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TOOLKIT FOR SOCIAL SERVICES AND POLICIES

Instituto Príncipe Real

Cases of dementia - If the person with Dementia disappears

Partners



Contents

1	Introduction	3
2	Behaviour changes.	4
3	What to try	8
4	Repetitive behaviour	8
5	Ambulation	9
6	Ambulation	10
7	If the person with Dementia disappears	14
	When the missing person returns home	

1. Introduction

Dementia is a rapidly growing public health problem due to the aging population, affecting approximately 50 million people worldwide.

Dementia is not a natural or inevitable consequence of old age

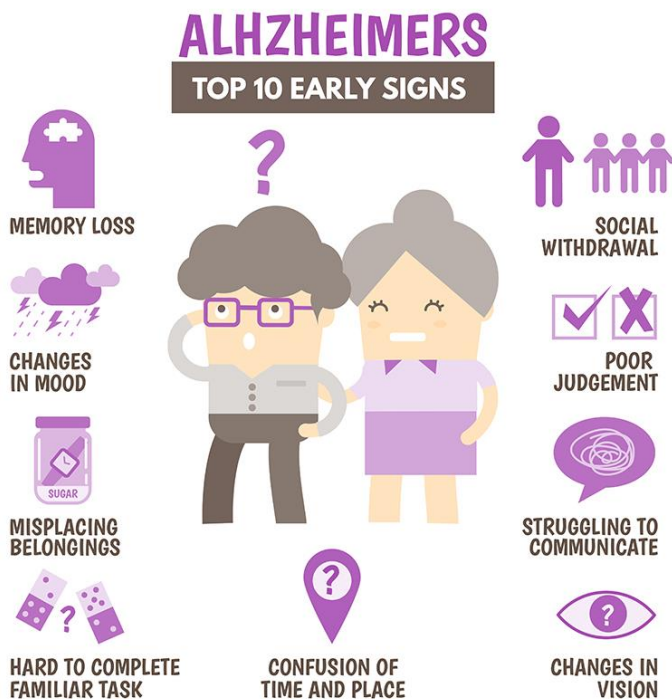
3

According to forecasts, this number is expected to triple by 2050, reaching 152 million people, the WHO warns.

Alzheimer's disease is the most common cause of dementia and is believed to cause 60-70% of cases, according to the United Nations agency.

Age is the major risk factor for cognitive decline, but dementia "is not a natural or inevitable consequence of old age," the WHO notes.

Some disorders, such as hypertension, diabetes, high cholesterol, obesity and depression, are associated with an increased risk of dementia. Other risk factors that can be changed are "social isolation and cognitive inactivity," says WHO.



The WHO calls for the implementation of a public strategy to prevent the disease. About 60 percent of people with dementia live in low- and middle-income countries, but "these countries are the least prepared to deal with this growing burden" .

2. Behaviour changes

Here we discuss some common behavioural changes in people with Dementia. The reasons for the changes are discussed and some general guidelines are provided to deal with them.

Changes in the behaviour of a person with Dementia are very common. These can be a huge source of stress for family members and caregivers. It can be particularly disturbing when someone, who was previously gentle and loving, behaves in a strange or agitated way.

4

Why is there a behaviour change?

There are many reasons why a person's behaviour may be changing. Dementia is a result of changes that occur in the brain and affect the person's memory, mood and behaviour. Sometimes the behaviour may be related to the changes that occur in the brain. Thus, behaviour can be triggered by these changes in the brain, but also by changes in the environment and health or by medications that the person is taking. Perhaps an activity, such as bathing, is felt to be very difficult to perform. The person may also not feel physically well.

Dementia affects people in different ways. Understanding why someone is behaving in a particular way can help you deal with this behaviour.

Where to start

You should discuss your concerns about changes in the person's behaviour with the doctor. This will be able to check if there is any physical illness or discomfort present, provide some advice and inform if there is any underlying psychiatric illness.

Dealing with behavioural change

Dealing with behaviour change can be very difficult and often a matter of trial and error. Always remember that behaviour is not deliberate. Anger and aggression are usually directed against family members and caregivers because they are closer. The behaviour is beyond the control of the person and the person can be quite frightened by it. The person needs to be reassured, even though he does not seem to have this need.

What to try

- A quiet, stress-free environment in which the person with Dementia can have a family routine can help avoid some difficult behaviours;
- Try to maintain the family environment. People with Dementia can be disturbed if they are in a strange situation or in a group of unknown people, where they feel confused and unable to communicate. The frustration caused by being unable to meet the expectations of others as well as their own may be enough to trigger a change in behaviour;
- If a behaviour becomes difficult, it is best not to attempt any form of physical contact, such as holding the person away from the place or approaching from behind. It may be best to leave the person alone until he or she has recovered or phoned a friend or neighbour for support;
- Try not to take behaviour personally;
- Try not to raise your voice;
- Do not punish the person, because not only can he not remember the event, but also be unable to learn from it;
- Speak slowly, in a calm and reassuring voice;

- Try not to feel provoked or engage in a discussion

Aggression

The aggression can be physical (example: beat) or verbal (example: use abusive language). Aggressive behaviour is usually an expression of fear, anger, or frustration.

What to try

- Aggression may be due to frustration. Locking the door may prevent the person from wandering, but may result in increased frustration;
- Activity and exercise can help prevent some aggressive manifestations;
- Approaching the person slowly and so that she can see it fully can help. Explain what will happen with short, clear sentences, such as "I'll help you take off your coat." This can prevent the person from having the feeling of being attacked and expressing aggression as a self-defence response;
- Verify that aggressive behaviour is related to getting something the person wants. If so, trying to anticipate the needs of the person can be an aid.

Exalted reactions

Some people with Dementia before a small setback or criticism present an exaggerated reaction. This may cause them to scream, make unjust accusations, become very agitated or stubborn, cry or laugh in an uncontrolled and inappropriate manner. The tendency to present exaggerated reactions is part of the disease and is called exalted reaction.

Sometimes an exalted reaction is the first sign of Dementia. These reactions may be a passing phase that disappears as the disease progresses or may remain for some time.

Exalted behaviour may be the result of:

- Stress caused by excessive demands of the situation;
- Frustration caused by misinterpretation of messages;
- Other underlying disease.

This behaviour can appear very quickly and can make family members and caregivers feel scared. However, trying to figure out what triggers exalted behaviour can sometimes prevent its onset. Keeping a journal can help identify the circumstances in which the behaviours occur. If this is not possible, you can find ways to deal with behaviour quickly and efficiently using some of the guidelines mentioned earlier.

Accumulation of things

People with Dementia often seem to be looking for something they believe to have disappeared and tend to accumulate objects to ensure that they do not get lost.

Accumulation behaviours can be caused by:

Isolation. When a person with Dementia is left alone or feels neglected, they can concentrate completely on themselves. The need to accumulate objects is a common answer;

- **Memories of the past.** Events of the present may evoke memories of the person's past, such as having lived with siblings who took their things or in a period of recession or war with a family to feed;
- **Loss.** People with Dementia continually lose parts of their lives. Losing friends, family, a significant role in life, an income and a memory they can trust, can increase the person's need to accumulate objects;
- **Fear.** Fear of being stolen is another common experience. The person may want to keep something precious and forget the place where he stored the object and then blame other people for stealing it.

3. What to try

- Learn the usual places where the person keeps things, and first look for the missing objects in those places;
- Give the person a drawer with various types of objects so that they can move in order to satisfy their need and to be occupied;
- Ensure that the person can find the way, since the inability to recognize the environment may be associated with the accumulation problem.

4. Repetitive behaviour

People with Dementia can say or ask the same things over and over again. They can also become very attached to you and be a shadow following you even to the bathroom. These behaviours can be very disturbing and irritating.

What to try

- If an explanation does not help, distracting the person can work. A favourite activity, food or a walk can help;
- Recognizing the feeling the person is expressing can help. For example - What do I have to do today? "May mean that the person is feeling lost and uncertain. Answering this feeling can help;
- Do not remind the person that she has already asked the question;
- Repetitive movements can be reduced by giving the person something else to do with the hands, such as a soft ball for tightening or folding clothes.

Based on Understanding and Dealing with Challenging Behaviours, Alzheimer's Scotland.

Who can help?

Discuss with your doctor your concerns about behavioural changes and the impact they have on you.

5. Ambulation

Here we will address the walking behaviour of some people with Dementia. The reasons for walking are discussed and some suggestions are made to control this behaviour.

Families and caregivers of people with Dementia may be, at some point, confronted with the problem of what to do if the person begins to wander. The walking behaviour is quite common and can be very disturbing for people concerned about the safety and well-being of people with Dementia.

This concern arises right at the moment of appointment, that is, in the very term Ambulation. Its meaning leads us to walk aimlessly, which does not usually correspond to the real meaning of this behaviour. In fact, when they walk, people with Dementia have a meaning, which may be related to old routines (picking up the child at school or going to the cafe at a certain time) or even with their profession (police, teacher, postman). However, memory loss and decline in the person's ability to communicate with Dementia may make them unable to explain why they need to walk at that moment - to wander.

Often there is a tendency for caregivers to say that people with dementia flee, but in reality what people want is to go home or go to work or, as we have said, to get the child to school. That is, the person aims to do something that is part of his life history and the memories he still has, even if he cannot verbalize them.

6. Reasons for walking behaviour

- **Changing the environment**

A person with dementia may feel insecure and disoriented in a new environment, such as in a new home or day care centre. The walking behaviour may stop as soon as the person gets used to the change. The walking behaviour can also be due to the fact that the person wants to escape from a noisy or busy environment.

- **Memory loss**

Ambulation may be due to short-term memory loss. The person can go out to the store or the house of a friend and then forget about why he left or where he went. The person may also have forgotten that his or her spouse warned that he would leave for a while and so look for him.

- **Excess power**

Ambulation can be a way to spend excess energy, which may indicate that the person needs occupancy and / or more regular exercise.

- **Search for the past**

As people become more confused, they can stroll around in search of someone or something about their past. They may, for example, look for a deceased spouse, an old friend or the house where they lived when they were children.

- **Express boredom**

As Dementia progresses, it becomes harder for the person to concentrate for some time. Ambulation can be a way for the person to keep busy.

- **Confuse the night with the day**

The person with Dementia may suffer from insomnia or wake up at dawn and become disoriented. In this sequence, you may think it's daytime and decide to go out for a walk. Difficulty in seeing or hearing loss can make the shadows or sounds of the night become confusing and distressing, so you should not go out alone.

- **Continue a habit**

People who were accustomed to walking long distances may simply wish to continue to do so.

- **Agitated**

Changes that have occurred in the brain can cause a feeling of restlessness and anxiety. The agitation can lead some people to walk from one place to another without apparent purpose. People with Dementia may be unable to recognize their own home and therefore want to leave.

- **Discomfort or pain**

Walking can ease discomfort, so it is important to find out if there is any physical problem or medical condition and try to cope with the situation. Some examples are the use of tight clothing, excessive heat or the need to find the bathroom.

- **A job to perform**

Sometimes people can leave home because they believe they have a job to do or are confused about the time of day or about the season. This may be related to an old function such as going to work in the morning and being home in the afternoon to stay with the kids.

Dreams

The inability to differentiate dreams from reality can lead the person to respond to something they dreamed, thinking that this happened in real life.

What you can try

The precautions you will take will depend on the personality of the person with Dementia as well as the ability of the person with dementia to deal with the different situations, the reasons for walking and also the fact that they live in a potentially dangerous environment or in a safe environment.

- A physical check-up will help identify whether the walking behaviour was triggered by pain, illness or discomfort;
- Discuss the side effects of the medication with your doctor. Try to avoid medications that may increase confusion, cause drowsiness and possible incontinence;
- **It is important to ensure that the person has some form of identification with him in case he gets lost.** An identification wristband with the name, address and phone number can be very helpful when the person is missing or is found. Another option is to use a medical alert bracelet, with the telephone number for contact. Similarly, it may be useful to sew labels with the person's name on the garments she regularly wears;
- If you are absent from home, for example on vacation, ensure that the person carries some form of identification that includes your current address;
- Some people find it helpful to keep a log or journal in order to see if there is any pattern in walking behaviour. This can occur at certain times of the day or in response to certain situations, which can later be more carefully controlled;
- Try to reduce the number of objects in view, as these can cause ambulation. Suitcases, coats, mailing letters, and work clothing may encourage the person with Dementia to wander;
- Consider placing ringers that ring when the outer doors are opened;
- Make a safe part of the garden so that it has a safe place for the person to walk;

- Often, it may make sense to inform neighbours and local marketers about the person's problem. Most people, after understanding the situation, are very helpful and can offer to contact you if they notice that the person left or some other behaviour.

7. If the person with Dementia disappears

- Stay calm;
- Do a thorough search indoors and out of buildings;
- Write down what the person was wearing;
- Alert the neighbours;
- Take a walk or drive, the block, the nearest area, and any places you visit regularly. If possible, someone should stay home in case the person shows up and picks up the phone;
- Contact your local police. Inform them that they have Dementia and express any concerns they may have regarding their safety;
- The police will request details and a description of the person and the clothing she wore. It is always helpful to have a recent photograph;
- The police can also ask about a person's family or favourite places;
- Recall old routines that the person may have remembered and want to perform

8. When the missing person returns home

- Notify the police immediately;
- Do not scold or show anxiety as worried or disturbed as you may have been. The person may have been confused and frightened;
- Reassure the person and return to the regular routine as soon as possible.

Who can help?

Discuss with your doctor your concerns about behavioural changes and the impact they have on you.