style-type: none"> • Lost ability to initiate & sequence • Visual spatial problems • Potential to get lost • Sleep disturbance

Progression of Alzheimer's disease (continued):

	Late stage	End-of-life
Description	Significantly impaired: <ul style="list-style-type: none"> • Memory • Communication • Ability to care for self 	<ul style="list-style-type: none"> • Complete withdrawal • Total care required
Cognitive changes	<ul style="list-style-type: none"> • Judgment significantly impaired • Ability to do simple tasks deteriorates • Difficulty understanding others & expressing self 	<ul style="list-style-type: none"> • Reduced or lost ability to speak, understand language or recognize significant others
Personality changes	<ul style="list-style-type: none"> • Loss of emotional reactions to people and situations • Potential lethargy or hyperactivity 	<ul style="list-style-type: none"> • Complete withdrawal or apathy
Functional changes	<ul style="list-style-type: none"> • May lose ability to do activities of daily living • Needs care and supervision 	<ul style="list-style-type: none"> • Requires total care

Source: ASO Core Materials 2004 

Review questions

5. There are 4 stages of Alzheimer Disease:

- _____
- _____
- _____
- _____

6. In the _____ stage, the person often says, "What is wrong with me? I can't remember", has difficulty following directions and difficulty finding the right words to say.

...communicating with people with dementia

Communicating with a person with dementia requires belief, creativity, understanding, patience and skill.

- Belief that every person, regardless of abilities, maintains a core of self that can be reached.
- Creativity in expressing both your feelings and your message.
- Understanding the effect of the disease on communication.
- Patience to slow down, listen, watch, wait for a response, repeat a phrase.
- Skill to convey messages or feelings effectively.
- Recognizing that culture affects communication.

Getting a message across

Set the stage

Communicating is always easier if other things are not happening at the same time. When trying to get your message across, make sure that there are few distractions. For example, if the TV or radio is distracting the person, turn it off.

Get the person's attention

Approach the person slowly and from the front. Gently touch a hand or arm to help get attention. Wait until she seems ready to listen before talking.

Make eye contact

Sit facing or standing in front of her, if possible. Keeping eye contact (if culturally appropriate) will help the person know who is speaking and may assist the person in concentrating on the message.

Speak slowly and clearly

Use simple words and short sentences to make the message clear. If the person has hearing problems, lowering the pitch of your voice is often better than increasing its volume.

Give one message at a time

Keep a conversation simple. Too many thoughts or ideas at one time can be confusing. Limit choices.

Pay attention

The person's reaction to what you say can give you some idea of how much is

understood. Watch facial expressions and body movements. Respond to moods and emotions especially when the words don't make sense or are inappropriate.

Repeat important information

If you are uncertain the message was understood the first time, repeat it using the same words.

Show and talk

Use actions as well as words. For example, if it is time to go for a walk, point to the door or bring the person's coat or sweater to illustrate what you mean.

Take time

To encourage communication, allow the person time to respond

Tips for Effective Communication

- Avoid arguing or reasoning
- Try not to take it personally
- Never question a person's ability to remember
- Do not say you understand if you don't
- Respond to the emotion behind the words
- Be patient

Source: Alzheimer Society of Canada

Review questions

7. Communicating with a person who has dementia requires:

- _____
- _____
- _____
- _____
- _____

8. Four tips for effective communication are:

- _____
- _____
- _____
- _____

... providing care for people with dementia

Dementia is a family matter and affects not only the person diagnosed with dementia but their family, siblings and friends. The effects and emotions vary from person to person.

Common feelings experienced by all:

- Fear
- Depression
- Frustration/despair/helplessness
- Grief
- Sense of isolation/loneliness
- Resentment/anger
- Embarrassment
- Guilt
- Sadness

What Does Dementia Feel Like to the Person Who Has It?

People with dementia may experience:

- Anger at the disease and towards others
- Frustration at the loss of abilities
- Sadness at their loss of a familiar life
- Fear of :
 - abandonment
 - loss of control and being controlled
 - humiliation
 - being excluded
 - being imprisoned
- Feeling of panic

What people with dementia need:

In order to provide support and care to a person with dementia it is important to understand what is needed beyond food, shelter and physical care.

- They need what all people need – only they may need some help to get it:
 - **Comfort:** tenderness, closeness, calming of anxiety, feeling of security, warmth and strength.

- **Attachment:** as human beings, we need bonds with others and this need does not lessen with dementia. When attachments are lost, there can be a feeling of insecurity and or a feeling that of not belonging.
- **Inclusion:** we all need to feel part of the group. As dementia progresses, it is easy to assume that because they have lost cognitive abilities, they are unable to interact within the group. They will begin to feel isolated, will retreat.
- **Occupation:** to be occupied means to be involved in the process of life. We have all had occupation since we were babies. The need for this does not change when we develop dementia. There are ways to promote occupation by allowing them to help, to feel needed, to take part in activities. You need to know something about the person's past to be able to include them in activities which interest them
- **Identity:** to know who one is, to have a sense of continuity, to have a story to tell. We can promote this for a person who has memory loss by holding onto their memories for them, showing empathy in the way in which we listen and respond.
- People with dementia need help in getting these needs met. As one need is met, the others will be affected and as a result the person will be less anxious, have less fear, have a feeling of self-worth, of being valuable and valued.

Your attitude is important!

- Treat the person with **dignity and respect**, as an adult not a child. Be courteous.
- **Be interested.** Value what the person is telling you. Listen and respond.
- Give **choices** when possible.
- **Recognize** a person's feelings. Don't negate them. You end up negating the person. Empathize if sad, angry, depressed.
- Respect their **privacy**. Everyone needs personal space.
- **Explain** what you are doing. It gives dignity to caregiving and it also helps them to be included in the world around them.
- **Encourage independence** wherever possible. However, recognize that the person may need to feel dependent at times when they feel insecure or frightened.
- **Praise** adds to self-esteem. It must be sincere.

Effects of Dementia on Family

Your support and care stretch beyond the person with the disease to his/her family. Understanding how the disease might be affecting family members will provide you with insight on how you might help.

Primary caregiver (e.g. spouse, partner, friend, etc.):

- Altered plans – may have to give up volunteer work, full-time or part-time job, travel plans, etc.

- Role changes – eventually need to take over roles that were the responsibility of their spouse, e.g. cooking, finances, yard work, etc.
- Isolation/loneliness – loss of companionship of spouse, friends stop visiting, calling
- Abandonment
- Fatigue – constant demands can lead to physical and emotional fatigue
- Grief

Adult children:

- Role reversal – now parenting the parent
- Unequal sharing of caregiving – resentment, anger directed to other siblings who may not share in the caregiving role
- “Caring from a distance” – dealing with the feeling of helplessness due to distance
- Resentment, guilt

Grandchildren:

- May be unwelcome
- Reduced time spent with own parent who is spending time caregiving
- It is an opportunity to learn about caregiving

Brothers and Sisters:

- Unable to have conversations
- May need to help with the caregiving role
- May find it hard to visit
- Feel threatened by the disease

Friends:

- May find it hard to visit
- Hard to include the person with dementia socially
- Can't share memories
- May feel threatened by the disease

Even though taking care of a family member at home might have been frustrating, and draining, the placement process is still one of the most difficult decisions for a spouse or family members to make. They are dealing with a variety of feelings. For example:

Guilt:

- They question themselves, “Are we doing the right thing?” “They won't know how to care for her/him.”
- Broken a promise – “I always said that I would never put my mother/father in a home.”

Failure:

- They feel they are not doing enough, are not loving enough or not willing to sacrifice enough

Financial Considerations:

- Unable to afford the care they want; e.g. cost of keeping their loved one at home with 24 hour care and realizing that it is not possible
- A spouse or family member may be concerned about their own financial future

Letting Go:

- Surrendering care of their loved one to strangers is very difficult
- Accepting the fact that the care will not be the same is also very hard
- Not sure what their role is after placement in a long term care home

Family Dynamics:

- All families are different, all with their own dynamics. Some in the family may not understand why placement – others may wonder why it wasn't done sooner.
- There are more intense emotions shown by the spouse of family members over placement

Quality of life for people with Alzheimer's disease is largely dependent on their interactions and relationships with others. Maintaining a connection can be a complex and challenging process. Some days it may seem that nothing is understood, while on others much is exchanged and felt. Try to make the most of the good days. Let the person and their family help you through the tough ones. Keep trying. It is important to remember that you are doing the best you can.

Source: Alzheimer Society of Ottawa; Tom Kitwood, *Dementia Reconsidered*

Review questions

9. Primary caregivers deal with a variety of feelings and emotions in caring for their loved one with dementia. Three of these are:

- _____
- _____
- _____

10. People with dementia need 5 things. Name 3 of them:

- _____
- _____
- _____

...dining

...what you need to know

- Too much stimulation can cause a person with dementia to have problems focusing on the task of eating.
- Too many items on the table can cause confusion.
- Some residents may no longer understand or remember appropriate dining behaviour. This may cause them to hoard or eat condiments like sugar and salt.

...what you can do

- Keep the dining experience simple:
 - Basic table setting – place only utensils required on the table
 - Give only one part of the meal at a time. For example, don't bring dessert until the main course is finished
 - Keep the room as free of distractions as possible. Turn off the TV and keep the music low.
- Seat residents when the meal is ready to be served. This might prevent those who have difficulty sitting for periods of time from leaving.
- Seat residents of similar cognitive abilities together.
- Help residents converse with one another during meal times.

Review questions

11. Too much _____ can cause a person with dementia to have problems _____ on the task of eating.

12. Keep the dining experience _____:

- _____ table
- Give only _____.
- Keep the room free from _____ as possible.

...fire safety

...what you need to know

- Some people may forget what the alarm bell means.
- Reactions to a fire alarm can vary from one person with dementia to another. The reactions can range from being frightened and withdrawn to being angry and agitated.
- The alarm may trigger memories from the past. For example some may think the alarm is a wartime air raid siren.

...what you can do

- Keep calm and relaxed during the alarm.
- Communicate to the staff on the next shift that the alarm occurred so that they are aware of any changes in behaviour related to the alarm.
- Consider silent alarms whenever possible; especially during the night or early morning.

Review questions

13. Some people with dementia may _____ what the alarm bell means.

14. Keep _____ during the alarm.

...restraints

...what you need to know

- Restraints should be used as a **LAST RESORT**.
- The use of restraints may produce a response that may result in increased agitation and injury.

...what you can do

- **Ensure all alternatives, by the team, have been tried before restraints are used.**
- If a resident is restrained ensure that the resident is safe and comfortable and the restraint is properly in place.
- If a resident is restrained ensure a plan is in place to work toward discontinuing it.

Review questions

15. The use of restraints may produce a response that may result in increased _____ and _____.
16. If a resident is restrained ensure that the resident is _____ and _____ and the restraint is _____ in place.

...lifts and transfers

...what you need to know

- The resident may not understand what the lift is for.
- Understanding instructions may be difficult.
- Changes in perception may cause a resident to misjudge depth. For example, he/she may feel like the bathtub has no bottom or that they are being lowered into a deep pool.

...what you can do

- Ensure the resident is aware and understands what you want to do:
 - Explain what you are doing slowly, one instruction at a time.
 - Show and tell. Show the person what you are about to do.
- Keep the room as quiet and free of distractions as possible.
- Continually reassure the person.
- To help relax the person, make conversation about subjects of interest to him/her.
- Always have 2 staff present when using a lift.
- Be prepared to respond to unpredictable movements or reactions.

Review questions

17. The resident may not _____ what the lift is for.

18. Ensure the resident is _____ and _____ what you want to do.

...team work

...what you need to know

Because of the symptoms of the disease people with dementia need continuity and consistency of care. The best ways to provide good dementia care is to work as a team. The collective team members bring many different backgrounds, education and perspectives that are essential to providing good care. Team members should include all those who are involved in the person with dementia's day-to-day life and care such as, family members, nursing, dietary, maintenance, activity and therapy staff.

...what you can do

- **Be flexible** - because each day can be different for a resident with dementia. Moods, mood, sleep pattern and abilities will vary from day to day. It will be difficult to stick to strict routines. Flexibility is the key to successfully completing tasks.
- **Sharing ideas** - if you have had success in your approach to care, activities etc. – PASS IT ON!! This will help ensure that the good care will continue when you are not there.
- **Listening carefully to your peers** - accept and learn from the experience of your peers. Respect and recognize that others sometimes have the “knack” with certain residents to “make it happen”. When times are challenging – support each other, talk about it, debrief.
- **Lend a helping hand** - an effective team recognizes that residents with dementia are every staff person's responsibility. A resident with challenging behaviour is not mine or yours but everyone's.
- **Appreciate unique ideas and concepts** - Working with residents who have dementia is exciting because of the challenge. Brainstorm with your peers. Be open to new and creative ideas – they just might work! Remember: **Nothing is written in stone** – if it works it was worth the try.
- **Appreciate cautiousness** - some challenges require a team to take the time to STOP, THINK, OBSERVE, and PLAN together. This slower approach can often result in the prevention of catastrophic reactions in residents and promote a safe work environment for staff.

- **Respect the beliefs, values and cultural differences of others** – recognize that we all bring our own set of beliefs, values, cultures and personalities to caregiving. These can enrich the work environment providing different perspectives and ideas. For example one staff may feel more comfortable using humour in a situation while someone else would use a kind, firm approach; recognize that both can result in success.

Review questions

19. List four ways that you can be a good team player:

- _____
- _____
- _____
- _____

20. List four possible team members:

- _____
- _____
- _____
- _____

Evaluation Form

**What you need to know to work with people with dementia
...A primer for those starting to work in dementia care.**

If you have used this primer in orientation of staff to your dementia care area, please assist the Champlain Dementia Network by completing the following:

1. Location of dementia care area:
? Hospital ? Retirement Home ? Community agency
? Long term care ? Other: _____

2. Which staff used the primer?
? HCA/PSW ? RPN ? Nutrition/dietary ? RN
? Housekeeper ? Other _____

3. Did you find the primer helpful?
? Yes ? No
Comments: _____

4. Do you have any suggestions for change?

Please send your completed form to:

Alzheimer Society of Ottawa and Renfrew County: Fax: 613-523-8522

Thanks for your help!