

The Dementia Compass



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Elizabeth Rhynold, MD
Kathi Hurley, RN BN MN
Cindy Hobbs, MD

The
Dementia
Compass

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Email: dementiacompass@HorizonNB.ca

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Dedicated to all the people
we have met whose lives
have been touched by dementia.
It has been our privilege to learn with you.



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Introduction

“No single map will help everyone get where they are going.”

The purpose of this booklet is to:

- Describe some struggles other people have encountered when helping individuals with dementia do their day-to-day activities.
- Outline some of the personality changes that some people notice as they help a person with dementia.

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- Suggest some strategies that might make your interactions easier.

People with dementia have problems with certain parts of their brains. Some of the different kinds of dementia include:

- Alzheimer’s disease
- Mixed dementia
- Lewy body dementia
- Parkinson’s disease dementia
- Fronto-temporal dementia
- Vascular dementia

Sometimes the cause of the dementia is not given a specific name. Regardless of the name given to the changes in the brain, each person with dementia will have parts of the brain that work well and parts that do not work anymore. This means that each

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affected person will have a different set of challenges.

You may clearly see the effects of the dementia. Many people with dementia are not aware of the changes that have occurred.

The information in this book is designed for people helping someone with dementia. This is often called caregiving. As a caregiver you will have your own unique strengths. We hope to build on those strengths by providing tips other people have found helpful.

Communication

Good communication skills can make life less stressful for you and the person you are trying to help.

You may have noticed that some people with dementia have trouble having a conversation. Maybe they:

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- Have difficulty finding the right words or finishing sentences *“Did you see that...thing...”*
- Use the wrong word or use made-up words *“Where did you put... those...cutters?”*
- Return to the language they used as a child.
- Swear or say embarrassing things.
- Just don’t talk as much anymore.

Some people with dementia have more trouble understanding what they are being told. It can be harder to understand when:

- Instructions aren’t one step at a time.
- People talk in long sentences.
- Groups of people are talking.

Telephone Issues:

- Initially people with dementia may avoid answering the phone.

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- They may also have difficulty passing on messages people leave. You may want to get an answering machine. Sometimes answering machines can be set to pick up calls if the person with dementia is home alone.
- Some people lose the ability to use the phone and may confuse the phone with the TV remote.
- Post important phone numbers close to the phone. The “speed dial” on some phones can be labeled with a person’s name.
- People with dementia may need more supervision if they no longer remember that “911” is an emergency number.

When you are talking:

- Help the person concentrate by turning off the TV and radio.
- Get the person’s attention by approaching slowly from the person’s front.

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- Try to speak slowly using simple words and short sentences without “talking down” to the person.
- Sometimes it helps to introduce yourself, even if you know the person well
“Hi Dad, it’s Mary.”
- Try not to quiz the person. Most people find it frustrating to be asked, *“Don’t you remember...?”*
- Instead of asking about recent events like, *“What did you have for breakfast?”*, ask about what’s happening now, *“Do you like that sandwich?”*
- Comments like, *“I’ve already told you that before.”* are not helpful and can be frustrating or hurtful for the person with dementia.

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When you are listening:

- Give the person time to respond.
- Try not to jump in and finish sentences or fill in words.
- It is usually not necessary to correct mistakes the person has made (for example a name, date or fact).
- Try not to get frustrated if you have been asked the same question or are told the same story.
- If you don’t understand, tell the person: *“I’m having trouble understanding you right now, I’m sorry. We can figure that out later.”*
- Sometimes if the words don’t make sense you can respond appropriately by reading the mood and say: *“I’m glad you enjoyed that.”* or *“I’m sorry that upset you.”*

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PART 1: **Day-to-day Routine**

The tasks we regularly do to keep clean and healthy are often called activities of daily living and include:

- brushing teeth
- combing hair
- shaving
- bathing or showering
- eating
- going to the bathroom (toileting).

Most of us have a routine that makes these activities seem easy. We have all had many years to practice these skills but when you think about it, they are complicated.

People with dementia may have difficulties with these activities because they can have changes in the parts of their brains that:

- Organize tasks with multiple steps.
- Tell them when it is time to wash or change clothes.
- Understand spoken instructions.
- Recognize when people are trying to help.
- Know how to use common tools like a comb or razor.

Imagine if you no longer recognized a toothbrush and someone was trying to stick one in your mouth. You might feel that you are being attacked and try to defend yourself.

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Getting ready in the morning

Many people with dementia do not pay as much attention to how they look. Over time they can lose the ability to dress and wash. Some people with dementia will not realize they need help and will refuse if you offer. You may need to watch to make sure they are still able to do these activities.

If you realize the person with dementia needs some help getting ready there are several ways you can help:

- Some people just need to be reminded what they need to do.
- Often people will need instructions. Remember to give instructions one step at a time.
- Sometimes spoken instructions aren't understood but actions can be imitated.

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- Finally, some people need a guiding hand to gently help them get started.

Three main things will help with anything you are trying to do:

- Remember, getting ready is not a race. You may have to change your pace. People with dementia can often read your body language and will know if you are rushed, distracted or frustrated. Give yourself as much time as possible.
- Be organized. Have the things you need available but don't put everything out at once because this can be confusing. (It's hard to brush your teeth with a comb.)
- There are a lot of things that need to get done in the morning. It is important to prioritize which activities are most important. If the person you are trying to help doesn't want to do something right now, try again later. Pick

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the time of the day that seems to be best for the person you are trying to help.

Dressing:

- Some people with dementia will put on yesterday's dirty clothes. Try gathering up dirty clothes after they get changed for the night.
- For the next morning, put clothes out in the order they need to be put on (underwear on top to be put on first).
- Put out clothes that they like to wear. Many people with dementia have favorite (older) clothes. Insisting that they wear newer clothes is often not helpful.
- Pants with elastic waist bands and shoes with Velcro are easier to get on and off.
- Sometimes people with dementia will layer their clothes. As long as the person with dementia does not get "overheated" this is okay.

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- Only have the clothes for the current season available.

Sometimes people with dementia no longer know how to put on pieces of clothing (putting a leg through the arm of a shirt). These people require one-on-one help getting dressed.

Teeth:

- If a toothbrush and toothpaste are not working, try a mouth rinse. If the person swallows it, ensure it is a rinse that is safe to swallow.
- Schedule teeth cleaning twice a year with a dentist and a dental hygienist who have worked with people with dementia.

Shaving:

- Use an electric shaver.

Hair:

- Suggest a low maintenance hair cut.

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Bathing and Showering

Each person with dementia will need a different approach to getting clean. Some people with dementia may not realize they have not bathed in a while and need to be gently reminded. On the other hand, you may need to change your usual standards. Unless the person has had a bathroom “accident”, it is often OK to help the person bathe or take a shower once a week.

Preparation:

- Ensure the room is warm and quiet.
- Turn your water heater down to 45°C.
- Buy “ouch-less” shampoo that doesn’t burn the eyes.
- Label items that are frequently used during the bath and put them on a special shelf. This will help the person with dementia to be as independent as possible.

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- Lay out the necessary things like soap and a towel.
- Remove all potentially dangerous items from the bathroom. “Draino” can look like shampoo.
- If you are concerned about safety, you may want an occupational therapist to come and see your bathroom to recommend things like hand-rails and a seat for the tub.

The Invitation to Bathe:

- Some people will bathe or shower if invited to the bathroom where everything is laid out.
- Many people with dementia will say “no” if asked if they “want” to have a bath while saying “your bath is ready” will work better.
- If the person refuses to bathe you may want to try asking them again later.

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- Sometimes it is very important that the person gets clean. That’s where knowing different bathing options is important.

Bathing options:

Question 1: How does the person like to get clean?

Bath

- Check the water temperature to avoid scalding.
- Putting fluorescent tape (colored duct tape) at the water level can help people with depth-perception problems.

Shower

- A walk-in shower is usually safer.
- Consider installing a hand-held shower head.

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Sponge bath

- People can get clean with a good scrub using soap and a face cloth.
- Try soaps that don't require a rinse with water (ask your local pharmacy if they have any available).

Towel bathing

- This is a method used to help people with late stage dementia.
- Warm towels and rinseless soap are massaged onto the skin while keeping the person covered.
- For more information see: "Bathing Without a Battle 2nd Edition" (see Additional Information).

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Question 2:

How much help does the person require?

- In general, you should always try to allow the person to do as much as possible for themselves. Some people only need a reminder. Sometimes you will only need to be there in case problems arise. Others need simple step-by-step directions. Some people will need hands-on help to get clean.
- Remember that the person you are trying to help may be embarrassed about being naked in front of you. With time, trust may develop and you may be able to help more.
- Some people do not want a family member to bathe them but will let a home-care worker (i.e. "the nurse") help. Don't wait too long as help early-on will make things easier in the long run.

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Remember:

- Getting clean doesn't have to start with the face or go in any particularly order.
- The whole body doesn't have to be cleaned at once.
- The needs and preferences of people with dementia change over time. Be prepared to change the routine.
- The person with dementia may need more help than you feel comfortable giving. At **any time** you can ask for some help from services available in your community.

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Going to the bathroom (toileting)

People with dementia often need help using the toilet. Remember, it takes a lot of steps to recognize the need to pee, find the bathroom, get the appropriate clothes removed and remember how to pee.

To minimize bowel and bladder "accidents":

- Try scheduling a bathroom break every two hours during the day, after each meal and before bed.
- Between bathroom breaks, watch for signs that the person may need to use the bathroom:
 - pulling on clothing or private parts
 - pacing or making repetitive noises.

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- Most people need to drink at least two litres of fluid a day. You may want to help the person drink liquids earlier in the day rather than before bed.
- It may be helpful to limit caffeine in the form of pop, tea and coffee.
- Help the person choose clothes that are easy to remove, like track pants with elastic waistbands.
- Get the person in front of the toilet before helping them take down their pants.
- Some people need a little privacy in the bathroom. If it is safe, turn away or step out but stay close by.
- As the person leaves the bathroom, gently rub hands with some hand sanitizer gel.
- Leave the bathroom light on at night.

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- In public, know where bathrooms are. Using the “family bathroom” can really help in malls, restaurants and airports.

Sometimes people with dementia will not make it to the bathroom in time. This can be hard on the person with dementia and the person trying to help.

- It’s important that you try not to show you are upset. The person with dementia did not do this on purpose.
- Drugs can’t fix this problem.
- The pharmacy has lots of different things that may help. Ask for “adult continence products”.
- A plastic cover on the mattress may help with cleanup.
- Commode chairs can be rented or purchased and put close to the bed.
- Talk to your health-care team if toileting is becoming a problem.

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Eating:

Eating is important to almost every culture. It can remain an enjoyable part of the day when helping someone with dementia if some simple changes are made in the daily routine. Remember, the routine will need to change as the effects of the dementia change.

Preparation:

- Provide a calm environment. Keep the noise and distractions to a minimum. Get rid of clutter on the table and sharp objects.
- Try to schedule enough time so meals aren't rushed.
- If dentures are loose get them refitted.
- Usually, it is best to prepare food that the person has always liked. Sometimes, they will

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only eat a very limited number of things. Focus on trying to get foods from each of the food groups (see Canada's Food Guide) rather than giving them new or "interesting" foods.

- People with dementia will often put food to their mouths without checking the temperature. Make sure you check for them, especially when using the microwave.
- Cut food into chewable pieces.
- Serve meals at the table with the person sitting in a comfortable chair.

Meal time:

- It may be necessary to say it is time to start eating. Give one step instructions like, "Eat your soup".
- Provide one item at a time and hand them the appropriate utensil.

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- You may need to show the person how to eat the food, for example put food on a fork and bring it to your own mouth.
- You can also try putting the utensil in the person’s hand and gently guiding it to their mouth. If the person is not swallowing, do not force food in.
- Some people with dementia won’t be able to use a fork or knife. Try nutritious finger foods.

When to update your health-care team:

- If the person you are helping isn’t swallowing properly or is coughing during every meal.
- If you notice the person isn’t eating or clothes are getting too big.

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PART 2:
Personality
Changes

We all have our own unique personalities which influence how we act and behave. People with dementia often have changes in their personalities. Our goal, when helping people with dementia, is to understand their personalities but not to change them.

Some of the personality changes that occur in people with dementia include:

- lack of motivation
- pacing and restlessness
- increased temper and stubbornness
- agitation and aggression
- altered reality: hallucinations and suspicions
- changes in sex drive
- rarely, violence.

Often, you know the person with dementia best. A sudden change in personality or

behavior could mean there is a new medical problem like an infection. It is important that you tell your health-care team.

For the most part personality changes are caused by the damage the dementia has done to the brain. Hopefully, as you get to know and understand the person’s new personality you will find it easier to provide help and companionship.

Lack of Motivation

Sometimes people with dementia act like they are “lazy” or “sleepy”. If this is a change in their personality and they aren’t sad, it could be something called apathy. Apathy makes a person spend more time sitting quietly without getting up and doing things. Many people find these changes very frustrating.

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- Try not to be offended when the person doesn’t seem to want to do anything with you any more.
- It is comforting to know that the person is usually quite content sitting quietly.
- It is important that everyone does some activity every day, so offer different activities until you find some the person likes (i.e. gardening, walking the dog, folding laundry).
- Try giving simple directions to get the person started like gently taking their hand and saying, “let’s go for a walk.”
- Sometimes the lack of motivation can lead to some stubbornness. Unless it is really important, try not to push the person into doing something if they refuse.

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Depression

Although apathy is common in people with dementia, it is important to be on the lookout for depression. Tell your health-care team if you notice any of the following changes:

- Sadness, crying.
- Lack of enjoyment or interest in things they recently cared about such as close family.
- Talk about suicide or wanting to die.

The Canadian Coalition for Seniors' Mental Health has more information for patients and families about depression and suicide at www.ccsmh.ca.

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Pacing and Restlessness:

The previous pages describe people with dementia who are not motivated to do anything. Other people with dementia are constantly on the move. Restlessness and pacing is sometimes called wandering.

Wandering can be challenging for a couple of reasons:

- Often the wandering person can be in the way.
- The wandering person may get out of sight and be in danger.

The need to move is coming from inside the person. This need cannot be controlled with reminders or with pills. Instead, it is important to think about the following two questions:

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1. Is the person as safe as possible?

- It may help to lock doors that lead outside, to stairs or to rooms with hazards like the stove and knives.
- Locks that are not at eye level or combination locks may be enough to keep some people from opening doors.
- You may also want to make sure the person can't get locked in a room.
- An occupational therapist can recommend home modifications like this.
- If possible, think about putting a fence around the yard.
- Some people use home security systems so they know if a door has been opened.
- Register with *MedicAlert Safely Home*® a program to help people get home if they get lost (www.alzheimer.ca search MedicAlert).

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If a person with dementia could be lost, **MINUTES COUNT! Do not delay, call the police immediately to help with the search.**

2. Is the person trying to tell you something?

- Not enough exercise – increase supervised exercise. Try walking arm-in-arm if the person tends to trail behind.
- Need to use the toilet – try pointing out the bathroom.
- Too many distractions – reduce noise levels.
- Feeling disoriented – stick to familiar environments.
- Not getting enough attention – try to involve the person in your activities, for example folding towels or picking weeds.
- Feeling a medication side effect – ask your health-care team to review medication in case one of them has restlessness as a side effect.

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Changes in Sleep

Changes in sleep are normal as people get older. Most people wake earlier and require fewer total hours of sleep per day. In addition to these changes, people with dementia can have other dramatic changes in their sleep patterns. Often people with dementia have changes with their internal clocks.

- Sometimes the person will try to go to bed too early.
- People often think they have to get up and go to work in the middle of the night.
- Some people will be restless, will rummage through drawers or rearrange the furniture.
- Others will think it is daytime and will start cooking, cleaning or will go for a walk to the mailbox.
- Some people develop a fear of the dark.

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Tips for improving sleep at night:

- Long naps during the day may decrease the amount of sleep at night.
- Exercise and seniors day programs increase activity during the day and decrease napping.
- Try to stick to a routine, especially at bedtime. Try a cup of warm milk with relaxing activities before bed.
- Avoid stimulating things like caffeine, loud TV shows and the news after 5 p.m.
- Sometimes people prefer to sleep in their day clothes or in a recliner. It may be best not to interfere.
- Nightlights may help the person who is afraid of the dark and can light the way to the bathroom.
- If the person wanders in the night, it is important to consider safety issues like locks on the door and wood-burning stoves.

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- For the most part, people with dementia need someone there at night.

Changes in sleep can have a major impact on the caregiver who is responsible overnight. Your health is important. If you are constantly feeling exhausted you should inform your health-care team.

Sudden changes in sleep may be caused by a medical condition. You should speak to your health-care team about changes in sleep.

Agitation and aggression:

Sometimes restlessness becomes extreme. You may be asked if you have noticed any “agitation or aggression”.

- Agitation is an “emotional disturbance.” Imagine being very uncomfortable but not knowing why and not being able to tell anyone

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– this might help you understand what it feels like to be agitated.

- Aggression is what people do when they have extreme emotions but can’t put them into words. A person with aggression will get “in your face,” shake their fist, push, yell, hit the walls or pound on the door.

If the person you are trying to help is becoming agitated or aggressive you must tell your health-care team. You and the team will need to do some detective work to see if there is a cause for this behavior that can be treated such as:

- Has the person become constipated?
- Do they feel too hot or too cold?
- Are they hungry or thirsty?
- Are they frustrated by people expecting too much?

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- Have they got pain from a tooth ache or arthritis?

Hopefully, the agitation and aggression will decrease but until then, here are some things other people have done which have helped:

- Stay calm and talk slowly. Try not to raise your voice, argue or correct.
- Give the person a little space. Don't make sudden movements unless they are doing something dangerous.
- Unless it is dangerous, try to give the person what they want. For example, if they want to sleep on the floor, put a mattress on the floor so they will be comfortable.
- Ensure the environment is as safe and comfortable as possible. Remove any sharp or breakable objects.

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- The TV and radio can be soothing to some people. Avoid violent movies/sports and the news. Try music, cooking shows, home repair shows and old-time movies. If this doesn't work, try turning off the TV and the radio.
- At the back of this booklet there are two surveys that can be completed to summarize important information about the person with dementia. They may help you make choices that will be soothing (see Appendix 1 & 2).

Altered Reality:

1. Suspicions:

People with dementia are dealing with a lot of changes in how they see the world:

- They may not be completely certain where they are.
- Often they can't rely on their memory to tell them where they put things.

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- Sometimes they don't recognize people they know very well.

Everyone around the person with dementia is still carrying on normally. This can lead to misunderstandings.

In addition to misunderstandings, the person with dementia may develop very strong beliefs or delusions. It is important to recognize that no amount of discussion will change these beliefs. This is very real to the person and they may become angry if you don't "believe" them.

Here are some examples of beliefs that people with dementia may have:

- Things they can't find have been stolen.
- Their husband or wife is having an affair.
- Their husband or wife has been replaced by a fake.

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- Not recognizing their home as their own.

If you have noticed any delusions you should tell your health-care team. Sometimes a medication may be started to decrease these experiences if they are distressing. While working with your health-care team, here are some things you can try:

- You don't need to correct these beliefs. Correcting may lead to unnecessary fights.
- Try to not be offended if the person accuses you of something you wouldn't normally do.
- If the person is upset that something has been stolen you might say, "I see you are upset about your missing wallet. I'll do my best to find it."
- If possible, try to distract the person with something they usually enjoy.

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- Sometimes the same item keeps getting lost, like a pen or glasses. It might help to have extras stored away.

2. Hallucinations:

The parts of the brain that receive information from the eyes, ears and nose can be affected by dementia. The person with dementia will experience different things depending on what part of the brain is affected.

- If the part of brain receiving information from the eyes is affected they may see things that aren't there (visual).
- If the part of brain connected to the ears is affected they may hear things (auditory).

These experiences are often called hallucinations.

Many factors can make it more likely that the person will experience hallucinations:

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- general - new environment, new medication (especially over-the-counter cold medications), infection.
- visual – poor lighting, shadows, poor vision (not wearing eyeglasses) or blindness.
- auditory – new hearing aids, radio or television in the background.

Things you can do to reduce the risk of hallucinations:

- Improve the lighting so that there are fewer shadows.
- Remove or cover mirrors if they cause problems.
- Try to make the environment as familiar as possible.
- Avoid disturbing television programs like the news or movies.
- Reduce background noise.

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Things you can do if hallucinations happen:

- Don't argue about what is real.
- Try to figure out how the hallucinations make the person feel and respond to those emotions.
- Speak to your health-care team as hallucinations are an important symptom of dementia. The team may try a medication to decrease the hallucinations.

Delusions and hallucinations may come and go over time. Update your health-care team about these symptoms. Often, the medications started for hallucinations and delusions are not required forever.

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Changes in Sex Drive

People with dementia may no longer have control over some aspects of their behavior. When that control is lost, the person may do things that they usually wouldn't do, to make themselves feel good including:

- touch other people
- initiate sex more often
- masturbate
- make sexual comments

This can come as a huge shock to friends, family and strangers. These actions do not have anything to do with "what kind of a person they were" earlier in life.

Here are some examples of the ways in which dementia can change a sexual relationship:

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- The person with dementia may have lost the ability to say what they want to do and they may act on their needs without asking.
- People with dementia can lose the ability to recognize their spouse and may look to others to meet sexual needs. This is not an insult and does not mean the person has “loose morals”.
- The person with dementia may not realize an action is socially inappropriate (i.e. masturbating in public).
- The person with dementia may want to have sex repeatedly. Sometimes they have simply forgotten they just had sex. It is okay to say “no.” A simple reminder may be all that is needed.
- There may have been a decrease in the sex drive of the person providing help to the individual with dementia (i.e. due to stress or tiredness). The person with dementia may not understand this change.

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- The person with dementia may have a decrease in sex drive.

Although every situation is different, here are some things you can try to help with changes in sexuality:

- Check that the skin around the genitals is not wet, unclean or sore.
- Try to not yell or get angry but calmly distract the person with some other kind of positive attention.
- Consider warning family and close friends so they aren’t shocked by inappropriate jokes and comments.
- Direct the person with dementia to a private place where it is more appropriate to masturbate.
- There may come a time when the person with dementia forms a new sexual relationship. It is important to ensure that the new partner is consenting.

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Violence

The part of the brain that controls anger can be damaged by dementia. Thankfully, most people with dementia never become violent.

Rarely, violence does occur. Even the most pleasant person can become violent. This has nothing to do with how the person lived earlier in life.

- Violence can include using fists, feet or common household items, like a rolling pin as weapons. This violence is a symptom of the disease and does not mean you have done anything wrong.
- Violence may mean that the dementia has become more serious. This is often a time when people with dementia need to move into a nursing home. This does not mean you have failed.

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- Violence is always an emergency and should never be ignored. Everyone helping a person with dementia should have an emergency plan. This plan will be different depending on where you live and who you go to for support. Appendix 3 can be used to outline your emergency plan on page 71.

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Additional Information

This booklet is called the “Dementia Compass” because it is a tool to get you going in the right direction. From here it is important you continue to get more information. You may want to share some of these references with family and friends.

Face-to-face advice can provide important information and support in difficult situations. Many communities have active support groups including:

The Alzheimer’s Society

- Anyone helping a person with dementia is welcome to contact the local Alzheimer’s Society branch. “It’s not just for Alzheimer’s Disease!”

Caregiver support groups

- Ask a local social worker or check on bulletin boards at your local hospital.

Don’t be afraid to reach out to your own doctor, friends and family for help.

There are many online sources of information. We highly recommend these:

- **The Alzheimer Society of Canada**
 - www.alzheimer.ca
- **Lewy Body Dementia Association**
 - www.lbda.org
- **National Institute on Aging: Caring for a Person with Alzheimer Disease**
 - www.nia.nih.gov/Alzheimers/Publication
- **The Canadian Coalition for Seniors’ Mental Health: “Delirium in Older Adults: A guide for seniors and their families”.**
 - www.ccsmh.ca/en/default.cfm#.

Other written resources recommended include:

- **Caring for your loved one. An education guide for caregivers of persons with dementia.** Baycrest Center for Geriatric Care. 2nd Canadian Edition.

- **The 36-Hour Day.** Nancy Mace and Peter Rabins. Warner Books, 2006.
- **A Caregiver's Guide to Lewy Body Dementia.** Whitworth and Whitworth. demosHEALTH 2010
- **Caring for a Loved One with Alzheimer's Disease. A Guide for the Home Caregiver.** Johns Hopkins Medicine, 2010.
- **Connecting the Dots:** Breakthroughs in communication as Alzheimer's advances. Judith London. New Harbinger Publications Inc. 2009.

Resources used in the preparation of this booklet include:

- Andrews J et al. 10 Helpful Hints for Carers. DSDC University of Stirling 2009
- Costello E et al. How to Bathe a Person With Dementia: An Evidence-Based Guide. Geriatrics & Aging 2009
- LeClerc CM et al. Geriatric Nursing 1998
- MAREP Alzheimer Resource Manual, 2000
- Rockwood and MacKnight Understanding Dementia: Part 4 Behavioral problems and conclusions. Pottersfield Press Ltd. 2001

- Sloane PD et al. Effect of Person-Centered Showering and the Towel Bath...JAGS 2004
- Barrick et al. Bathing Without a Battle. 2nd Ed. Springer Publishing Co. 2008
- www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=391
- www.RNAO.ca
- www.helpguide.org/elder/alzheimers_behavior_problems.htm
- Canada food guide: www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php
- www.alzstore.com
- www.thiscaringhome.org
- www.nbasc.ca
- www.caring.com

Appendix 1 Life Story

(Fill in the parts that are applicable.)

My name is

Most of my friends call me

I was born on in

I grew up in
and came from a family of

I met my spouse

I married on

I have children. Their names are:

I have grandchildren and great
grandchildren. Their names are:



People I regularly see or talk about include:

I would like you to know I had many interests
which included the following:

My favorite things to do in my childhood were:

My favorite things to do as an adult (include
hobbies):

My favorite types of books and music are:

This is what I like to do to relax:



My favorite things are:

I worked most of my life as:

I belonged to various groups, committees, volunteer work, that included:

My spiritual beliefs included:

Three accomplishments/successes/ achievements that I am most proud of are (consider including education, certificates, courses etc.):

I have had these pets over the years:



Other things you should know about me include: (Please consider including military service. Is your military service something you like to talk about?)



Please indicate below:

- YES, I give consent for this information to be shared with the people around me so they know more about me.
- NO, I do not give consent for this information to be shared with the people around me.

Signature of patient or substitute decision-maker:

.....

Date:

Appendix 2 Sensory Preferences

Favorite smells: examples include roses, pine, sea air, foods, soaps and perfumes, laundry detergent

Disliked smells: examples include specific foods cooking, soaps and perfumes

Favorite foods: examples include sweets, salty snacks, cold or warm (ice cream vs. oatmeal)

Disliked foods: examples include specific flavors like curry, cinnamon, fish

Favorite food textures: examples include crunchy, chewy, drinking through a straw, drinks with or without ice, milkshake thickness



I like to have something in my mouth: examples include chewing gum, peppermints, toothpick, straw of hay, cigarette

Preferred background noise: examples include favorite types of music, nature sounds, quiet, talk radio

What volume is preferred?

Favorite TV/radio shows:

Disliked background noise: examples include specific types of music, television, quiet



Room temperature preference:

What clothes are usually worn inside:

examples include t-shirt, vest, long-sleeve shirt with buttons or without, sweater, shoes, slippers

Favorite fabrics: (wool, silk, cotton, polyester, rough textures, fuzzy textures)

Disliked fabrics:

Level of personal contact: (please circle)

Enjoy holding hands or a pat on shoulder? **Yes No**

Having hair brushed? **Yes No**

Having face or hand lotion put on? **Yes No**

Massage? **Yes No**



Favorite resting position: examples include rocking in a chair, reclining in a LazyBoy, sitting in a firm chair, lying down in bed

Preferred level of activity: walking, dancing, rocking, being still, changing position

Something in the hands?

Examples include a rosary, cigarette, cell phone

Other



Night time routine:

Normal bedtime

.....

Before bed routine

.....

Pajamas/night dress/other

.....

Sheets tucked in or loose

Weight of blankets

Morning routine:

Time of waking

Time of getting out of bed

Breakfast? **Yes No**

Bathing routine:

Shower, bath, other

Preferred soaps or other products

.....

Adapted from Life History and Sensory Preference Survey,
Tracy McGrath BPE, Recreation therapist



**Use this space to outline
your emergency plan:**

Support person #1

(brother, sister, son, daughter, friend)

Name:

Phone Number:

Support person #2

Name:

Phone Number:

Taxi company

Phone Number:

Local crisis intervention
Phone number sticker

**Emergency
phone number:
911**



If you have noticed gradual changes in memory and thinking, it may be helpful to read about dementia. As time goes by you will likely have new questions. The Dementia Trilogy is a set of three booklets about dementia.



An Introduction to Dementia lists the earliest signs of dementia. It helps answer some of the more common questions like, “What is the difference between dementia and Alzheimer’s disease?”



The Dementia Compass offers some tips to help a person with dementia with their day-to-day activities. It also describes some personality changes that can be symptoms of dementia.



Later in the Dementia Journey provides helpful yet sensitive information to help focus on comfort in the later stages of dementia.

*Feedback about The Dementia Trilogy—
“Most noteworthy is the manner in which they were written: in simple language made easy to understand... the information provided has given us the power we need to face the future together.” Marie C.*