

Distressed Behaviour as Communication

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Introduction to behaviour as communication

When we refer to 'behaviours' in terms of care provision, we are almost always talking about people with dementia, and we almost always mean something negative related to why a person refuses to see things our way. If you think about that sentence, we are the ones being illogical and stubborn – expecting someone with brain damage to behave as if they don't have a condition beyond their control.

Let's begin with an attitude adjustment:

Not: The person **IS** a problem;

Rather: The person **HAS** a problem.

A word about dementia

Dementia is the progressive loss of memory, thinking skills, judgement, and verbal communication skills. It is a symptom in dozens of diseases, but the most common form is Alzheimer's disease. Related to these are vascular dementia (or multi-infarct dementia) caused by small strokes and Lewy Body disease. Many people also have a combination of these. We have used the term 'dementia' in a general way throughout this course rather than distinguishing between the many forms, because it is more important to understand the unique individual who has dementia than to understand the form of dementia the person has.

A word about older adults *without* dementia

Although this course is aimed primarily at understanding behaviours in people with dementia, you may find that the guidelines work for people *without* cognitive impairments as well. We all want to be understood, but we don't always want to explain ourselves. We are all stubborn and resistant to logic about *something*, usually something related to our fears, and with older adults, often a fear of losing a level of independence. Pay attention to the ideas that follow, keeping in mind specific people you care for and see how broadly you can apply the lessons.

Part 1: General guidelines

Understand the message

- **Behaviour is a form of communication.** It is never meaningless, even when we don't understand the message.

- **Resistant behaviour is a coping mechanism.** Violence is **NOT** a normal symptom of Alzheimer's disease. Violence in someone with Alzheimer's disease always has an external cause, and often, we're it. Violence, or at least agitation, can also be a side effect of certain medications. (Violence may be a part of certain rarer forms of dementia, but again it is usually due to lack of impulse control in upsetting situations. A history of alcoholism or psychiatric illness may also play a role.)
- Understand motivation. ***The person with Alzheimer's disease always makes sense to themselves.*** This is the single most important fact to keep in mind throughout this course. If you can figure out the *meaning* behind behaviour, you can help the person return to a state of well-being. Often this is just a matter of being a good listener. We will talk more about this a little later.

Understanding the reasons a person may not want to do as we say

When a person doesn't follow our directions, we too often describe them as 'resistant to care' or 'uncooperative', instead of realising that we would probably act the same way if we were in their shoes. **People resist when they are uncomfortable with the situation, event or people involved.**

The five big causes of discomfort to remember:

Fatigue. Do you know anyone who doesn't get crabby when overtired? When fatigued, we're also likely to find it difficult to concentrate and 'think straight'. It is literally hard work for people with dementia to follow directions and perform 'simple' tasks. They tire easily and can be exhausted by the process of dressing, for example. By the end of the day, they may not be able to do the things they could manage in the morning when they were fresher.

Frustration. When our desire to say something or do something is thwarted, the natural reaction is frustration. We're likely to lash out randomly, verbally or physically. (Have you ever hit a vending machine that didn't give you your change?) People who could once dress themselves with ease, but now can't line up their shirt buttons or tell the back of their trousers from the front, may feel both frustrated and inadequate. As their verbal abilities also deteriorate so that even expressing their frustration is difficult, it is easy to see how their discomfort could escalate. (Watch for this frustration in people with physical disabilities that interfere with their agility and mobility as well.)

Fear and Confusion. If we don't understand what's expected of us, we say we're *confused*, and we're often *afraid* of making a mistake. We tend to resist the activity any way we can. People with dementia are easily confused and/or frightened by procedures or expectations that no longer make sense to them.

This can mean anything from setting the table to taking a bath. If someone says they *won't* do something, it is often because they are afraid they *can't* do it right any more. Many experts consider fear the number one emotion felt by people with dementia. We have a huge responsibility in helping them to feel safe and capable.

Pain, discomfort and other physiological causes. When we don't feel well, we are not likely to be at our most cooperative. People with dementia are no different. We'll cover this in greater detail in the next section.

Environment, both physical and emotional. We'll be discussing this in detail a little bit later.

More on physiological causes of discomfort:

When we don't feel well, we usually aren't very cooperative. Look for all these signs of physical discomfort in the people you care for.

Effects of medication

Most older adults take multiple medications, often prescribed by multiple physicians. These medications may:

- Interact badly with each other,
- Have a variety of upsetting side effects,
- Cause an allergic reaction in some individuals,
- Have been prescribed in a dosage that doesn't work well for certain individuals taking them.

Examining a person's pills is good place to start if you are looking for sources of discomfort. Many older adults are over-medicated or under-medicated (ie taking the wrong dose), or inappropriately medicated (ie taking the wrong medication). For example, while something like Valium may have a calming effect on someone *without* dementia, it often causes agitation in those who *do* have dementia.

Another problem is that spouses may 'share' medications, as in, "Here take one of mine." There is a 'Herman' cartoon in which Herman's wife says, "You're all out of your green pills. Do you want a blue and a yellow one?" Unfortunately, too many people are willing to make convenient, but potentially dangerous, substitutions, especially when the high cost of their medication is an ongoing concern.

Among the common uncomfortable side effects of *many* medications are:

- Dizziness
- Sleepiness or sleeplessness
- Anxiety or agitation
- Loss of appetite, or increase in appetite or thirst

- Confusion or ‘fuzzy thinking’
- Upset stomach
- Frequent urination, diarrhoea or constipation

If you were dealing with any of these things, chances are you wouldn’t pay close attention to anyone’s directions either.

Impaired vision or hearing

If people don’t see well, they may misinterpret their environment. If they don’t hear well, they may not hear or understand directions. Sometimes the result is amusing. There is a line of greeting cards that features two hearing-impaired people exchanging comments. For example:

Woman 1: Valentine’s Day is one of my favourite days of the year.

Woman 2: Oh yes, on Valentine’s Day, I’d love to go out for your favourite beer.

More commonly, however, both conditions can cause people to be anxious or fearful – and understandably resistant.

Acute illnesses

Among the most common illnesses in long-term care situations – besides colds and the flu – are bladder and urinary tract infections (UTIs). Because the symptoms, at least initially, are usually less obvious to the carer, and people with dementia often can’t directly say, “I’m having trouble urinating,” UTIs may go undetected until they are severe.

Chronic illness

Chronic illnesses are often accompanied by **chronic pain**. Ask anyone who has arthritis. At least one research study has concluded that undiagnosed pain is the number one cause of agitation in people with dementia. Most pain medication is given on a PRN basis (which means the person must request it), but most people with dementia aren’t even able to say they need an aspirin for a headache, never mind ongoing medication for a bad hip. Nevertheless, you can ‘see’ pain in:

- Clenched fists or jaws
- Glazed eyes
- Tight neck and shoulders
- Arms held around the stomach
- Rubbing of a joint
- Hand held to forehead
- Withdrawal from activities
- Sensitivity to noise

Once you see it, **anticipate it**.

- If a person wakes up with stiff joints each morning, try to get a doctor to recommend ibuprofen or aspirin upon rising.
- Or perhaps you can help them ease into the day with a cup of tea or coffee before exercising the joints by getting dressed.
- Or perhaps a physical therapist can suggest some morning stretches.

Dehydration

Dehydration is extremely common and commonly overlooked. People with dementia often forget to drink and how to ask for a drink. If you put a water jug beside their bed, they rarely see it as a means of relieving thirst. Some medications cause dryness in the mouth, too. We should all have at least 48 ounces (approximately 1.5 litres) of liquid each day, and more in hot or dry conditions, which includes well-heated rooms in wintertime, but few of us get that much.

The side effects of being dehydrated include:

- Confusion and fuzzy thinking (so dementia is always aggravated by dehydration).
- Constipation (which is another source of discomfort).
- Urinary tract infections (because the urine becomes highly concentrated).

The bottom line: Provide opportunities to drink at all meals as well as between all meals. Almost no one is *over-hydrated*.

Constipation

People who are constipated are usually uncomfortable, but I have never met a person with dementia who could (or would) say, "I haven't had a bowel movement in four days."

1. Most people are embarrassed to say such things.
2. As dementia progresses, the person loses the verbal skills for such a statement.
3. People with dementia have lost the memory needed to keep track of events over the last four days.

Untreated constipation can lead to impaction, a serious condition that can also contribute to delusional behaviour. Try to prevent constipation with proper diet, hydration and exercise. Do not rely on the regular use of laxatives, as this can lead to other problems.

Depression

It is not surprising that many people, upon learning that they have Alzheimer's disease or another form of irreversible dementia, become depressed. People who are depressed are often uninterested in participating in life.

- They don't eat properly.
- They don't care about getting dressed and looking good.
- They don't have an interest in participating in activities.

- Plus, poor diet and inactivity can aggravate their dementia-like symptoms.

These things can often be reversed if they begin to get exercise and eat properly, which is important, since if we simply judge by appearances, it is easy to label someone with depression as someone with dementia. A proper and early diagnosis is always important, in part because if a person is depressed, we now have a wide range of effective anti-depressant medications to help. Don't hesitate to call the doctor on this one.

Physical discomfort

There are many ordinary signs of discomfort that can cause us to lose our concentration or our interest in participating in the activity at hand. Have you ever sat through a meeting when you desperately had to go to the bathroom? How closely were you concentrating on the topic of that meeting?

Other common causes of physical discomfort could be that the person is:

- Hungry or thirsty
- Cold or hot
- Wearing clothes that are too tight or too scratchy
- Badly positioned in their wheelchair and can't adjust themselves

Look for the logical cause and solve it.

Summary of understanding motivation, as described so far

Begin with an attitude adjustment: Not: The person IS a problem; Rather: The person HAS a problem.

- Behaviour is a form of communication. It is never meaningless, even when we don't understand the message.
- Resistant behaviour is a coping mechanism. Violence is NOT a normal Alzheimer's disease symptom. Violence in someone with Alzheimer's disease always has an external cause, and often, we're it.
- Understand motivation. The person with Alzheimer's disease always makes sense to themselves.

When the person you're caring for shows symptoms of discomfort, look first for:

- Fatigue
- Frustration
- Fear and Confusion
- Pain, discomfort and other physiological causes

Physiological causes may include:

- Effects of medication
- Impaired vision or hearing (which may cause the person to misunderstand situations/events/instructions)
- Acute illnesses
- Chronic illness, often accompanied by chronic pain
- Dehydration
- Constipation
- Depression
- Physical discomfort, ie the person is hungry, cold, hot, needs to use the bathroom

The role of physical and emotional environment on comfort

We are all affected by our environment, but many things we take for granted present problems for the frail and elderly, and those with dementia. Begin by looking for the 'too-s' in the environment:

Too large

People with dementia seem to be more comfortable in home-size rooms. Large dining rooms, all-purpose activity rooms and completely unfamiliar rooms tend to set off alarms of fear and confusion.

Too dark/too bright

Most people develop vision problems which require them to wear glasses for at least some purposes as they age.

- With age, our ability to read small print and distinguish fine details tends to deteriorate.
- Many people have problems with depth perception.
- Many are less able to distinguish among subtle shades of colour.
- Others have a compromised visual field. For example, cataracts create cloudy vision in the centre of the field and other problems decrease peripheral vision.
- Older eyes need much more time to adjust from outdoor to indoor light. Moving from outdoors to an interior hallway may cause temporary blindness, lasting for as long as 10 minutes, in which case it's important to give the person a chance to sit down until their eyes can adjust.
- People over 70 generally need two or three times more illumination than a 20-year-old would to perform a task.
- But they are also more sensitive to glare, which can actually feel painful.

People with dementia have the added challenge of trying to make sense of these vision problems with a brain that often has a damaged visual-spatial and depth-perception sense. That means that:

- A dark border on carpeting may look like a ditch or hole that must be jumped across.
- Checkerboard tiles seem to be an obstacle course.

- The shadow of vertical blinds across a floor may look like stairs.
- Busy, multi-coloured carpets may seem to have items that need to be picked up – fuzz, fruit, flowers, etc.
- Stairs carpeted with a busy flower pattern may look like a flat surface.
- A highly polished floor may look wet and slippery.
- A chair piled with clothes in a semi-darkened room may look like a scary animal.
- People may close their blinds on a sunny day because they don't know how to adjust them to remove the glare without removing the light.

Too noisy

Many people as they age also develop a hearing impairment, which means that background music, air conditioning, vacuum cleaners, and refrigerator noises can interfere with their ability to hear conversations or directions. For many, this is a cause of anxiety.

People with dementia, on the other hand, often have acute hearing and become highly sensitive to noise, especially sharp, sudden noises, such as slamming doors, clinking dishes, and intercom voices. (Intercoms can be especially disconcerting since the sound has no body to go with it; people don't expect walls to talk.) At the same time, they may also become agitated by constant noise such as background music or even too much conversation.

Too cluttered/crowded/stimulating/distracting/confusing

One of our most basic human needs is to feel safe and secure, and one of the most primitive human fears is the fear of falling. Naturally, most people will avoid entering a room – or will try to leave a room – which compromises or threatens their sense of safety.

People with dementia, particularly Alzheimer's disease, suffer losses in proprioception and their vestibular sense, which basically has to do with recognising where their bodies are in space. One result is that it is difficult for people with dementia to manoeuvre through a crowded room or make sense of a cluttered room.

- That means if the only empty chair is accessible only by passing closely among five other people, one of whom has a walking frame and two who are in wheelchairs, the person is more likely to simply turn around and walk out of the room.
- Similarly, if a craft room is set up so that the tables are covered with everything needed for an elaborate craft project, rather than just the first step of that project, people with dementia may be confused and overwhelmed and walk away.
- A room can also have too many overall distractions – background music, multiple activities, people milling about or entering and leaving, elaborate wall decorations, etc.

- Perhaps because of the damage to the parts of the brain that deal with their visual-spatial sense and proprioception, people with dementia often need more personal space. If you approach too quickly, touch the person's shoulder from behind, or stand too close, they may feel threatened. This does not mean that people with dementia do not appreciate having their hands held or being hugged, but that you must be sure they are comfortable with your presence before you attempt to touch them for any reason (including bathing, dressing, etc).

Too boring

But just as a room can be too stimulating, it can also be too boring. We all need down time, quiet time. Many people enjoy time to think their own thoughts, reminisce, mull over events, weigh various sides of a concern. But we also need *some* stimulation. If we are bored, we will look for something to do. If we, as carers, fail to provide meaningful activities for people (with or without dementia) we may not like some of their choices for relieving boredom.

Too new/unfamiliar

The need to feel safe and secure also makes people crave the old and familiar rather than the new and unfamiliar.

- Going on an outing to a new restaurant, for instance, can cause anxiety for a person with a walking frame. They must figure out how to manoeuvre to a table and to the bathroom. (What if it's too far?) And what if they've gone to all that trouble, and they don't like the food?
- When a person has dementia, even the familiar can seem unfamiliar. They may have lived in the same care home or assisted living community for three years, but in their mind, they may be 30 years old again, and nothing is as they remember it. Each day, they may feel as if they're waking up as a stranger in a strange land. (Occasionally, this can work in your favour. One woman with dementia who didn't recognise her surroundings thought her husband had finally got around to the redecorating she had been nagging him about, and was full of praise for his good taste.)
- Be aware, too, of temporary unfamiliarity you create with elaborate decorations at holiday times. This can add to the confusion of someone with dementia, especially if the decorations represent a different religious faith than their own.

Too hot/too cold

The body's ability to control its temperature seems to deteriorate with age as well. Once women have passed the stage of hot flashes in menopause, the chief problem for many people – both men and women – is staying warm.

- Many people will require a jumper even on a warm day, and you will notice that their hands and feet are much colder than other parts of their bodies.

- They are often less physically active than their carers, which means they may be uncomfortable in air-conditioned surroundings, and highly susceptible to draughts.
- They may require thermostats to be set at a higher temperature in winter.
- On the other hand, when outdoors in summer, older people are more prone to heat stroke, perhaps in part because they sweat less and may fail to drink as many liquids as they need.

Too many choices

People with dementia can be easily overwhelmed by too many choices, too.

- If you show them a calendar of the day's events, they will have more trouble deciding what to do (and may say they are happy right where they are, thank you very much) than if you say, "This afternoon there is a children's chorus coming in and there is also a reading group. Which would you prefer?"
- If you open their wardrobe and say, "What would you like to wear?", they may say they have no idea. If you show them a red jumper and a blue one, they can usually tell you their preference readily.
- If they are given a menu for lunch, you may find they can't decide, and when they do and you bring it, they may complain that they wanted what the person seated next to them is having rather than what you brought.

Too little privacy

Many of the older adults in our care lived alone for many years. They are not used to having someone they perceive as essentially a stranger present as they get dressed, bathe and go to the toilet. Many women are truly modest, while many men are embarrassed, especially if their carer is a woman. Chances are, you would feel the same in their position. Be respectful of those emotions.

It's impossible to overestimate the influence of environment. Nevertheless, the problems of environment can be overcome in large measure by creating an atmosphere of warm and loving support, and building in routines and rituals that eventually breed familiarity and comfort.

People will always stay
where they feel they belong,
ie where they are comfortable.

Summary of how environment influences behaviour

Environmental comfort is influenced by:

- Size
- Noise levels
- Lighting

- Clutter/crowding
- Real or perceived safety/security

Look for the environmental 'too-s':

- Too large
- Too loud
- Too crowded
- Too cluttered
- Too new/unfamiliar
- Too many choices
- Too many distractions
- Too little privacy
- Too little light
- Too unsafe/scary

The problems of environment can be overcome in large measure by creating an atmosphere of warm and loving support, and building in routines and rituals that eventually breed familiarity and comfort.

People will always stay where they feel they belong, ie where they are comfortable.

Other explanations for general behaviour

In addition to all the reasons mentioned above, people's behaviour may be motivated by these reasons:

Competency questioned

This refers to both the older person who questions their *own* competency and the person who feels *we* as carers are unfairly questioning their competency. A person may refuse to do something when they are afraid of failing. Thus, a woman may refuse to set the table when she no longer remembers where the utensils belong, or a man who doesn't know how to add up his golf score may say he's no longer interested in playing golf. On the other hand, the same man may also be upset if you suggest he *can't* perform a task, such as driving.

Unrealistic expectations

The opposite of questioning a person's competency is expecting too much. There may be carers who pressure a person to dress themselves because they manage well in the mornings when they are more alert and rested, or on a good day when their clothing is simplified for them. However, when that same person must put on a suit and tie for a special event that is also making them nervous, they may need help that is given subtly and graciously. Provide it.

Reality confrontation

People with dementia, because of the damage to their brain cells, eventually see themselves living in a past reality. Thus, a woman may be 90, but she sees herself as 30 (and won't recognise herself in the mirror) with young children to raise. That is 'truth' to her, and if you try to tell her that she doesn't need to worry about getting home before her children return from school because they grew up years ago, she is likely to be extremely upset and say, "Why won't you believe me?"

Lifetime personality

Face it. Some people have always been difficult to live with. Some people get overly worried and agonise about things; others are chronic complainers or easily angered. You aren't likely to change them, but you may be surprised by what consistent kindness can accomplish.

'Be yourself'
is the worst advice you can give to some people.

If the squeaky wheel gets the grease – meaning most of your time and attention – it's also important to realise that the person who is always quiet and well-mannered is easy to *neglect*. Just because they haven't asked for help in some form doesn't mean they don't need it.

Life experiences

On the other hand, some people are bad-tempered because they've had difficult lives. Some are suspicious or mistrustful of others because they have been badly mistreated by strangers or even loved ones in the past. Be sensitive to their feelings. Perhaps the classic example of insensitivity is telling a German Jewish immigrant that it's time for a shower – 'shower' was the euphemism used by Nazi authorities in concentration camps just before they gassed their prisoners to death. Who wouldn't resist?

Prejudice

Old experiences and customs may resurface as dementia progresses. In past generations, men were used to being the boss, the head of the family, and/or the unquestioned voice of authority. Women were expected to be submissive, not equal partners. The vast majority of carers of the elderly are women, and consequently, men are often resentful of carers who take over 'their' roles. ("Who made you the boss?" the man might say.)

It is generally more helpful if female carers instead tap into male chivalry by asking for their help. For instance, even if you are helping *him* get dressed, you might say, "This is a nice shirt. Could you help me by putting your arm up like this? . . . You're going to look very dapper when we're done."

On the other hand, women residents in long-term care settings can often treat carers like servants, which is difficult to be on the receiving end of. When racism is involved, it can be particularly hard to take.

The most important lesson here is not to take disparaging behaviour personally. If a resident treats you badly, chalk it up to a tragic side-effect of the disease, not a tragic flaw in the resident.

A summary of miscellaneous motivations

Most people are also motivated to some degree by the following factors:

- Questioned competency - either our doubts about them, or their doubts about themselves
- Our unrealistic expectations of them
- Our failure to join, or at least accept, their reality
- Their lifetime personality
- Their life experiences
- Their prejudices

What you can do as a carer to determine the cause of discomfort

The first step toward solving any problem is to define it. If someone you are caring for is upset, it is up to you to determine the cause. We have just gone through many potential messages that a person may be giving through their behaviour. How can you determine the *real* message?

When a person does not have dementia or is only mildly confused, **ask them directly**: “You seem upset. I’m sorry. Can you tell me what’s wrong?”

If the person no longer has the verbal skills to tell you the cause, you will need to **become a detective**. Ask yourself:

When

At exactly what point did the person’s discomfort begin? We have a tendency to think it was when the person began screaming at us, but the reality is that they probably showed signs of anxiety long before. A person who grabs the sides of a doorframe, for instance, is clearly demonstrating they are uncomfortable entering that room. A person who says, “I hate baths,” is giving us an early sign that our approach is already wrong.

Where

Where was the person when the discomfort began? If a person is grumpy at breakfast, their discomfort may have started in their room, because we failed to pay attention when they told us they were not ready to get out of bed.

Who

Who was with the person when the discomfort began?

- Sometimes a carer has a poor technique with a resident.
- Sometimes the carer reminds the resident of someone they dislike, and nothing that carer can do will ever be right in the resident's eyes.
- Sometimes a person needs a carer of the same sex and sometimes the opposite is true.
- Sometimes two carers are present when a resident would feel more comfortable (less 'managed') with only one.

What

What was happening, what was the setting? Check the environment carefully. What could possibly have been upsetting to the resident, including the behaviour of other residents or staff?

How

How did it begin? Perhaps when the carer suggested that it was bath time, the resident was only slightly resistant, saying, "Oh no, not again." Usually they were not happy about baths, but with coaxing they got through it well enough. But perhaps as the carer helped them undress, they bumped their elbow on the chair and everything went downhill from there.

Now can you answer **Why?**

The answer is probably, "Not always."

Irene Barnes, R.N. told this story (paraphrased here) in Patty Wooten's book, 'Heart, Humor and Healing':

At 4am in a dementia unit, a terrible clatter came from the end of the hallway. The carer went to the resident's room, but all was dark and still. Then the clatter came again, from the resident's bathroom. Slowly the carer opened the door, and saw a ceiling tile on the floor and the male resident standing on the sink counter, facing the wall, with his hands in the air. "Here," he said, "Help me get the straw out of the loft for the cows."

If he hadn't been able to verbalise that request, would we have understood what he was trying to do and seen the good sense it made based on his earlier life?

There is no substitute for knowing your resident well.

Summary of how to determine motivation

Whenever possible, ask directly: "You seem upset. I'm sorry. Can you tell me what's wrong?"

If the person cannot verbalise the cause of their discomfort, become a detective. Look at who, what, where, when and how to determine why.

Know the person well.

When you understand the message, you can change the behaviour

But first ask: Is it really important to change the behaviour?

- Is the behaviour causing discomfort to the person exhibiting it?
- Is the behaviour causing discomfort to others, besides me?
- **Can I just let it be?**

Some behaviours are irritating to us, but self-comforting (or at least harmless) to the person exhibiting them. Consider:

- *So what if she insists on putting her shoes in the laundry basket? Now I know where they are.*
- *So what if he wants to wear his baseball cap to bed? He sleeps well with it on.*
- *So what if he's asked the same question 16 times in 20 minutes? He doesn't know that.*

Ask instead, 'Can I let it be?'

If the behaviour *is* important to change, there are three key guidelines:

Three rules for handling a person's discomfort

Many, many causes of discomfort in the people we care for can be overcome by creating an atmosphere of warm and loving support, which means basically three things:

- 1) **Affirm the person's feelings.** This is often more important than actually solving the problem. *"I know this is frustrating for you. . . . I'm so sorry you're in pain . . . You must be tired now."* We all want to be understood and we all want to have our feelings recognised as being valid. Feelings almost always overrule logic in any disagreement. If you rationally try to explain to me why I am no longer a safe driver, I will never see your point of view until you recognise how devastating to my independence giving up driving is going to be. (The line from the old 50s song 'It's My Party' applies here: *'You would cry too, if it happened to you.'*)
- 2) **Solve the problem at hand, whenever possible.** As described previously, that may simply mean stopping what you are doing, or it may require specific action, such as providing food and drink, taking the person to the bathroom, or giving them a jumper.
- 3) **Look for positive ways to engage the person.** Distraction and relocation are often key, and again that means: **know your residents well.** Be able to answer the following questions about each resident:
 - Who are the people s/he likes best?

- Where does s/he most like to be?
- What are his/her five favourite foods, songs, clothes, memories, activities?
- What are three things s/he invariably finds calming and soothing?
- What are five things that are guaranteed to make him/her laugh or smile?

Use those things to find means of creative distractions. You can distract someone with:

- Your voice
- Your body
- Your direction
- Refreshments
- Props (anything that amuses, surprises or arouses curiosity)

When it's too late to practice preventive interventions, plan ahead for next time. Ask:

What might have diffused the situation?

Assuming we can identify why a resident is upset, what might we have done differently? This is the million-dollar question.

Many times, the answer is to back off. In the example of the person who became increasingly uncomfortable with bathing, the best solution might have been to forget the bath for now and have their elbow checked.

Nevertheless, brainstorm with your co-workers and ask:

'What else *could* I have done?'
Then look for all the possible right answers.

Don't waste time berating yourself for what you *should* have done. In any given situation in life there are almost always multiple solutions to problems, multiple choices we can make. Sometimes we have to try several roads before we reach the destination we want. The key is to know when to turn around and try something new. Or as Dennis Healy said, "**Follow the rule of holes; when you're in one, stop digging.**"

At the same time, don't be too quick to discard ideas that may seem 'off the wall'. **Sometimes unusual things work.**

But if a solution works today, don't count on it working tomorrow. And the opposite is also true: **just because something *didn't* work today, doesn't mean it *won't* work tomorrow.**

Experiment. When one thing doesn't work, look for another potential right answer. Persevere.

Guidelines for controlling your own behavioural messages

To be an effective carer you must:

- Recognise how your behaviour (including body language and tone of voice) influences the person you're caring for.
- Be flexible.
- Practice 'compagination' – Robert Fulghum's word for compassion mixed with imagination.
- Keep your sense of humour.

If you get it wrong now and then, don't be too hard on yourself. Give yourself credit for trying.

The toughest kind of mountain climbing
is getting out of a rut.

Summary of general problem-solving guidelines

The first thing is to ask yourself, "Is it really important to change the behaviour? Can I just let it be?"

If the behaviour *is* important to change, there are three essential guidelines:

- 1) Affirm the person's feelings; show empathy.
- 2) Solve the problem directly, if possible.
- 3) Look for positive ways to engage the person.

The key to engaging someone is to know them well. You should be able to answer these questions:

- Who are the people s/he likes best?
- Where does s/he most like to be?
- What are his/her favourite foods, songs, clothes, memories, activities?
- What are three things s/he invariably finds calming and soothing?
- What are five things that are guaranteed to make him/her laugh or smile, or feel loved and nurtured?

Use that information to find creative means of engagement or distraction. Try using:

- Your voice
- Your body

- Your direction
- Refreshments
- Props

Avoid berating yourself with 'shoulds', but for future reference, try to think of all the things you could have done to diffuse the situation.

- Back off. Follow the rule of holes: When you are in one, stop digging.
- Look for *all* the possible right answers, however unusual they may seem.
- Recognise that what *did* work today, may not work tomorrow, and what didn't work today *may* work tomorrow.
- Experiment. Persevere.

Effective carers:

- Recognise how their behaviour (including body language and tone of voice) influences the person they're caring for.
- Are flexible.
- Practice compassion mixed with imagination.
- Keep their sense of humour.

If you blow it now and then, don't be too hard on yourself. Give yourself credit for trying. The toughest kind of mountain climbing is getting out of a rut.

Part 2: Specific Behaviours

In Part 1, we talked a lot about general messages behind general behaviours. In this section we will be talking about typical messages behind *specific* behaviours. In the past, we often called these 'difficult behaviours' or 'challenging behaviours' and we gave them negative names like 'wandering' and 'hoarding'. However, if you keep in mind that the person with dementia always makes sense to themselves, these behaviours all have logical causes and almost never have a negative intent.

Let's begin by discussing mobility.

Walking about and/or wanting to go home

It is ironic that we do our best to keep many frail older adults mobile because exercise is good for them, but we often complain about the active mobility of people with dementia, when *their* walking about is good for them, too – just harder for us to keep up with sometimes.

We no longer use the word 'wandering' because it implies a purposelessness, when in reality, most people with dementia simply aren't able to verbalise their purpose, or they forget what they started out to do somewhere along the

journey. Do not be critical of them unless you have never stood in front of an open fridge wondering what on earth you opened the door for.

Here then, is a summary of some of the logical reasons people get up and walk about. They may be:

- Looking for the bathroom
- Looking for food or drink
- In pain, looking for relief
- Uncomfortable and need to stretch their legs
- Restless – a side effect of their medication
- Searching for familiar faces (friends and relatives who may or may not be living)
- Trying to escape the noise, tension or commotion of another person/room
- Too hot or too cold
- Trying to escape a task/activity perceived as too difficult
- Bored or feeling useless
- Tired, looking for a bed to lie down on
- Acting on old routine such as leaving work for home (men tend to walk to work out problems or frustration; women generally walk because of perceived obligations)
- Seeking fresh air, which may be triggered by outdoor clothing or a view

Walking, especially outdoors, is not only good for the body, but often also good for the soul. It is a 'mindless' exercise in that, except for those who are disabled, it takes little concentration. Indeed, walking is used by many as a means of clearing the mind from the congestion of the day or working through problems. We can walk with one another, enjoying the other's presence and still remain silent thinking our own thoughts.

Three types of walkers who DO pose risks

There are three types of walkers, however, who *do* pose a challenge for careful carers.

1) The person on a mission. These are almost always people with moderate dementia who are living in a past reality, such as the woman who sees herself as a young mother who must be home when her children return from school, or the gentleman who believes he is a young man who must get to work on time. People on a mission are determined to leave the building because they feel the weight of responsibilities, and they need to be talked out of their panic.

Two things are vital to keep in mind here:

- a) **There are no easy answers.** You may have to do a lot of experimenting and brainstorming to find a solution. Sometimes no good solution is ever found, but eventually the 'Man (or Woman) on a Mission' phase passes.

- b) **You must join their reality.** You will never convince the woman that her children are grown, or the man that he is retired. In fact, this is a good time to point out one of the primary rules: **You will never win an argument with someone who has dementia.** The ‘truth’ is whatever that person perceives it to be. Instead, you must find a way to make that person comfortable. Once again, that comes from knowing the person well and asking questions as needed to find out more about what he or she is troubled by. **Always show empathy and affirm his or her feelings.**
- Some people have tried diverting the woman by *asking* about her children, especially about the mischief her son Jack has got into lately. (But if she says angrily, “I haven’t got time to talk; I need to get home!”, just apologise and back off.)
 - Others have diverted the man who believes he has to go to work by simply removing the obligation – it’s Saturday, it’s the weekend, you’re on holiday today, the boss gave you the day off, or anything that will ring true for that person.
 - Sometimes you have to let a person ‘do their own thing’ before you can divert them. You may be able to let a person leave home or your residence while being closely watched. Usually the person will walk only a short distance before feeling lost and uncertain where they are. A staff member may catch up with them, start a conversation and gently lead them back. Or a woman determined to go to work can sit for a while at a ‘bus stop’ (park bench) before a staff member comes out to say, “We just called the bus company and found the buses are running late today. How about coming in for a cup of coffee before you go back to waiting?”
 - Knowing the real problem is essential. The wife of one man who kept wanting to visit his deceased mother ‘down the road’, found she could divert him by saying, “Your mother’s doing fine. I just talked to her a little while ago on the phone. She asked about you and I told her you were fine, too.” That was all he wanted – reassurance that his mother was fine; the relationship was fine.

Remember these are not perfect answers, but ideas others have tried, sometimes with success. We hope they inspire you to come up with your own creative solutions.

2) The frequent faller. This is the person determined to remain mobile by walking, but who is a safety risk because they have a history of falling. It’s a matter of managing risk; a serious moral dilemma that needs to be discussed with the person at risk (as much as it’s possible to do so, if they have dementia), the family, doctor, support person such as a physical therapist, and care staff. Here are some things which *may* decrease the risk:

- To decrease restlessness, make sure s/he is accompanied on exercise walks at least twice a day.

- Have a physical therapist work with the person to help him/her become accustomed to hand rails, a walking frame or other mobility aids. Be patient in helping the person to develop the habit of using them.
- Find alternatives for any medications that interfere with balance and perception or that cause dizziness and vision problems.
- Add cushioning to his/her clothing (elbow, knee and wrist pads, a helmet, long sleeves, long trousers, even padding on their bottom).
- Increase illumination in hallways, bathrooms and dining rooms, and provide visual cues about their location.
- As much as possible, remove obstacles that are likely to cause tripping (loose rugs, low tables, things stored in hallways).
- Be sure rooms they use are uncrowded, easy to manoeuvre.
- Make sure two people are there to help with difficult manoeuvres such as bathing and going to the toilet. Make sure s/he is accompanied as needed to the bathroom.
- If s/he is likely to fall out of bed, substitute a lower bed or put the mattress on the floor.

3) The pacer. Pacers are the people who seem to need to walk constantly. They must be dressed on the run, fed on the run and groomed on the run. They represent a small percentage of people with dementia, and the cause of their need to pace is so far poorly understood. They present challenges – how to get the extra calories in them to make up for those lost by constant movement, how to bathe and dress them, how to get them to bed at night – but their behaviour is more irritating than harmful, as far as we know now. (Much study remains to be done.) Some people *have* been successful in finding another absorbing, repetitive (but sedentary) activity with which to distract individual pacers. Again, knowing your resident well may help you find the key to a pleasurable alternative for him/her.

Wanting to go home

Some people, either while seated, or as they walk about, say, “I want to go home.” Remember that as people’s vocabulary diminishes, they tend to use one word or phrase to cover a multitude of meanings. Thus ‘mother’ may refer to anyone close to the person with dementia, including daughters, sisters and friends. **People who want to ‘go home’** are:

- Saying they feel unsafe, insecure
- Looking for comfort, warmth, love and a place where they feel they belong
- Often also giving a simple message such as ‘I’m hungry’, ‘I’m tired’, or ‘I have to go to the bathroom’, because home is where most *prefer* to eat, sleep and use the bathroom.

Pay attention and help them find the comfort or solution they need.

Summary of walking about and wanting to go home

Logical explanations for behaviour:

- Looking for the bathroom
- Looking for food or drink
- In pain, looking for relief
- Uncomfortable; needs to stretch legs
- Restlessness as a side effect of medication
- Searching for familiar faces (friends and relatives who may or may not be living)
- Trying to escape the noise, tension or commotion of another person/room
- Too hot or too cold
- Trying to escape a task/activity perceived as too difficult
- Bored or feeling useless
- Tired, looking for a bed to lie down on
- Acting on old routine such as leaving home for work
- Walking helps 'clear the mind'
- Seeking fresh air

A few strategies*:

People on a mission

- Let them go
- Distract them
- Talk them out of panic

Frequent fallers

- Make sure they are accompanied on regular exercise walks.
- Help the person become accustomed to mobility aids and handrails.
- Find alternatives for any medications that interfere with balance and perception or that cause dizziness and vision problems.
- Dress them in long sleeves and trousers, elbow, knee, wrist pads, helmets.
- Increase illumination in hallways, bathrooms and dining rooms, and provide visual cues about their location.
- As much as possible, remove obstacles that are likely to cause tripping (loose rugs, low tables, things stored in hallways).
- Be sure rooms they use are uncrowded, easy to manoeuvre.
- Make sure two people are there to help with difficult manoeuvres such as bathing and going to the toilet.
- If they are likely to fall out of bed, substitute a lower bed or put the mattress on the floor.

Pacers

- Learn to dress and feed them on the run.
- Make up for lost calories.
- Look for other engaging activities.

A person who wants to leave is telling us they feel:

- Insecure, unsafe, out of place
- A need for comfort, love, a sense of belonging
- Uncomfortable (which may be a simple physical discomfort caused by needing a jumper or needing to use the bathroom).

*All strategies are based on the idea that you have already affirmed the person's feelings, tried to solve the problem and provided a pleasant distraction.

Afternoon fatigue

Banish the word 'sundowning' from your vocabulary, too. 'Sundowning' is another awful word used unfairly in association with people who have dementia as if it is a bizarre behaviour characteristic of their condition. We *all* 'sundown'. Essentially it means that we tend to get tired as the day wears on and we're sensitive to changes in the atmosphere later in the day – and may be restless or crabby as a result.

People with dementia are typically most alert in the morning after they've had a good night's sleep. By afternoon they've used up their energy resources in getting dressed, groomed and maybe bathed, eating a couple of meals, and participating in an exercise programme or other group events. They are tired, and rightfully so. We (with the exception of night owls who just begin to wake up after 5pm) tend to be tired too by mid-afternoon, and we are not contending with a disease which is destroying our brain cells.

You will notice that people with dementia tend to become restless either because of what is happening in the routine of the residence (eg shift change) or what usually happened at that time of day in the earlier part of their lives (eg their children returned from school, their husbands came home from work, they began preparing dinner etc).

- Some people can be helped through this period of the day by being given a chance for a nap. (As dementia progresses, most people need an increasing amount of rest, and may require both morning and afternoon naps.)
- Some people are helped by a calming activity, such as a cup of herbal tea, a meditative/spiritual service, or a chance to sit on a garden swing seat.
- Other people are comforted by becoming involved in something related to their former routine, such as making dinner by cutting up vegetables for soup or fruit for a salad, or reading to visiting nursery school children.

We'll say it again: There is no substitute for knowing the person well so that you will know what is likely to work.

Summary of afternoon fatigue

Like all of us, people with dementia often become tired, restless or both, sometime between mid-afternoon and early evening.

Restlessness is usually triggered either by the routine of where they are (eg shift change) or what usually happened at that time of day in the earlier part of their lives (eg their children returned from school, their husbands came home from work). You can help them through this period by trying the following:

- Give them a chance for a nap.
- Provide a calming activity.
- Involve them in an activity related to their former routine.

If you know the person well, your chance of success is increased.

Sleep disturbances

Sleep disturbances are often caused by the physiological changes to the brain in older people. Older people:

- Get less deep sleep
- Have to urinate during the night more often
- Have a hard time staying warm throughout the night, and
- Have more periods of wakefulness which may be prompted in part by stiff joints.

Thus, many of the causes of sleep disturbances are the same as the causes for walking about and wanting to go home.

- Looking for the bathroom. (Take them.)
- Looking for food or drink. (Try herbal teas.)
- In pain, looking for relief. (Try aspirin or ibuprofen.)
- Uncomfortable; need to stretch legs. (Walk a bit.)
- Restlessness as a side effect of medication. (Change medication.)
- Searching for familiar faces which may mean friends and relatives who may or may not be living. (Try using large photographs, tape recorded messages from loved ones (when possible), or items of clothing such as a jumper from that loved one.)
- Trying to escape the noise, tension or commotion of another person/room. This could include the disruption caused by staff making rounds, changing incontinence products, etc. (Be sensitive!)
- Too hot or too cold. (Easily adjusted, but may switch several times during the night.)

On the other hand, there are a number of other miscellaneous potential causes of sleeplessness or sleep disturbances. Perhaps the person:

- Is a night-owl; always has been, always will be
- Used to work the late shift; is reverting to old patterns
- Had too much caffeine or alcohol during the day or evening
- Had too little exercise during the day; isn't tired

- Had too much exercise and is overtired
- Had too much stimulation during the day and is still wired
- Had a bad dream and can't separate nightmare from reality (or is still upset by violence on the TV news which also is too real)
- Is upset by other evening routines (prefers bath at night, likes to go to bed with a book; preferences aren't honoured)
- Is seeing scary shadows caused by poor lighting
- Wakes up and thinks it must be time to get up (this belief is often triggered by seeing the clothes which were laid out for them the night before in order to facilitate morning dressing)
- Is unaccustomed to sleeping alone, misses warmth of spouse
- Misses their favourite pillow, pyjamas, blanket, quilt . . .

It must also be said that many people with Alzheimer's disease, for reasons that are not well understood, go through a period when their circadian rhythm is reversed, and they are more alert at night than during the day. This eventually passes, but often it is this middle-of-the-night restlessness that prompts family members to seek residential care for the person.

If you know the person well, you will know how to provide a balanced amount of stimulation during the day and how to meet their needs for a pleasant evening routine. Recognise, however, that evening routine does not begin with tucking the person into bed and saying, "Don't let the bed bugs bite," but with everything that happens from mid-afternoon onwards, including a relaxing and not too filling dinner, so that food can be digested before bed.

Honour preferences for evening routines. For people who used to retire to bed with a smile on their face because of their favourite evening TV shows or comedies; purchase the videos, or find them online, and let the routine continue. (Avoid violent programmes and upsetting news programmes.) Many people will have enjoyed reading in bed or in a cosy armchair – the evening newspaper, a good book, or an inspirational text. If they are no longer able to read, they might enjoy being read to.

Also honour bedtime rituals whatever they may be.

- Does he want to check that the front door is locked?
- Does she wash only her hands and face at bedtime, or take a full bath?
- Does he like a bedtime snack of a biscuit and warm milk to keep from waking up hungry in the middle of the night?
- Does she brush her teeth and then urinate or vice versa?
- Does he like to fall asleep with the radio playing (or earphones) and a night light or does he like to read himself to sleep, keeping a bedside light on?
- What's her favourite form of sleepwear – flannel pyjamas or a silky nightgown?

- Is he warm enough? Does he need an extra blanket or socks on his feet? (Many restless people are eased into sleep by the simple act of putting socks on their feet, because cold feet are not conducive to deep sleep.)
- How does she like her covers arranged – tucked in or out? How many pillows does she need? Does she have a preferred body position that will help her sleep comfortably?
- What else comforts her – a picture of her husband on the nightstand? A goodnight hug or kiss from staff? A rosary or prayer book or prayers recited aloud? A favourite hat, a teddy bear, blanket, pillow? Would she sleep better beside a body pillow which helps simulate the shape of her husband who was her bedside companion for 50 years? Does she need a foot or back rub?

In a long-term care setting, a person who stays up late or gets up during the middle of the night should be able to be accommodated by staff. A game of checkers may be good for both of you. If a lady was once a nightshift nurse, giving her a clipboard and some pretend charts may satisfy her need to ‘work’.

Look for creative solutions. Here are a few more ideas:

- If the person is having nightmares, don’t turn on the evening news before bed, and consider what diet changes might help.
- Look for the obvious. Does their neighbour keep them awake with loud snoring?
- Also look for patterns. Does the person always wake at about midnight? Perhaps like most of us, their body temperature changes during the night and they need an extra blanket. Try putting that blanket over them every night at 11.45pm and see if that makes a difference.
- Some people may need help using the bathroom during the night. Again, the need to urinate usually follows patterns – every night at 2am, for example – and can be anticipated. At the same time, however, avoid waking the person unnecessarily to change incontinence products or give the person medicine etc. (In institutional settings, sometimes state regulations create conflict here, but regulators can be educated.) Remember the primary goal is the person’s comfort.
- Go with the flow. Some people are more comfortable sleeping in a recliner than on their beds. In institutional settings, they sometimes feel safer curling up on a sofa near the carers’ station than in their lonely bedrooms. Be flexible.
- Be innovative. Some carers set the tone for bedtime by playing tape recordings of lullabies or crickets chirping, or they sit outside watching the sunset with the restless person. Some people have had success putting herbal pillows which have been heated in the microwave (and stay warm for up to an hour) under the neck and shoulders of the person to induce relaxation that leads to sleep.

Summary of sleep disturbances

Logical explanations for behaviour:

- Looking for the bathroom
- Looking for food or drink
- In pain, looking for relief
- Uncomfortable; needs to stretch legs
- Restlessness as a side effect of medication
- Searching for familiar faces (friends and relatives who may or may not be living)
- Trying to escape the noise, tension or commotion of another person/room
- Too hot or too cold
- Person is a night owl; always has been, always will be
- Used to work late shift; is reverting to old patterns
- Had too much caffeine or alcohol before bed or has indigestion/heartburn
- Had too little exercise during the day; isn't tired
- Had too much exercise; is overtired
- Had too much stimulation during the day and is still wired
- Had a bad dream; can't separate nightmare from reality
- Is upset by evening routines which don't follow past preferences/habits
- Is unaccustomed to sleeping alone or out of familiar surroundings
- Awakens and thinks it's time to get up (especially if clothes are laid out for next day)

A few strategies for sleep disturbances:

- Be sure lighting is adequate to dissipate fears, and lessen likelihood of hallucinations.
- Check medications for side effects which contribute to restlessness, hallucinations or bad dreams.
- Provide a comforting snack – warm milk and a biscuit?
- Provide person with favourite pyjamas, pillow, blanket, other comforting items.
- Eliminate or lower caffeine intake.
- Be sure person has adequate daytime exercise.
- Adjust thermostat or clothing/bedding.
- Be sure person has calm evening with comforting routines.
- Provide an enjoyable activity to keep person occupied.
- Don't set out next day's clothes where person can see them.
- Avoid disturbing person during night unnecessarily.
- Be flexible. If the person sleeps better in a recliner, let them.

Gathering, shopping, and rearranging

This is another category of behaviours that was once referred to in negative terms such as 'hoarding', 'rummaging' and worse. Please use the new terminology.

Although there are a lot of similarities among these behaviours, they are usually prompted by varying motives. Let's look at them one at a time:

Gatherers

Logical explanations for **gathering** behaviour most often fall into two categories:

- Saving for a 'rainy day'. (Fears loss, doesn't want to be hungry, cold, poor.)
- Trying to keep object safe. (Often what is hidden is money, jewellery, food.)

Many of today's elderly were strongly influenced by the Great Depression of the 1930s when work was scarce and many people did not have adequate food or clothing or even warm shelter. Others knew deprivation and rationing in war. Morris Massey, author of 'The People Puzzle', said that we are more influenced as children (and may continue to be as adults) by what we did *without* than by what we had. Thus, if we grew up in poverty, financial security is likely to be very important to us. (If we grew up with wealth, we may also value financial security, but are more likely to take it for granted, ie assume it will continue to be part of our lives.) Many of today's elderly are great savers, and consider wasting anything a sin. At home they may save magazines, newspapers, string, glass jars and innumerable other items we might consider useless, but they consider 'future usables'.

This gathering pattern may continue when they move into a residential care setting either because it's a well-established pattern or because they are trying to make up for the loss of everything they couldn't bring with them when they 'downsized' to their new location.

At other times people gather items to 'keep them safe'. People with memory loss are particularly prone to having frightening episodes when something treasured is lost – either because the person forgot where they put it or because it was carelessly discarded. (A set of dentures wrapped in a paper napkin can easily be tossed out inadvertently.) Often the person is determined never to let it happen again, but because they cannot count on their brain to help them remember where they put something, they gather many and put them everywhere. Coins and chocolate bars may be hidden in every drawer throughout the house. Handbags are weighted down with napkins, sugar packets and even cutlery.

A word about women's handbags

One reason so many women in residential care homes are mistaken for visitors rather than residents is that many of them carry their handbags with them everywhere they go. Men continue to feel in control of their lives if they can have keys and change in their front pockets and a wallet in the back pocket, but for

many women, especially those with dementia, their handbag becomes their whole identity. Francis Zeger, a family carer, described the contents of his mother's handbag which "was her world."

- The rosary was her church
- A photo was her family
- A house key was her home (which had been sold)
- Her driver's license represented her car (also sold)
- Her chequebook was her bank (account closed)
- Two small flags were her country
- Plasters and a nail file were her medicine cabinet.

She didn't have much she could truly call hers anymore, and her handbag symbolised virtually all of it. When a woman hoards cutlery in her handbag, it may need to be taken out now and again to be washed, but don't be hasty in trying to persuade women to clean out their handbags. For many women, it represents everything they value.

It's also important to help people overcome or, if possible, prevent their fears of loss.

- Truly valuable items should not be left in the care of someone with brain damage. Get a safety deposit box for valuables or store them with a trusted family member.
- Develop a routine for the storage of glasses, dentures and hearing aids. Again, the carer should assume ultimate responsibility, but be sensitive to the person's desires. If she wants her hearing aid kept in a jewellery box under the bed at night, that's fine.
- Never throw a paper napkin in the rubbish or a cloth one in the laundry without checking it for valuables. Sift through rubbish bins regularly too, especially those in resident's rooms.
- If keeping a key is important to the person, make sure it is attached to a colourful, oversized key ring that is hard to misplace.
- Keep rooms neat. Items are harder to find in clutter.
- Pay attention to hiding places, so you know the likely places to look when an item is lost.

Rearrangers

People who **rearrange**, on the other hand, are usually:

- Looking for their own things.
- Looking for something that is 'missing' (which may be anything familiar or reassuring).

In the early stages of dementia, people who spend time going through cupboards and drawers – their own or someone else's – are looking for their own things. Sometimes they don't realise they are rearranging in someone else's room. Sometimes they can't find what they want in their own room, so they start looking in other people's rooms. ("If it's not here, it must be there.") In the early

stages, they may indeed be looking for a specific item, although they may forget what it is halfway through the search.

Later, they may simply be searching for something that they recognise or that brings comfort in some way. Many people have suggested that the person whose memory is fading is looking for their lost self, their disappearing identity. Occasionally when questioned, someone will even say, "I'm looking for myself." It's hard to know how common this might be, but most people who rearrange are expressing discomfort.

Shoppers

There are exceptions, however. Most often the exceptions are **shoppers**.

Shoppers tend to:

- Be looking for interesting things, and may no longer have a sense of impropriety in taking someone else's things.
- Believe an item is misplaced; they will take it and put it 'where it belongs'.

In the early stages of dementia, a person still retains clarity over what belongs to them and what doesn't. In the later stages, brain damage may cause them to lose their inhibitions and they may have no compunction about confiscating anything that appeals to them. However, it may not be related so much to morality as to a distorted reality. As dementia progresses, the person tends to be living in a past reality, and even if they are living in a residential care community, they see themselves as being 'at home'. In our homes, *everything* belongs to us, so everything we pick up is 'ours'. At other times, people will simply have a sense that an item belongs somewhere else and move it (sometimes to their handbag).

In addition, some people have always enjoyed shopping. It's important to give them opportunities to continue this pursuit, either through items that are actually for sale in a residents' shop or gift shop, or in a 'free zone'. Many nursing homes and assisted living communities, for instance, have set up dressing tables where women can try on and take with them whatever gloves, scarves, hats, or jewellery they find appealing.

Sometimes their sense of where things belong is job-related. A man who spent most of his work life as a car parts dealer was used to going into small drawers and retrieving items for customers – a practice he continued after moving into a care home. When given his own chest of small drawers, he stayed in his own room, spending many contented hours rearranging his socks and the other contents of the drawers.

Similarly, a woman who had been an assistant for many years in a women's dress shop was used to refolding jumpers on shelves and straightening out clothes on hangers. She was given a chance to help (on a limited basis) with preparing laundry for delivery back to the residents' rooms.

There are a number of ways to prevent people from entering areas where they cannot shop.

- Locks or child-safety latches work on cupboards, drawers and doors.
- Some residents are provided with their own room keys to keep unwanted visitors out.
- Some homes have experimented with stable-style doors, where the bottom half is kept closed.
- Others have stretched ribbons with Velcro ends across the middle of door frames (aiming for the same effect as police tape to keep people out).
- Another clever idea is to use theatre-style velvet ropes hooked across the doorway, as is done not only before theatre doors open, but across the doorways of rooms in historical homes where visitors are not welcome to walk.

Returning items

When someone does get into another resident's room and takes something which doesn't belong to them, the only way you are likely to get them to give it up easily is to give them something else to hold, preferably something else they value.

Let's say Mrs Jones is carrying Mrs Smith's floral paperweight. The savvy carer will say, "Oh, Mrs Jones! You're just the person I want to see. Would you mind helping me get some things down from these shelves?" The carer begins lifting some decorative items from the shelves and handing them to Mrs Jones. Soon Mrs Jones must put down Mrs Smith's paperweight in order to take the items from the carer. The carer begins to talk to her about the items she's handed to Mrs Jones. "Aren't these silk flowers beautiful? Do you like the blue or the yellow ones better?" Mrs Jones now has a suitable alternative to Mrs Smith's paperweight, and the carer can return it to the room before it's even discovered missing. If you don't have another decorative item to substitute, try a watering can and ask her to help water plants or give her a plate of biscuits to hold – anything that will divert her attention.

The problem is more complicated, of course, if Mrs Jones is wearing Mrs Smith's jumper and Mrs Smith sees her in it and lets the world know. "She's wearing *my* jumper! Take it off! That's mine!" Chances are, Mrs Jones is just going to pull it more tightly around herself. That's when it's key to recognise that the problem belongs to Mrs Smith, not Mrs Jones. Mrs Jones is perfectly content wearing Mrs Smith's jumper. Mrs Smith is the one who is upset and needs our attention.

- 1) First, it's important to acknowledge the problem and affirm Mrs Smith's feelings. "That certainly looks like your red jumper, Mrs Smith. I know your red jumper is one of your favourites, and you have wonderful taste in clothes. It must be upsetting to see someone else apparently wearing your clothes."
- 2) Second, we must try to solve the problem. If Mrs Smith does not have dementia herself, she can be reasoned with. Let her know that you will find a

way of removing the jumper from Mrs Jones without upsetting her so that the jumper doesn't get damaged, and that you will take steps to keep Mrs Jones away from her clothing. (We are assuming, of course, that Mrs Jones *does* have dementia or she would not be likely to have taken Mrs Smith's jumper.) But if Mrs Smith also has dementia, she may not be easy to reason with. When you have affirmed her feelings, find out if she is cold now and needs a jumper herself. If she does, try to cover her instead with an especially soft blanket or quilt that will make her feel cosier and more pampered than any jumper would. Offer her a cup of tea or hot chocolate to warm her insides, too. Indulge her for a bit. When she has calmed down, you can turn your attention to getting the jumper off Mrs Jones.

- 3) You will only succeed in removing the jumper from Mrs Jones if you take her into a steam bath or other exceedingly warm place where she is more comfortable without it, or if you offer her an even more appealing alternative. Maybe she can be wrapped in a wonderfully soft blanket or quilt like the one you have offered to Mrs Smith (but she needs to take off her jumper to feel the really luxury of it), or maybe someone has donated a fur coat for just such a diversion as this, and again, she won't be able to appreciate the great feel of the satin lining if she doesn't take off the jumper. And sometimes it's easier than that. Sometimes Mrs Jones will put on someone else's red jumper because she can't find her own. If you find it for her, she'll gladly make the switch because she likes hers better anyway.

As in all else, the key is to experiment. Keep looking for more right answers.

Summary on gathering, shopping and rearranging

Logical explanations for 'gathering':

- 'Rainy day' syndrome; fears loss or doing without.
- Trying to keep object 'safe'.

Logical explanations for 'shopping':

- Likes to shop.
- Looking for interesting things (no longer has a sense of items belonging to others).

Logical explanations for 'rearranging':

- Looking for own things.
- Looking for something that is missing (may be anything familiar or reassuring).
- Belief that an item is misplaced; person will take it and put it 'where it belongs'.

A few strategies for gathering, shopping and rearranging:

- Pay attention to hiding places so that objects can be found when needed.

- Attach large or bright identifiers to objects to make them easier to find (large key ring, for instance).
- Take away valuables such as precious jewellery to avoid risk of their loss; promise to be responsible yourself for the safekeeping of such items as dentures and hearing aids.
- Keep rooms neat – items are harder to find in clutter.
- Create safe, acceptable areas to shop, gather and rearrange.
- Always check contents of rubbish bins before throwing away.

Paranoia, hallucinations, and delusions

Paranoia/suspiciousness

Many people with dementia have feelings of paranoia (believing others intend to harm them) and suspiciousness. This is logical when you know something is terribly wrong and you don't know how to fix it.

Here are some of the other reasons for such behaviour:

- **Blaming someone else removes the blame from the person who knows something is wrong, but doesn't understand what,** and may be terrified that they are losing their mind. If I can't find my money, it is much less frightening to think someone stole it – bad as that also is – than to think it's my own fault. If I can't remember what's happened to it, I must be crazy. *Please, don't let me be crazy.*
- **Based on loss/grief.** If the person is missing their dog who died years ago – or was given away before they moved into the care home – they may say someone stole it, because they can't imagine and don't remember what else could have happened.
- **Their environment doesn't make sense; they fear for their own safety/comfort.** If I wake up every morning, and because of brain damage, don't know where I am, I'm going to be very suspicious of everything that happens. *Who are these people who are trying to take my clothes off? What is this they are feeding me here? I'm cold; why don't they understand that?*
- **Fear of abandonment,** especially by spouse or other loved ones. If I don't understand what's happening around me – if my world is no longer making sense – and the only person I can count on is my spouse, I may fear that they will leave me too, or that they already have. *Maybe that woman who comes in each day to dress me has stolen my husband's heart! I am going to be left all alone, and I'm very scared!*

It is not unusual for people with other disabilities who are dependent on carers to have similar fears which lead to suspiciousness, particularly if they have known other hardships in their lives.

How you can help?

Helping people through these feelings requires patience, and an understanding that paranoia and suspiciousness usually disappear as dementia progresses – particularly if you provide a safe and nurturing environment. As with all other behaviours, it's important to affirm the feelings, solve the problem, if possible, and engage the person in another interesting activity.

Here are a few suggestions for some specific situations:

The person who thinks their money has been stolen

- Affirm that it must be frightening to feel you've lost control of your money.
- Then help the person to look for the purse or wallet by saying, "Let's work on this together. I'm sure if we put our heads together, we can find it."
- Ignore any suggestion that you 'stole' the money and simply concentrate on finding it.
- If you know the person well, chances are you know their hiding places, and can find it relatively easily.
- To keep it from happening in the future, tag it in some way. Put the money in a large, difficult-to-hide piggy bank. Put a large red ribbon on the purse to make it more eye-catching.
- If the person is in a long-term care setting, valuable items should be left with trusted relatives, and staff should assume ultimate responsibility for the things which must stay with the person, such as glasses, hearing aids and dentures.
- You may be able to provide duplicates of some easily misplaced items, such as costume jewellery.

Paranoia related to loss

- Look for alternatives. Provide a new pet, or suggest playing with the neighbour's puppy, for instance.
- Help the person to develop new friendships – and recognise this may take months.

Person feels they are a stranger in a strange land

- Look for ways to make them feel more comfortable.
- Introduce yourself every time you enter the room.
- Explain what you're doing there and what you're about to do as you reach each step.
- Move slowly and don't rush. A suspicious person may perceive fast movement as an attack.

- Look for ways to add familiarity to the environment by including pictures of loved ones, a favourite blanket or chair among their belongings.
- Repeatedly point out the landmarks on the way to important places. “See the big potted palm tree? That means we’re coming to the dining room.” Eventually the potted palm will be comforting, a sign that they’ve learnt their way around the strange land.

Delusions and hallucinations

Someone who is **hallucinating** sees things which aren’t there. (They may also hear voices or believe they smell illogical odours such as the smell of paint.) For example, it is not uncommon for people with dementia to ‘see and hear’ people in the room who aren’t there (often relatives and friends who have died, but workmen seem to be a close second). There are, however, logical reasons for many hallucinations. Here are a few:

- **Side effect of medication, infection, fever, fatigue.** Note that this applies to people who do not have dementia as well as those who do. It is important to look for alternatives to medications which cause hallucinations, especially frightening hallucinations such as insects crawling on one’s skin that may lead to scratching, skin breakdown, and major anxiety. It’s also important to simply give the person a thorough physical examination, since other diseases and conditions can cause hallucinations.
- **Self-comforting technique.** Many people talk aloud to companions who aren’t there as far as we can see or hear. Often the person gains great satisfaction or peace from these ‘conversations’. Who knows? Perhaps they are more real than we can perceive. If the visitors are not upsetting to the person, you don’t have to do anything, but if they are, look for guidance from the person with dementia as to what to do. One woman found that her mother regularly heard and saw workmen in an adjoining room. If she went in and said, “It’s time to leave now,” and then told her mother they were all gone, it didn’t seem to work. However, if she made a point of loudly shooing them out, and then asked her mother, “I think they’re all gone now, do you still see anyone?” (ie she gave control back to her mother), that sufficed.
- **May simply be visual impairment.** When vision deteriorates, it’s hard to tell whether a flower on the carpet is real or part of the pattern. Many people will stoop to pick it up. Poor vision can also make an inanimate object appear real and scary – clothes piled on a chair, as we noted earlier, may look like a frightening animal. Have a cognitively-aware person with vision impairment walk you through your residence to tell you where they are tripped up mentally or physically. Creating overall even lighting, increasing the light level and cutting daytime window glare (sheer

curtains help) are three needs that almost all nursing homes, day care centres and assisted living communities are not yet meeting adequately.

- **Person may have a hard time separating reality from nightmare or television.** Dreams and nightmares are no less real to people with dementia than reality. Similarly, people with dementia at some point do not separate what they see on the screen from the reality of their living rooms. Nightmares can usually be eliminated if we pay attention to medications, diet, environment and bedtime routines. It's easy to turn off violent television programmes (including the evening news), but be aware of what else might be upsetting. Consultant Mary Lucero tells the story of a daughter who was able to leave her father alone for the day if she turned the TV to the family channel where he watched 'I Love Lucy' reruns and other innocuous programmes. One day, however, she returned home and found him highly agitated about "all the children, too many children." When this happened several days in a row, she checked with the channel and found they had changed the programming schedule. Her father was being discombobulated by 'The Brady Bunch'.

Delusions, on the other hand, are *false* beliefs. Delusions are often based on:

- **Past experience.** A person still thinks they're a carpenter, lawyer, or teacher because their short-term memory has been destroyed by brain damage and they are now living in a past reality.
- **A physical need.** A person thinks they haven't been fed because they're still hungry or thirsty; or a lady may think she's having labour pains because her stomach hurts.
- **An emotional need.** A person believes their money is stolen because they can't find it, and doesn't want the problem to be their fault.

Again,

- Affirm the feelings (and provide reassurance when it's an emotional need)
- Solve the problem (especially when the delusion represents a physical need)
- Provide a pleasing distraction or alternative activity to help the person get their mind off the delusion.

It's especially important not to deny the person's perceived reality or to respond sarcastically. If I believe that I am a school teacher, recognise that I am doing the best I can with my remaining brain cells. Join my reality in whatever way you can sincerely do so, without it being demeaning. Some people will help me find ways to continue 'teaching' by leading a singalong, reading stories to the visiting

nursery school children, or carrying around an exercise book and a teacher's trade journal. Others may ask me about the classes I teach, the subjects I most like, my favourite students and the mischief-makers. The fact that we speak in present tense rather than past tense does not matter.

Caution:

It should also be noted that some people's delusions have a deep psychological cause for which a psychiatrist or clinical psychologist may be able to provide help. Most of us are not qualified to counsel people who may have suffered childhood or spousal abuse or other traumas. But we can love them.

Brief summary of paranoia, hallucinations and delusions

Logical explanations for paranoia and suspiciousness:

- It's a scary world when you don't understand what's going on around you and don't want to believe you are losing past strengths ("I couldn't have misplaced my keys; somebody must have taken them").

Logical explanations for hallucinations:

- Side effect of medication, infection, fever, fatigue.
- Self-comforting technique.
- Visual impairment causes misinterpretation.
- Unable to separate nightmare or TV from reality.

Logical explanations for delusions:

- Living in past reality.
- Physical need.
- Emotional need.

A few strategies for hallucinations, delusions, suspiciousness:

- Check medications, and carry out a physical examination.
- Improve lighting, and other factors contributing to visual impairment.
- Provide assistance in finding missing objects or keep duplicates.
- If person seems worried about responsibility for item, tell them you'll be glad to be responsible for it so they can let their mind rest.
- Help person to save face. Do not respond defensively or sarcastically.
- Move slowly, don't rush. Person may perceive fast movement as an attack.
- Briefly explain what you're doing and why. Person may not understand even routine procedures.
- A person who scratches their skin out of the delusion that insects are crawling on them is at risk of infection. Keep skin covered.
- Some people's delusions have a deep psychological cause; a psychiatrist or clinical psychologist may be able to help.

Repetitive behaviours

Repetitive behaviour may be verbal or physical. Here are some suggestions for causes and interventions:

The person who is worried about an upcoming event and repeatedly asks about it

- It is usually best not to mention upcoming events until they are nearly upon us, even if the event is pleasurable. If someone's daughter is coming to visit next Thursday for lunch, you may not need to mention it to them before late Thursday morning, otherwise, you may be subjected to endless repetitions of "When will Susan be here?".
- If the event produces its own anxiety, such as a visit to the doctor, this advice is even more crucial.
- Remember that if you *must* listen to continual repetitions of a question, the person is not trying to irritate you on purpose. They truly have no memory of having asked you previously, and your growing testiness after the fiftieth repetition will completely baffle the person. "Why are you getting so annoyed?"
- If you want to avoid continual questions, you might try writing the answer on a note the person can keep in their pocket or handbag, or provide some other cue. A man who was anxious each day about when his daughter was coming to pick him up from the day centre was comforted by being shown repeats of a video recording of her telling him when she was arriving and how she was looking forward to seeing him.

The person needs a change in medication

- Many medications have a side effect of anxiety. Check out this possibility.

The person has a physical need

- A person who keeps asking, "When is lunch?" may actually mean, "I'm hungry. Feed me."
- Always look for the other ways to interpret the question – the kernel of truth, the hidden meaning. Then recognise that telling the person lunch is in an hour is not solving the problem. Tell them instead, "Lunch is still an hour away. Would you like a banana in the meantime?"

The person finds repetitive behaviour self-comforting

- People will sometimes have little routines that drive us mad. A pacer, for instance, may insist on fiddling with the window blind in the activity room every time they pass through. That may be an irritant, but it isn't harmful.
- On the other hand, some people may continually pick at the threads of their clothes, or worse, scratch at a mole or age spot. They need something else to occupy their hands. Sometimes you can put a bright bracelet on the person who picks at their clothes, and they will fiddle with

that instead. Sometimes you can give a person something else to hold in their hands as a distraction.

Whenever you can channel persistent behaviour into a useful activity, don't hesitate to do so. Many people with dementia find great satisfaction in work that requires repetitive motion: raking, sweeping, dusting, sanding, wiping counters, washing windows, folding towels etc. These not only build self-esteem, but provide exercise as well, both of which contribute to better sleep.

As in all things, solutions come from constant experimentation – looking for every possible right answer – and from knowing residents well.

Summary of repetitive behaviour

Logical reasons for repetitive behaviours:

- A person who is worried about an upcoming event, may continuously repeat a question about it, having no memory of asking the question previously.
- A person may have a physical need; the person who keeps asking, “When is lunch?” may actually mean, “I’m hungry. Feed me.”
- A person who is anxious, fearful or worried may find persistent behaviour self-comforting.

A few strategies for repetitive behaviours:

- Be patient.
- Use signs, symbols, audio or video recordings to help the person.
- Check medications; check for signs of medical problem.
- Offer distractions or find useful things for the person to do.

Screaming, shouting, verbal noises

People who constantly shout, scream or moan are very difficult to be around and often misunderstood. This is one area where we still have much work to do. However, here are a few ideas:

Logical reasons for screaming, shouting, verbal noises:

- It can be a self-comforting technique for those who are frightened by their environment (particularly moaning).
- The person is in pain or suffering some other discomfort (needs to go to the bathroom, is cold, hungry, wants to go to bed, change position etc) and can no longer be precise. As we noted at the beginning of this course, pain is widely untreated or under-treated in people with dementia.
- It is a means to resist a care procedure that the person doesn't want or understand.
- The person is feeling threatened or frustrated.

- The person is bored (particularly if the noise is a droning sort). Many people who make a nearly constant droning noise will instantly stop if they are engaged in a conversation.
- *Some* people are just loud, with booming voices!

A few strategies for screaming, shouting, verbal noises:

- Give the person a thorough physical examination.
- Identify yourself, explain the procedure that you are about to do (one step at a time) and the reason for it.
- Try to make the environment more familiar, homely, relaxing.
- Keep routines and staff as consistent as possible.
- Spend some time giving the person your undivided, non-task-related attention.
- Talk in a soothing voice, play soothing background music or sounds (crickets, waves breaking on shore, rainfall).
- Involve the person in an activity they enjoy.
- If the person is not hypersensitive to being touched, make sure they get plenty of hugs, stroking, hand massages.

Blessed are the flexible, for they shall not be bent out of shape.

This is the end of the course.

Please now move on to take the online test by logging into your account at www.dailysparkleonlinelearning.co.uk