

DEMENTIA

A Carer's Handbook

Introduction

Here are some facts:

- There are currently (2013) around 800,000 people with dementia in the UK, and that number is rising steadily;
- There will be over a million people with dementia by 2021;
- The current estimate is that the number of people with Dementia will double in the next 30 year;
- Two thirds of people with dementia live in the community while one third live in a care home;
- Around 80% of people living in care homes have a form of dementia;
- There are over 17,000 younger people with dementia in the UK;
- There are over 11,500 people with dementia from black and minority ethnic groups in the UK;
- Two thirds of people with dementia are women;
- The proportion of people with dementia doubles for every 5 year age group;
- One third of people over 95 have dementia;
- 60,000 deaths a year are directly attributable to dementia;
- Delaying the onset of dementia by 5 years would reduce deaths directly attributable to dementia by 30,000 a year;
- Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn annually;
- There are around 670,000 carers of people with dementia in the UK;
- Unfortunately most types of dementia cannot be cured*.

“Some forms of dementia, such as Alzheimer’s disease, are degenerative. That is, they get worse over time”

“There will be over a million people with dementia by 2021”

* Can dementia be cured?

Most forms of dementia cannot be cured, although research is continuing into developing drugs, vaccines and other treatments. Drugs have been developed that can temporarily alleviate some of the symptoms of some types of dementia.

What exactly is Dementia?

The term 'dementia' is used to describe a syndrome (which is a group of related symptoms) which may be caused by a number of illnesses in which there is progressive decline in multiple areas of brain function.

Dementia therefore occurs as a result of changes to the structure of the brain and progressive damage to the brain cells. The gradual changes and damage to brain cell function are caused by a build-up of proteins in the brain. These proteins are different for each type of dementia.

Although dementia is primarily a condition associated with older people, there are also a significant number of people (currently around 15,000) who develop dementia earlier in life.

Some forms of dementia, such as Alzheimer's disease, are degenerative. That is, they get worse over time. How fast dementia progresses will depend on the individual person and what type of dementia they have. Other forms of dementia, such as vascular dementia, may be non-degenerative and may not get worse over time.

What are the symptoms?

Symptoms of dementia may include the following:

Loss of memory – this particularly affects short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long-term memory is usually still quite good.

Mood changes – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.

Communication problems – including a lack of understanding, poor judgement, problems finding the right words for things, for example describing the function of an item instead of naming it. Thinking speed/mental agility may be impaired.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

Some people also become restless or display repetitive behaviour. They may also seem irritable, tearful or agitated. Some people with dementia also develop other problems such as depression, disturbed sleep, aggression, inappropriate sexual behaviour and incontinence, although the latter issues tend to be associated with more advanced dementia. People with dementia may become apathetic (uninterested) and have problems controlling their emotions. They may also behave inappropriately in social situations and aspects of their personality may change. A person with dementia may lose empathy (understanding and compassion), they may see or hear things that other people do not (hallucinations), or they may hold false beliefs. They may also lose interest in social interactions.

“Alzheimer's disease - The most common cause of dementia, usually affecting older people, over 65 years of age”

What are the illnesses that cause Dementia?

There are several diseases and conditions that result in dementia. These include:

Alzheimer's disease – The most common cause of dementia, usually affecting older people, over 65 years of age. During the course of the disease the chemistry and structure of the brain change, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign. (But see MCI below).

Vascular dementia – If the oxygen supply to the brain fails due to vascular disease, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes and are associated with slowness of thinking and overall mobility.

Dementia with Lewy bodies – This form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning and problem solving. Memory may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease such as tremor and slowness of movement.

“Becoming forgetful, however, does not necessarily mean that you have dementia”

Fronto-temporal dementia (including Pick's disease) – In fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs. Usually develops in people under 65 years of age.

Rarer causes of dementia

There are many other rarer diseases that may lead to dementia, including progressive supranuclear palsy, Korsakoff's syndrome, Binswanger's disease, HIV/AIDS, and Creutzfeldt–Jakob disease (CJD). Some people with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease may also develop dementia as a result of disease progression.

Mild cognitive impairment (MCI)

Some individuals may have noticed problems with their memory, but a doctor may feel that the symptoms are not severe enough to warrant a diagnosis of Alzheimer's disease or another type of dementia, particularly if a person is still managing well. When this occurs, some doctors will use the term 'mild cognitive impairment' (MCI). Recent research has shown that individuals with MCI have an increased risk of developing dementia. The conversion rate from MCI to Alzheimer's is 10-20 per cent each year, so **a diagnosis of MCI does not always mean that the person will go on to develop dementia.**

Diagnosis of Dementia

Not surprisingly, many people fear they have dementia, particularly if they think that their memory is getting worse.

Becoming forgetful, however, does not necessarily mean that you have dementia: memory loss can be an effect of ageing, and it can also be a sign of stress or depression. In rare cases, dementia-like symptoms can be caused by vitamin deficiencies and/or a brain tumour. Diagnosis should always be undertaken by a trained and experienced GP or specialist.

The specialist may be a geriatrician (a doctor specialising in the care of older people), a neurologist (someone who concentrates on diseases of the nervous system) or a psychiatrist (a mental health specialist). The doctor may carry out a number of tests including:

- an assessment of the person's symptoms – for example, how long have memory problems existed;
- a full assessment of mental abilities, including possibly a Mini Mental State Examination (MMSE);
- a physical examination;
- a review of the current medication being taken;
- a range of tests, including blood tests to rule out other possible causes of symptoms, such as a vitamin B deficiency;
- brain scans, such as a computerised tomography (CT) scan or preferably a magnetic resonance imaging (MRI) scan, so that the condition and structure of the brain can be examined.

Can dementia be prevented?

At present, it is not clear what causes most of the diseases that lead to dementia and what can be done to prevent dementia itself. The evidence does indicate that a healthy diet and lifestyle may help protect against dementia.

In particular, exercising regularly, avoiding fatty foods, not smoking, drinking alcohol in moderation and keeping mentally and socially active into old age may help to reduce the risk of developing vascular dementia and Alzheimer's disease.

Treatment

Alzheimer's disease

In March 2011, the National Institute for Health and Clinical Excellence (NICE) issued revised guidance on treatment, recommending that people in the mild-to-moderate stages of Alzheimer's disease should be given treatment with one of the acetylcholinesterase inhibitors. The latest NICE guidance also recommends a different type of drug (memantine, trade name Ebixa) for people with severe Alzheimer's and some of those with moderate disease.

Dementia with Lewy bodies

People with dementia with Lewy bodies may be offered an acetylcholinesterase inhibitor if their non-cognitive symptoms, such as hallucinations, delusions or associated aggressive behaviour, are very distressing.

Vascular dementia

People with vascular dementia will not be offered an acetylcholinesterase inhibitor, except as part of a clinical trial. This is because of a lack of evidence that these drugs are effective for symptoms of vascular dementia.

Treatment should be aimed at the underlying cardiovascular (heart and circulatory) problems.

NB. The National Clinical Director for dementia is leading the work to implement the recommendations contained within the report - *The use of antipsychotic medication for people with dementia into the over-prescribing of antipsychotic medication*. The report states:

“These drugs appear to be used too often in dementia and, at their likely level of use, potential benefits are most probably outweighed by their risks overall. This is a problem across the world, not one just restricted to the NHS.”

Understanding and respecting the person with dementia

When a person with dementia finds that their mental abilities are declining, they often feel vulnerable and in need of reassurance and support.

Helping the person feel valued

The person with dementia needs to feel respected and valued for who they are now, as well as for who they were in the past. There are many things that the people around them can do to help, including:

- trying to be flexible and tolerant;
- making time to listen, have regular chats, and enjoy being with the person;
- showing affection in a way they both feel comfortable with;
- finding things to do together, like creating a life history book.

What's in a name?

It's important that people address the person with dementia in a way that the person recognises and prefers. It is important to remember that:

- Some people may be happy to be called by their first name or nickname;
- Others may prefer younger people, or those who do not know them very well, to address them formally and to use courtesy titles, such as Mr or Mrs.

Behaviour which appears to be over familiar can be very upsetting.

Respecting cultural values – at the heart of a dignified existence

Those who know should explain the person's cultural or religious background, and any rules and customs, to anyone from a different background so that they can behave accordingly. These may include:

- respectful forms of address;

- what they can eat;
- religious observances, such as prayer and festivals;
- particular clothing or jewellery that the person (or those in their presence) should or should not wear;
- any forms of touch or gestures that are considered disrespectful;
- ways of undressing;
- ways of dressing the hair;
- how the person washes or uses the toilet.

“Behaviour which appears to be over familiar can be very upsetting”

Acting with courtesy

Many people with dementia have a fragile sense of self-worth; it's especially important that people continue to treat them with courtesy, however advanced their dementia. This includes:

- Being kind and reassuring to the person you're caring for without talking down to them;
- Never talking over their head as if they are not there - especially if you're talking about them. Include them in conversations;
- Avoiding scolding or criticising them;
- Looking for the meaning behind their words, even if they don't seem to be making much sense. Whatever the detail of what they are saying, the person is usually trying to communicate how they feel;
- Trying to imagine how you would like to be spoken to if you were in their position.

Respecting privacy

- Make sure that the person's right to privacy is respected;
- Suggest to other people that they should always knock on the person's bedroom door before entering;
- If the person needs help with intimate personal activities, such as washing or using the toilet, do this sensitively and make sure the door is kept closed if other people are around;
- Everyone involved - including the person's friends, family members, carers, and the person with dementia themselves - reacts to the experience of dementia in their own way.

Helping the person feel good about themselves

There are lots of things you can do to help the person with dementia feel good about themselves.

When you spend time with someone with dementia, it is important to take account of their abilities, interests and preferences. These may change as the dementia progresses. It's not always easy, but try to respond flexibly and sensitively.

Supporting the person to express their feelings

Dementia affects people's thinking, reasoning and memory, but the person's feelings

remain intact. A person with dementia will probably be sad or upset at times. In the earlier stages, the person may want to talk about their anxieties and the problems they are experiencing.

- Try to understand how the person feels;
- Make time to offer them support, rather than ignoring them or 'jollyng them along';
- Don't brush their worries aside, however painful they may be, or however insignificant they may seem. Listen, and show the person that you are there for them.
- Offering simple choices
- Make sure that, whenever possible, you inform and consult the person about matters that concern them. Give them every opportunity to make their own choices;
- When you are helping someone, always explain what you are doing and why. You may be able to judge the person's reaction from their expression and body language;
- People with dementia can find choice confusing, so keep it simple. Phrase questions so that they only need a 'yes' or 'no' answer, such as 'Would you like to wear your blue jumper today?' rather than 'Which jumper would you like to wear today?'

"When you spend time with someone with dementia, it is important to take account of their abilities, interests and preferences"

Tips: maintaining respect

- Avoid situations in which the person is bound to fail, as this can be humiliating. Look for tasks that they can still manage and activities they enjoy.
- Give plenty of encouragement. Let them do things at their own pace and in their own way.
- Do things with the person, rather than for them, to help them retain their independence.
- Break activities down into small steps so that they feel a sense of achievement, even if they can only manage part of a task.
- Our self-respect is often bound up with the way we look. Encourage the person to take pride in their appearance, and compliment them on how they look.
- Try not to correct what the person says to you, the accuracy of the information is not as important as what the person is trying to express.

Supporting other carers

Make sure that anyone involved in caring for the person has as much background information as possible, as well as information about their present situation. This will help them see the person they're caring for as a whole person rather than simply 'someone with dementia'. It may also help them to feel more confident about finding conversation topics or suggesting activities that the person may enjoy.

"Dementia affects people in every walk of life. It does not discriminate"

If someone is not used to being around people with dementia, it may help to emphasise the following points:

- Dementia is nothing to be ashamed of. It is no one's fault;
- Anyone can suffer from dementia;
- Dementia affects people in every walk of life – it does not discriminate;
- If the person tends to behave in ways that other people find irritating or upsetting, this may be because of the dementia - it's not deliberate;
- The person with dementia may remember the distant past more clearly than recent events;
- They are often happy to talk about their memories, but anyone listening needs to be aware that some of these memories may be painful.

Always try to remember

- Each person with dementia is a unique individual with their own individual experiences of life, their own needs and feelings, and their own likes and dislikes;
- Although some symptoms of dementia are common to everyone, dementia affects each person in different ways;
- We all need to feel valued and respected and it is important for a person with dementia to feel that they still have an important part to play in life. Give encouragement and reassurance and support other family members to understand the person's needs and concerns.

Acknowledgement: [Alzheimers Society Factsheet](#)

Looking after someone with Dementia

“Quality outcomes for people with dementia: building on the work of the National Dementia Strategy” (September 2010) states:

By 2014, all people living with dementia in England should be able to say:

- I was diagnosed early;
- Those around me and looking after me are well supported;
- I can enjoy life;
- I understand, so I make good decisions and provide for future decision making;
- I am treated with dignity and respect;
- I feel part of a community and I'm inspired to give something back;
- I get treatment and support which are best for my dementia, and my life;
- I know what I can do to help myself and who else can help me;

I am confident my end of life wishes will be respected. I can expect a good death.

These outcomes will be supplemented by a similar series of specific evidence-based statements being developed in partnership with the Alzheimer's Society and with people with dementia and their carers. For example:

Outcome	Descriptor
I was diagnosed early	People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.
I understand, so I make good decisions and provide for future decision making	Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.
I get the treatment and support which are best for my dementia, and my life	Everyone living with dementia will receive the best dementia treatment and support, no matter who they are or where they live. They will feel that their personal needs have been appropriately assessed and that their treatment and potential consequences of treatment have been well planned and delivered in a coordinated way that is appropriate to their individual needs and preferences. They will be able to exercise personal choice in social care and ongoing support will be of a high quality.
I am treated with dignity and respect	People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.
I know what I can do to help myself and who else can help me	People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.
Those around me and looking after me are well supported	People living with dementia will feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.

Outcome	Descriptor
I can enjoy life	People living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia.
I feel part of a community and I'm inspired to give something back	People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research.
I am confident my end of life wishes will be respected. I can expect a good death	People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well co-ordinated and planned so that they die in the place and in the way that they have chosen.

For them to have any meaning at all, outcomes and statements of intent have to be supported by clear and precise actions on the ground which underpin the very best possible care of people with dementia. These actions are in the role of the Carer, and it is clear that caring for someone with dementia presents a range of practical issues that can differ significantly from those faced by other carers.

People with dementia often feel vulnerable as their condition progresses and they increasingly rely on other people to do things for them. As a carer of someone with dementia, you'll want to do everything you can to reassure and support them while helping them retain some level of independence. Although some symptoms are common to many people with dementia, each person's experience of the disease will be different.

Helping with everyday tasks

When a person with dementia finds that their mental abilities are declining, they're likely to feel anxious, stressed and scared. They may be aware of their increasing clumsiness and inability to remember things, and this can be very frustrating and upsetting for them. **As a carer, you can help them feel more secure by creating a regular daily routine in a relaxed environment where they're encouraged and not criticised.**

Involving the person you care for in everyday tasks may make them feel useful and improve their sense of self-worth. They could help with the shopping, laying the table or sweeping leaves in the garden, for example.

As the illness progresses, these tasks may become harder for them to manage independently, and you may need to give them more support. Offer support sensitively and don't be critical of their attempts. It can be very important for them to feel that they're still useful. In the early stages of dementia, memory aids can be used around the house to help the person remember where things are. For example, you could put pictures on cupboard doors of what's inside, such as cups and saucers. This may help

to trigger their memory and enable them to retain their independence a little longer.

Hobbies and interests

Many people with dementia still enjoy their previous hobbies or interests. For example, if they liked cooking, they may be able to help you make a meal. Going for a walk or gardening can provide exercise and fresh air. Or they may prefer listening to music or playing a board game. Caring for a pet cat or dog can bring a lot of pleasure to some people. If the person you care for was very sociable and outgoing or if they have a large family, they may really enjoy visits from one or two family members or friends. Remember, they may struggle to keep up with conversations if they have a lot of visitors at the same time.

“When a person with dementia finds that their mental abilities are declining, they’re likely to feel anxious, stressed and scared”

Health and nutrition

It’s important that the person you care for eats healthily and gets some exercise. The longer they stay fit and healthy, the better their quality of life will be.

If the person you care for doesn’t eat enough or eats unhealthy food, they can become susceptible to other illnesses. People with dementia can become more confused if they get ill.

Common problems for people with dementia include:

- not recognising foods;
- forgetting what food they like;
- refusing or spitting out food;
- resisting being fed;
- asking for strange food combinations.

How you can help

Involve the person you care for. For example, if you feed them, you could put the cutlery in their hand and help guide it to their mouth. You could also involve them in preparing food if they are up to it. Try and stay calm. If you feel stressed at mealtimes, the person you care for will probably be stressed too. Make sure you have plenty of time for meals so you can deal with any problems that arise.

“It’s common for people with dementia to experience incontinence”

Try to accommodate behaviour changes. It’s likely that the person you care for will change their eating patterns and habits over time. Being aware of this and trying to be flexible will make mealtimes less stressful for both of you.

If you think the person you care for may have health or dental problems, get help from your GP or dentist. You could also contact a local carers’ group to speak to other people who may have experienced similar difficulties.

If someone with dementia smokes, replace matches with disposable lighters to lower the risk of them accidentally causing a fire. If the person you care for drinks alcohol, check whether this will cause any side effects if they take dementia medication. If in doubt, ask your GP for advice.

Incontinence

Incontinence can be difficult to deal with and can be very upsetting for the person you care for. It's common for people with dementia to experience incontinence. This can be due to urinary tract infections, constipation causing added pressure on the bladder, or medication. A person with dementia may also simply forget to go to the toilet or may forget where the toilet is. They may have lost the ability to tell when they need the toilet.

How you can help

There are many ways to help with incontinence, but it's important to be understanding, retain a sense of humour and remember that it's not their fault. You may also want to try the following:

- Put a clear sign on the toilet door, such as a photo of the toilet.
- Keep the toilet door open and make sure that the person you care for can access it easily.
- Make sure they can remove their clothes. Some people with dementia can struggle with buttons and zips.
- Look out for signs that they may need to go to the toilet, such as fidgeting and standing up and down.
- Get adaptations to the toilet if necessary.

Personal hygiene

People with dementia can become anxious about certain aspects of personal hygiene and may need help with washing. For example, they may be scared of falling when getting out of the bath, or they may become disorientated in the shower. The person you care for may not want to be left alone or they may resist washing because they find the lack of privacy undignified and embarrassing. Try to do what's best for them.

“People with dementia can become anxious about certain aspects of personal hygiene and may need help with washing”

Preparing for the future

Introduction

People who have dementia, or who are worried that they may develop it in future, are often concerned about how decisions about their medical treatment would be made if they lost the ability to decide for themselves. They may fear that they would be forced to receive life-sustaining or life-prolonging treatments long after they were able to achieve an acceptable or tolerable level of recovery, length of life or quality of life.

The Mental Capacity Act 2005 gives people in England and Wales a statutory right to refuse treatment, through an 'advance decision'. An advance decision allows a person to state what forms of treatment they would or would not like should they become

unable to decide for themselves in the future.

Read more about this important topic on the [Alzheimer's Society](#) website.

What It's Like to Have Dementia

By R Morgan Griffin
WebMD Feature

Understanding dementia symptoms from the inside can make you a better caregiver – and bring you closer to your loved one.

You know how frustrating and heartbreaking dementia symptoms are from the point of view of a caregiver. You know the pain of slowly seeing a loved one slip away. But what is it like for her? What is it like for a person to slowly – or sometimes quickly – forget almost everything she ever knew?

Dementia is ultimately a lonely condition, and you can never truly know what it's like for your loved one. But by asking experts – and people who are themselves in the early stages of the disease – we can get some idea.

"It's devastating," says Mary Ann Becklenberg, of Dyer, Ind., who was diagnosed with Alzheimer's disease in 2008 at the age of 62. "I am acutely aware of all those areas in which I am not competent anymore, both small and large. Coming to terms with my own deficiencies is so hard."

"Dementia is ultimately a lonely condition, and you can never truly know what it's like for your loved one"

Learning something about the other side, beyond the dementia symptoms you see, could make you feel closer to your loved one. It could also make you a more understanding and effective caregiver.

Memory Loss: "Everything Became Fuzzier"

Dementia symptoms result from damage to the brain caused by disease or injury. As brain cells die, it becomes difficult or impossible to store new memories or access old ones. Sometimes dementia comes on suddenly, after a stroke or head injury. Often it comes on more slowly as the result of conditions like Alzheimer's disease or Parkinson's disease. Most causes of dementia cannot be reversed.

Mary Ann Becklenberg is in the early stages of Alzheimer's disease, but her dementia symptoms have already had an enormous impact on her life. In 2006, she had to leave her position as a clinical social worker because she could no longer meet the responsibilities. "The world became much less defined than it had been," says Becklenberg. "Everything became fuzzier." The diagnosis didn't come until later. John Becklenberg says that he first knew that his wife had Alzheimer's disease after she returned from a monthlong trip to California.

"I was there with her for a week of her stay," he says. "But when she got back, she didn't remember that I'd been there at all."

"That was so hard," says Mary Ann Becklenberg, who now serves as an Alzheimer's Association early stage adviser. "John listed all these things we did and places we

went, and I didn't remember any of them. That was when we knew."

Dementia Symptoms: What Memory Loss Means

Some people think of memory loss superficially, as merely forgetting words or names. But it's much more profound than that. Everything we do is premised on memory. When you walk into the kitchen to make dinner, your actions are almost unconscious. You grab food from the fridge, turn on the oven, take out plates and silverware – your memories are a foundation, and they give you a context for what you're supposed to do in a given situation.

"Each step has to be reasoned out and thought through"

For a person with dementia, that context is ripped away.

A woman with Alzheimer's disease may walk into a kitchen and have no idea why she's there or what she's supposed to be doing. She might still be able to make dinner – especially in the early stages of the disease – but it's a struggle. Each step has to be reasoned out and thought through. That's why people with dementia tend to act more slowly than they once did.

In the advanced stages of the disease, the actions of a person with dementia may seem irrational. But Beth Kallmyer, MSW, director of client services for the national office of the Alzheimer's Association in Chicago, says that they often make a kind of warped logic.

"Our brains are built to reason," says Kallmyer, "and even when the brain has been affected by a disease like Alzheimer's, it's still struggling to reason." The problem is that as memories are lost, the brain just doesn't have enough information to interpret situations correctly.

Dementia Symptoms: What Caregivers Should Know

As a caregiver, you may find certain dementia symptoms frustrating, baffling, and sometimes frightening. But what is the other side of the story? What is your mother doing -- and feeling -- when she puts her wedding ring in the freezer or accuses you of stealing from her? Here are some clues to understanding dementia behavior.

Forgetting. Obviously, memory loss is the essential dementia symptom. What is it like? We've all experienced the frustration of losing our keys seconds after we had them in our hands. Imagine that frustration, magnified and repeated constantly throughout the day.

In the early stages, people are well aware of this particular dementia symptom. They know that they're losing their memories.

"Think about how you'd feel if someone brought in your granddaughter and you didn't know who she was," says Kallmyer. "You know you should know who she is, but you just don't. You'd feel humiliated, frustrated, and afraid."

What's especially confusing to caregivers is that while the condition may be progressive, individual memories may pop in and out. One day, your mother doesn't remember how to turn on the oven. The next, she successfully roasts a turkey. That sort of inconsistency is just a typical dementia symptom.

Difficulty communicating. One early-stage dementia symptom is difficulty following conversations, even though the person might cover it up well. “Sometimes, it really is easier to go along -- to laugh and pretend that I know what a person is talking about,” says Becklenberg. “I guess you could say I’m doing it to save face.”

“... most examples of “lying” are dementia symptoms rather than intentional deception”

It's understandable, experts say. It's a natural desire to avoid the humiliation of having to say, “I don't remember,” over and over again.

As the disease progresses, these dementia symptoms worsen. A person's language might become artificially complex and contorted, as he navigates around the countless words that have dropped out of his vocabulary. There will come a point where he'll have difficulty articulating even basic needs. “Sometimes, the best a caregiver can do is guess,” says Kallmyer.

“Lying” and Confabulation. Pretty quickly, caregivers learn that they can't trust their loved one's answers even to very basic questions like “What did you have for lunch?” These apparent lies can make caregivers feel betrayed and angry.

It's true that in the early stages of the disease, people with dementia might fib to cover for memory loss. But most examples of “lying” are dementia symptoms rather than intentional deception. “They're more like an unconscious defense mechanism,” says Kallmyer. Specifically, it's called confabulation – unconsciously replacing lost memories with fabrications.

What's behind this dementia symptom? Our brains are always trying to make sense of things, to impose order on the information we take in. But when a person has dementia, whole experiences are constantly being lost, which makes it difficult for the brain to get its bearings. So the unconscious mind fills in the gaps, swapping in an old memory or coming up with a plausible alternative.

As a caregiver, you might be disturbed when your father sits down to Christmas dinner and says, “Happy Thanksgiving!” But from his perspective, he has no memory of opening gifts 20 minutes ago. Instead, he sees extended family sitting around the dining room table and makes an unconscious guess as to why they're there. His brain tries to fill in for the missing information. Sometimes it's right and sometimes wrong.

Anxiety and Depression. It can be difficult for a caregiver to see a loved one – who may have been generally optimistic and easygoing when she was well -- become anxious or depressed. Both are common dementia symptoms, and it's hardly surprising. While their memories may fade, people with dementia are aware of what's happening to them, at least in the early stages. They know that they have an incurable, degenerative disease. They can feel the scope of their world becoming more and more confined as they lose freedoms like driving. They know that they're losing part of themselves too.

“Prior to having this disease, I wasn't a person who needed to ask for help much,” says Becklenberg. “But now I do, and it's been a blow to my self-assurance and self-esteem. I can't participate fully in life like I used to, and it's a huge loss.”

Wandering. It's not uncommon for a person with dementia to wander – to walk out of the house in a seemingly random direction. Caregivers can find this dementia symptom mysterious. Why would a loved one leave the safety of his home to wander through unfamiliar streets?

Sometimes, it's aimless, the product of boredom. But in other cases, there's a reason behind this dementia symptom. When a person has dementia, even the house she lived in for decades might suddenly be unfamiliar. Confused, she wants to get out and search for a place that she recognizes and where she feels safe. "Sometimes people who wander from their homes say that they're trying to go home," says Kallmyer. "It confuses caregivers, but the person might mean a different home – maybe the home she grew up in."

Fear and Aggression. As the world becomes more confusing, and even their closest family members seem like strangers, people with dementia can feel defenseless and afraid, trapped and angry. Sometimes they can become physically aggressive, which can be frightening for a caregiver. How could your loved one turn on you?

Look at this dementia symptom as a defense mechanism -- you're not the real target of the aggression. Instead, a person with dementia is trying to fight back against the confusion and chaos. Kallmyer says that if a loved one is prone to aggression, it could reflect a specific problem that she can't articulate. Sometimes just getting more physical activity during the day can reduce this dementia symptom, too.

Paranoia. A person with dementia may become irrationally suspicious of the people around him. He might become convinced, again and again, that someone has stolen his wallet. It can be demoralizing – after all the work you do as a caregiver, being called a thief a couple of times a day isn't fun.

But Kallmyer urges people to look at this dementia symptom from the other person's perspective. "Imagine that you go to get your wallet right where you left it and it's gone," says Kallmyer.

"You positively know you didn't move it – because you have no memory of doing that. So the only logical conclusion is that someone else did. That's the reality from the perspective of a person with dementia."

Finding the Message in Dementia Symptoms

When it comes to understanding dementia symptoms, Kallmyer says that there are limits to what a caregiver can do. "Sometimes, the behavior of a person with dementia will have no meaning," she says. "The disease is just destroying their brain cells, and their actions have no rhyme or reason."

But other times, Kallmyer says, seemingly irrational dementia

"As the world becomes more confusing, and even their closest family members seem like strangers, people with dementia can feel defenseless and afraid, trapped and angry"

"I think that we've actually felt closer as a result of this disease"

symptoms will cloak a message that you can decode. “We like to think of all behaviors as forms of communication from a person with dementia,” she tells WebMD. Taking the time to interpret and understand could not only get your loved one what he needs, but also bring you closer together. While the relationship you once had with your loved one will fade away, you may forge a new and different but still meaningful connection.

John and Mary Ann Becklenberg can't know what the future holds for them, but for now they're focusing on what they have.

“I think that we've actually felt closer as a result of this disease,” says John Becklenberg, who is the primary caregiver for his wife. “I've had to slow down some and take more time with her.”

Mary Ann Becklenberg is grateful. “Caregivers really don't get the respect that they deserve,” she says. “They're the unsung heroes of diseases like Alzheimer's.”

She also has some advice. “Despite the difficulties, I'd urge caregivers and people with [dementia] to try to find the humor in their lives,” she says. “John and I laugh about things, and it helps. People really need to know that.”

Alzheimer's Disease: Tips for Maintaining a Normal Life

Living with Alzheimer's disease is a challenge for anyone. It's difficult to remember things, make decisions, and find your way around the way you used to. It can be frustrating a good deal of the time, but there are good days and bad days. Here are some helpful tips and things you can do to make things easier for yourself -- to make things feel a bit more normal again.

How Do I Cope With My Memory Problems?

To help cope with memory problems:

- Always keep a book with you to record important information, phone numbers, names, ideas you have, appointments, your address, and directions to your home.
- Place sticky notes around the house when you need to remember things.
- Label cupboards and drawers with words or pictures that describe their contents.
- Place important phone numbers in large print next to the phone.
- Ask a friend or family member to call and remind you of important things that you need to do in the day, like meal times, medication times, and appointments.
- Use a calendar to keep track of time and to remember important dates.
- Use photos of people you see often labeled with their names.
- Keep track of phone messages by using an answering machine.

“Place sticky notes around the house when you need to remember things”

What's the Best Way to Plan the Day?

In planning your day:

- Find things to do that you enjoy and are able to do safely on your own.
- It will be easier to accomplish tasks during the times of the day when you feel best.
- Allow yourself the time to do the things you need to do, and don't feel rushed or let other people rush you.
- If something gets too difficult, take a break.
- Ask for help if you need it.

How Do I Avoid Getting Lost?

To keep from getting lost:

- Ask someone to go with you when you go out.
- Ask for help if you need it and explain that you have a memory problem.
- Always take directions for where you're going with you.

What Will Make Communicating Easier?

Communicating with others will be easier if you:

- Always take your time, and don't feel rushed.
- If you need to, ask the person you're speaking with to repeat what he/she is saying or to speak slowly if you do not understand.
- Avoid distracting noises, and find a quiet place to talk.

What About Driving?

Driving can be of particular concern for Alzheimer's patients. Here are some things to consider:

- Have someone else drive you where you need to go.
- If you tend to get lost or confused easily, consider alternative modes of transportation.
- Drive only in areas that are familiar to you.
- Contact organizations like the Alzheimer's Association to learn what local transportation services are available.
- The Department of Motor Vehicles will assess your driving skills if you're not sure whether you should drive.

At some point, it may no longer be safe for you to drive.

How Do I Take Care of Myself at Home?

To make sure you are well taken care of at home, put some of these measures into place early so they become routine:

- Local Alzheimer organizations or your doctor will be able to tell you how to get help with things like shopping, housekeeping, meals (including home-delivered meals),

and transportation.

- Ask a neighbor you trust to keep a set of house keys.
- Ask a friend or family member to help you to organize your closets and drawers to make it easier for you to find things.
- Ask a family member to check things out around the house, such as electrical appliances, mail, and perishable food items.
- Keep a list of important and emergency numbers by the phone.
- Have family, friends, or a community service program call or visit daily to ensure that everything is all right.
- Ask someone to check your smoke alarm regularly.

How Do I Maintain My Responsibilities?

- Arrange for direct deposit of checks, such as your retirement pension or Social Security benefits.
- Inform your bank if you have difficulty keeping track of your accounts and record keeping. They may provide special services for people who have Alzheimer's.

It is important to realize that at some point, it will become too difficult or dangerous for you to live by yourself. But, in the earliest stages of the disease, many people do manage on their own -- with support and help from friends, family, and community programs and with simple adjustments and safety practices in place.

Acknowledgements

This guide has been produced, not unusually, through the collection and reproduction of a variety of material from a variety of sources. Special mention must go to the Alzheimer's Society (<http://www.alzheimers.org.uk/>) who undertake outstanding work in their field, and who publish material which is of enormous benefit to those who suffer from Alzheimers disease, and those who care for them on a daily basis.

Anyone who wants a greater understanding of the disease is urged to study their excellent material closely, some of which has been used in the production of this document.

Useful Organisations

Age UK

York House

207-221 Pentonville Road

London N1 9UZ

T 0800 169 8787 (general enquiries)

0800 169 6565 (advice line)

E contact@ageuk.org.uk

W www.ageuk.org.uk

Provides information and advice for older people in the UK. Age UK has been created by the merger of Age Concern and Help the Aged.

Alzheimer's Society

Devon House
58 St Katharine's Way
London E1W 1LB
T 020 7423 3500
E info@alzheimers.org.uk
W alzheimers.org.uk

The UK's leading care and research charity for people with dementia, their family and carers.

Care Quality Commission

National Correspondence
Citygate
Gallowgate
Newcastle upon Tyne NE1 4WH
T 03000 616161
E enquiries@cqc.org.uk
W www.cqc.org.uk

Regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in England. Formerly the Commission for Social Care Inspection (CSCI).

Carers UK

20 Great Dover Street
London SE1 4LX
T 0808 808 7777 (free carers' line, Wednesday and Thursday 10am-12pm and 2pm-4pm)
E info@ukcarers.org
W www.carersuk.org

Provides information and advice to carers about their rights, and how to access support. See in particular the booklet Residential and nursing home care.

Counsel and Care

Twyman House
16 Bonny Street
London NW1 9PG
T 0845 300 7585 (advice line, weekdays 10am-4pm except Wednesdays 10am-1pm)
E advice@counselandcare.org.uk
W www.counselandcare.org.uk

Provides advice, information and financial support for older people, their families and carers. Useful factsheets include Help at home, What to look for in a home care agency and Community care and the NHS: guide to making complaints.

Elderly Accommodation Counsel (EAC)

3rd Floor

89 Albert Embankment

London SE1 7TP

T 020 7820 1343

E info@eac.org.uk

W www.eac.org.uk

www.housingcare.org (sister site)

Produces information and advice about accommodation for older people, aimed at older people themselves, their families, carers and advisors, and all those who work with them. See the range of factsheets, and the booklet For you and yours.

Local Government Ombudsman

PO Box 4771

Coventry CV4 0EH