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Intellectual Output 2.2

MODULE 1



DEMENTIA: forms, dealings and philosophies of approach

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M.1.1 Different forms of dementia and their characteristics

Dementia is a general term for loss of memory and other mental abilities severe enough to interfere with daily life. It is caused by physical changes in the brain. Alzheimer's is the most common type of dementia, but there are many kinds.

As people get older, memory loss can become a problem. It's normal for memory to be affected by stress, tiredness, or certain illnesses and medications. This can be annoying if it happens occasionally, but if it's affecting a person's daily life or it becomes worrying, medical advice should be sought.

But dementia isn't just about memory loss. It can also affect the way people speak, think, feel and behave. It's also important to remember that dementia is not a natural part of ageing.

What is dementia?

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning. This may include problems with:

- memory loss
- thinking speed
- mental sharpness and quickness
- language
- understanding
- judgement
- mood
- movement
- difficulties carrying out daily activities

There are many different causes of dementia. People often get confused about the difference between Alzheimer's disease and dementia. Alzheimer's disease is a type of dementia and, together with vascular dementia, makes up the vast majority of cases. People with dementia can become apathetic or uninterested in their usual activities, or may have problems controlling their emotions. They may also find social situations challenging and lose interest in socialising. 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). Because people with dementia may lose the ability to remember events or fully understand their environment or situations, it can seem as if they're not telling the truth, or are wilfully ignoring problems. As dementia affects a person's mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with dementia will therefore usually need help from friends or relatives, including help with decision making.

Why is it important to get a diagnosis?

Although there is no cure for dementia at present, if it's diagnosed in the early stages, there are ways to slow it down and maintain mental function. A diagnosis can help people with dementia get the right treatment and support, and help those close to them to prepare and plan for the future. With treatment and support, many people are able to lead active, fulfilled lives. The symptoms of



dementia tend to worsen with time. In the much later stages of dementia, people will be able to do far less for themselves and may lose much of their ability to communicate.

How common is dementia?

In 2015, the number of people with dementia was approximately 10.5 million in Europe. The projections are alarming, as the number of affected people is predicted to increase to 13.4 million by 2030 and to 18.7 million by 2050.

According to the European Commission, the most common causes of dementia in the EU is Alzheimer's disease (about 50-70% of cases) and the successive strokes which lead to multi-infarct dementia (about 30%). Other causes are Pick's disease, Binswanger's diseases, Lewy-Body dementia, and others.

Frequently used classifications of dementia

While the different types of diseases vary, there are some frequently used classifications to describe them:

Cortical Dementia: The brain damage primarily affects the brain's cortex, or outer layer. It tends to cause problems with memory, language, thinking, and social behavior.

Subcortical Dementia: Affects parts of the brain below the cortex. Subcortical types tend to cause changes in emotions and movement in addition to problems with memory.

Progressive Dementia: This type gets worse over time, gradually interfering with more cognitive abilities and daily activities.

Primary Dementia: This type does not result from any other disease. Alzheimer's disease is a primary type.

Secondary Dementia: The condition occurs as a result of a physical disease or injury.

Some types fit into more than one of these classifications. For example, Alzheimer's disease is considered both progressive and cortical.

M.1.1.1 Alzheimer's disease

Signs and symptoms of Alzheimer's disease

Alzheimer's disease is a progressive condition, which means the symptoms develop gradually over many years and eventually become more severe. It affects multiple brain functions. The first sign of Alzheimer's disease is usually minor memory problems. For example, this could be forgetting about recent conversations or events, and forgetting the names of places and objects.

As the condition develops, memory problems become more severe and further symptoms can develop, such as:

- confusion, disorientation and getting lost in familiar places
- difficulty planning or making decisions
- problems with speech and language



- problems moving around without assistance or performing self-care tasks
- personality changes, such as becoming aggressive, demanding and suspicious of others
- hallucinations (seeing or hearing things that are not there) and delusions (believing things that are untrue)
- low mood or anxiety

Who is affected?

Alzheimer's disease is most common in people over the age of 65. The risk of Alzheimer's disease and other types of dementia increases with age, affecting an estimated 1 in 14 people over the age of 65 and 1 in every 6 people over the age of 80. But around 1 in every 20 cases of Alzheimer's disease affects people aged 40 to 65. This is called early- or young-onset Alzheimer's disease.

Getting a diagnosis

As the symptoms of Alzheimer's disease progress slowly, it can be difficult to recognise that there's a problem. Many people feel that memory problems are simply a part of getting older. Also, the disease process itself may (but not always) prevent people recognising changes in their memory. But Alzheimer's disease is not a "normal" part of the ageing process. An accurate and timely diagnosis of Alzheimer's disease can give you the best chance to prepare and plan for the future, as well as receive any treatment or support that may help.

If possible, someone who knows the sufferer well should be with them as they can help describe any changes or problems they have noticed. If a person is worried about someone else, they should encourage them to make an appointment and perhaps suggest that they go along with them. There's no single test that can be used to diagnose Alzheimer's disease. And it's important to remember that memory problems do not necessarily mean that the person has Alzheimer's disease.

If Alzheimer's disease is suspected, the sufferer may be referred to a specialist service to:

- assess the symptoms in more detail
- organise further testing, such as brain scans if necessary
- create a treatment and care plan

How Alzheimer's disease is treated

There's currently no cure for Alzheimer's disease, but **medicines** are available that can help relieve some of the symptoms. Various other types of support are also available to help people with Alzheimer's live as independently as possible, such as making changes to their **home environment** so it's easier to move around and remember daily tasks. **Psychological treatments** such as cognitive stimulation therapy may also be offered to help support their memory, problem solving skills and language ability.

People with Alzheimer's disease can live for several years after they start to develop symptoms. But this can vary considerably from person to person. Alzheimer's disease is a life-limiting illness, although many people diagnosed with the condition will die from another cause. As Alzheimer's disease is a progressive neurological condition, it can cause problems with swallowing. This can lead to aspiration (food being inhaled into the lungs), which can cause frequent chest infections. It's also common for people with Alzheimer's disease to eventually have difficulty eating and have a reduced appetite.

There's increasing awareness that people with Alzheimer's disease need palliative care. This includes support for families, as well as the person with Alzheimer's.



Can Alzheimer's disease be prevented?

As the exact cause of Alzheimer's disease is not clear, there's no known way to prevent the condition.

But there are things one can do that may reduce their risk or delay the onset of dementia, such as:

- stopping smoking and cutting down on alcohol
- eating a healthy, balanced diet and maintaining a healthy weight
- staying physically fit and mentally active

These measures have other health benefits, such as lowering the risk of cardiovascular disease and improving the overall mental health.

M.1.1.2 Vascular dementia

Vascular dementia is a common type of dementia caused by reduced blood flow to the brain. It tends to get worse over time, although it's sometimes possible to slow it down.

Symptoms of vascular dementia

Vascular dementia can start suddenly or come on slowly over time. Symptoms include:

- slowness of thought
- difficulty with planning and understanding
- problems with concentration
- mood, personality or behavioural changes
- feeling disorientated and confused
- difficulty walking and keeping balance
- symptoms of Alzheimer's disease, such as problems with memory and language (many people with vascular dementia also have Alzheimer's)

These problems can make daily activities increasingly difficult and someone with the condition may eventually be unable to look after themselves.

Getting diagnosed

If in doubt, a suspected sufferer should see their GP if they think they have early symptoms of dementia, especially if they are over 65 years of age. If it's spotted at an early stage, treatment may be able to stop the vascular dementia getting worse, or at least slow it down. The GP can do some simple checks to try to find the cause of your symptoms and they can refer the sufferer to a memory clinic or another specialist for further tests if needed.

There's no single test for vascular dementia. The following are needed to make a diagnosis:

- an assessment of symptoms – for example, whether there are typical symptoms of vascular dementia
- a full medical history, including asking about a history of conditions related to vascular dementia, such as strokes or high blood pressure
- an assessment of mental abilities – this will usually involve a number of tasks and questions
- a brain scan, such as an MRI scan, CT scan or a single photon-emission computed tomography (SPECT) scan – this can detect signs of dementia and damage to the blood vessels in the brain

Treatments for vascular dementia



There's currently no cure for vascular dementia and there is no way to reverse any loss of brain cells that occurred before the condition was diagnosed. But treatment can sometimes help slow down vascular dementia. Treatment aims to tackle the underlying cause, which may reduce the speed at which brain cells are lost. This will often involve:

- eating healthily
- losing weight if the person is overweight
- stopping smoking
- getting fit
- cutting down on alcohol
- taking medication, such as medicines to treat high blood pressure, lower cholesterol or prevent blood clots

Other treatments including physiotherapy, occupational therapy, dementia activities (such as memory cafés) and psychological therapies can help reduce the impact of any existing problems.

Outlook for vascular dementia

Vascular dementia will usually get worse over time. This can happen in sudden steps, with periods in between where the symptoms don't change much, but it's difficult to predict when this will happen. Home-based help will usually be needed, and some people will eventually need care in a nursing home. Although treatment can help, vascular dementia can significantly shorten life expectancy. But this is highly variable and many people live for a number of years with the condition or die from some other cause.

Causes of vascular dementia

Vascular dementia is caused by reduced blood flow to the brain, which damages and eventually kills the brain cells. This can develop as a result of:

- narrowing and blockage of the small blood vessels inside the brain
- a single stroke (where the blood supply to part of the brain is suddenly cut off)
- lots of "mini strokes" that cause tiny but widespread damage to the brain

In many cases, these problems are linked to underlying conditions – such as high blood pressure and diabetes – and lifestyle factors such as smoking and being overweight. Tackling these might reduce the risk of vascular dementia in later life, although it's not yet clear exactly how much the risk of dementia can be reduced.

M.1.1.3 Dementia with Lewy bodies

Dementia with Lewy bodies (DLB) causes problems with mental abilities and a number of other difficulties. The symptoms tend to come on gradually and get slowly worse over several years, although treatment can help.

Problems with mental abilities

As with other types of dementia, dementia with Lewy bodies typically causes problems with:

- thinking speed
- understanding
- judgement
- visual perception
- language



- memory (but significant memory loss may not occur until later on)

These problems may be constant but typically tend to come and go. There are also other symptoms of dementia with Lewy bodies that can help distinguish it from other types of dementia, such as:

- marked swings between alertness and confusion or sleepiness – this can happen unexpectedly and change over hours or days
- slow movement, stiff limbs, tremors (uncontrollable shaking) and shuffling when walking – similar to Parkinson's disease
- seeing or sometimes hearing things that aren't there (hallucinations) – these can range from pleasant to distressing
- fainting, unsteadiness and falls
- disturbed sleep – this could be talking in sleep, acting out dreams or sleepiness during the day
- difficulty swallowing
- depression

Daily activities become increasingly difficult and there may be further health problems, such as an injury after a fall or a chest infection caused by accidentally inhaling food.

M.1.1.4 Mixed dementia

In the most common form of mixed dementia, the abnormal protein deposits associated with Alzheimer's disease coexist with blood vessel problems linked to vascular dementia. Alzheimer's brain changes also often coexist with Lewy bodies. In some cases, a person may have brain changes linked to all three conditions — Alzheimer's disease, vascular dementia and dementia with Lewy bodies. Researchers don't know exactly how many older adults currently diagnosed with a specific type of dementia actually have mixed dementia, but autopsies show that the condition may be significantly more common than previously realized. Autopsy studies play a key role in shedding light on mixed dementia because scientists can't yet measure most dementia-related brain changes in living individuals. In the most informative studies, researchers correlate each participant's cognitive health and any diagnosed problems during life with analysis of the brain after death.

Symptoms of Mixed dementia

Mixed dementia symptoms may vary, depending on the types of brain changes involved and the brain regions affected. In many cases, symptoms may be similar to or even indistinguishable from those of Alzheimer's or another type of dementia. In other cases, a person's symptoms may suggest that more than one type of dementia is present.

Getting diagnosed

A diagnosis of mixed dementia comes after a brain autopsy. Most individuals whose autopsies show they had mixed dementia were diagnosed with one specific type of dementia during life, most commonly with Alzheimer's disease.

For example, in the Memory and Aging Project study involving long-term cognitive assessments followed by eventual brain autopsy, 94% of participants who were diagnosed with dementia were diagnosed with Alzheimer's. The autopsies of those diagnosed with Alzheimer's showed that 54 percent had coexisting pathology. The most common coexisting abnormality was previously



undetected blood clots or other evidence of vascular disease. Lewy bodies were the second most common coexisting abnormality.

Causes and risks

Although mixed dementia is infrequently diagnosed during life, many researchers believe it deserves more attention because the combination of two or more types of dementia-related brain changes may have a greater impact on the brain than one type alone. Evidence suggests that the presence of more than one type of dementia-related change may increase the chances a person will develop symptoms.

Treatment and outcomes

Because most people with mixed dementia are diagnosed with a single type of dementia, physicians often base their prescribing decisions on the type of dementia that's been diagnosed. No drugs are specifically approved to treat mixed dementia. Medical experts who think that Alzheimer's disease is among the conditions contributing to a person's dementia may consider prescribing the drugs that are approved for Alzheimer's.

Many researchers are convinced that growing understanding of mixed dementia, coupled with recognition that vascular changes are the most common coexisting brain change, may create an opportunity to reduce the number of people who develop dementia. Controlling overall risk factors for diseases of the heart and blood vessels may also protect the brain from vascular changes.

M.1.1.5 Other types of dementia

Creutzfeldt-Jakob disease

Prion diseases, such as Creutzfeldt-Jakob disease, occur when prion protein, which is found throughout the body but whose normal function isn't yet known, begins folding into an abnormal three-dimensional shape. This shape change gradually triggers prion protein in the brain to fold into the same abnormal shape. CJD causes a type of dementia that gets worse unusually fast. More common causes of dementia, such as Alzheimer's, dementia with Lewy bodies and frontotemporal dementia, typically progress more slowly.

Through a process scientists don't yet understand, misfolded prion protein destroys brain cells. Resulting damage leads to rapid decline in thinking and reasoning as well as involuntary muscle movements, confusion, difficulty walking and mood changes. CJD is rare, occurring in about one in 1 million people annually worldwide.

Experts generally recognize the following main types of CJD:

Sporadic CJD develops spontaneously for no known reason. It accounts for 85 percent of cases. On average, sporadic CJD first appears between ages 60 and 65.

Familial CJD is caused by certain changes in the chromosome 20 gene coding the biological blueprint for prion protein. People who develop familial CJD do so because they inherited the genetic changes from a parent. Familial CJD accounts for about 10 to 15 percent of cases. It develops, on average, at a younger age than sporadic CJD, with some genetic types appearing as early as ages 20 to 40.



Acquired CJD results from exposure to an external source of abnormal prion protein. These sources are estimated to account for about 1 percent of CJD cases. The two most common outside sources are:

- Medical procedures involving instruments used in neurosurgery, growth hormone from human sources or certain transplanted human tissues.
- Meat or other products from cattle infected with bovine spongiform encephalopathy ("mad cow disease"), recognized in the mid-1990s as the cause of variant CJD (vCJD). Scientists traced this new type of CJD to consumption of beef from cattle whose feed included processed brain tissue from other animals.

Frontotemporal dementia

The nerve cell damage caused by frontotemporal dementia leads to loss of function in these brain regions, which variably cause deterioration in behaviour and personality, language disturbances, or alterations in muscle or motor functions. There are a number of different diseases that cause frontotemporal degenerations. The two most prominent are:

- a group of brain disorders involving the protein tau
- a group of brain disorders involving the protein called TDP43.

For reasons that are not yet known, these two groups have a preference for the frontal and temporal lobes that cause dementia.

FTD used to be called Pick's disease after Arnold Pick, M.D., a doctor who in 1892 first described a patient with distinct symptoms affecting language. Some doctors still use the term "Pick's disease." Other terms you may see used to describe FTD include frontotemporal disorders, frontotemporal degenerations and frontal lobe disorders.

Less occurring types of dementia

Other types of dementia where the brain function is affected include:

- Huntington's disease
- Normal Pressure Hydrocephalus
- Posterior Cortical Atrophy
- Parkinson's Disease Dementia
- Korsakoff Syndrome

To find out more about these other less common types of dementia, online sources can provide some initial overview.

M.1.1.6 Tests for diagnosing dementia

There's no single test for dementia. A diagnosis is based on a combination of assessments and tests. These may be done by a GP or a specialist at a memory clinic or hospital.

Taking a history



This is usually done by a GP. If the patient is referred to a specialist, a more detailed history will be taken. It helps if someone who knows the patient well is also with them, as they can help describe any changes or problems they've noticed.

The doctor will:

- ask how and when symptoms started and whether they're affecting daily life
- check whether any existing conditions, such as heart disease, diabetes, depression or stroke, are being properly managed
- review any medication the patient is taking, including prescribed medicines, those bought over the counter from pharmacies, and any alternative products, such as vitamin supplements

Mental ability tests to diagnose dementia

People with symptoms of dementia are given tests to check their mental abilities, such as memory or thinking. These tests are known as cognitive assessments, and may be done initially by a GP. There are several different tests. Probably the most common one used by GPs is the General Practitioner Assessment of Cognition (GPCOG).

Although these tests can't diagnose dementia, they may show there are memory difficulties that need further investigation. Most tests involve a series of pen-and-paper tests and questions, each of which carries a score. These tests assess a number of different mental abilities, including:

- short- and long-term memory
- concentration and attention span
- language and communication skills
- awareness of time and place (orientation)

It's important to remember that test scores may be influenced by a person's level of education. For example, someone who can't read or write very well may have a lower score, but they may not have dementia. Similarly, someone with a higher level of education may achieve a higher score, but still have dementia.

Blood tests to check for other conditions

The GP will arrange for blood tests to help exclude other causes of symptoms that can be confused with dementia. In most cases, these blood tests will check:

- liver function
- kidney function
- thyroid function
- haemoglobin A1c (to check for diabetes)
- vitamin B12 and folate levels

If the doctor thinks the patient may have an infection, they may also ask them to do a urine test or other investigations.



Dementia brain scans

Brain scans are often used for diagnosing dementia once the simpler tests have ruled out other problems. Like memory tests, on their own brain scans can't diagnose dementia, but are used as part of the wider assessment. Not everyone will need a brain scan, particularly if the tests and assessments show that dementia is a likely diagnosis. These scans may also be used to check for evidence of other possible problems that could explain a person's symptoms, such as a stroke or a brain tumour.

An MRI scan is recommended to:

- help confirm a diagnosis of dementia and the type of disease causing the dementia
- provide detailed information about the blood vessel damage that occurs in vascular dementia
- show shrinkage in specific areas of the brain – for example, the frontal and temporal lobes are mainly affected by shrinkage in frontotemporal dementia, while usually just the temporal lobes are affected in the early stages of Alzheimer's

A CT scan can be used to check for signs of stroke or a brain tumour. But it can't provide detailed information about the structure of the brain. Even if a brain scan doesn't show any obvious changes, this doesn't mean someone doesn't have dementia.

Other types of scan, such as a SPECT scan or a PET scan, may be recommended if the result of the MRI or CT scan is uncertain. Most people won't need these types of scans, however. Both SPECT and PET scans look at how the brain functions, and can pick up abnormalities with the blood flow in the brain. If a specialist is worried that epilepsy may be causing the dementia symptoms, an EEG may be taken to record the brain's electrical signals (brain activity), but this is rare.

FURTHER READING: Please, refer to the [Alzheimer's society cognitive assessment toolkit](#)

M.1.2 How to deal with dementia patients

Professional and home-based carers looking after someone who has dementia are likely to face many practical issues in their daily life.

People with dementia can feel vulnerable as their condition progresses and they increasingly rely on other people to do things for them. It is important that people who have dementia feel reassured and supported, while retaining some level of independence. Although some symptoms are common to many people with dementia, each person's experience of the disease and how they cope with it will be different.

Helping someone with dementia 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. If you are looking after someone with dementia, 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 look after 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.

How you can help:

The main way you can help someone with dementia is by offering support sensitively and try not to be critical of what they do. It can be very important for the person with dementia to feel that they're still useful. In the early stages, memory aids can be used around the home 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.

Keeping up hobbies and interests when someone has dementia

Many people with dementia will still enjoy their hobbies or interests. For example, if they like cooking, they may be able to help make a meal. Going for a walk or gardening is a simple way to get some exercise and a sense of achievement. 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. However, they may struggle to keep up with conversations if they have a lot of visitors at the same time.

Maintaining good health and nutrition in someone with dementia

It's important that the person you care for has a healthy, balanced diet and gets some exercise. The longer they stay fit and healthy, the better their quality of life will be. If you want some easy exercises, look online for some sitting exercises. 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 food-related 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

This behaviour is usually due to confusion, or irritation in the mouth caused by dental problems, rather than wanting to be awkward. If you're concerned about the person's eating behaviour, speak to their GP.

How you can help:



- Involve the person you care for. For example, if they cannot feed themselves, 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 able to.
- Try to 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.
- 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 their GP or dentist. You could also contact a local carers' group to speak to other people who may have experienced similar difficulties.
- If the person 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 if this is recommended alongside any medication they make take. If in doubt, ask their GP.

Dealing with incontinence in someone with dementia

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 also have lost the ability to tell when they need the toilet.

How you can help:

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 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 – you may be able to get these through a care and support needs assessment.

If you're still having problems with incontinence, ask your GP to refer you to a continence advisor, who can advise on things like waterproof bedding or incontinence pads.

Helping someone with dementia with their 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.

Helping someone with dementia sleep well

People with dementia often experience disturbed sleep. They may wake up during the night or be restless. These problems may get worse as the illness progresses. People with dementia may also have painful illnesses such as arthritis that cause, or contribute to, sleep problems. Some medication can cause sleepiness during the day and interfere with sleep at night. Sleeping pills can be used with care in people with dementia. However, "sleep hygiene" measures are best for people with dementia – for example, no naps during the day, regular bedtimes, and avoiding alcohol or caffeine at night.

Taking care of carer's own wellbeing

When you care for someone who has dementia, you may find it difficult to stay positive. Remember that you are not alone, and that help and support is available. Talk to someone about your worries. This could be a family member or friend, a member of your local dementia support group, or your GP can refer you to a counsellor in your area.

It is important for a carer's physical health and psychological wellbeing that they are able to take a break (respite) from care. Carers may also need respite care if they have to go into hospital or meet other important commitments.

Friends, relatives and neighbours can provide respite care at home. You can also arrange home respite care through home care agencies or, in some areas, your local authority. Care away from home can confuse some people with dementia, both while they are away and when they come back. If you decide on respite care away from the person's home, it is a good idea to visit beforehand to check that it meets the needs of the person with dementia.

Caring for someone with dementia can be frustrating and stressful at times, but there are many organisations that can help. Research online what's available to you in your local area.

M.1.2.1 Validation therapy

Validation is a method of communicating with and helping disoriented people often with dementia. It is a practical way of working that helps reduce stress, enhance dignity and increase happiness. Validation is built on an empathetic attitude and a holistic view of individuals. When one can "step into the shoes" of another human being and "see through their eyes," one can step into the world of disoriented very old people and understand the meaning of their sometimes bizarre behaviour.

Validation theory explains that many very old disoriented people, who are often diagnosed as having Alzheimer type dementia, are in the final stage of life, trying to resolve unfinished issues in order to die in peace. Their final struggle is important and we, as caregivers, can help them. Using Validation techniques we offer disoriented elderly an opportunity to express what they wish to express whether it is verbal or non-verbal communication. Validation practitioners are caring, non-judgemental and open to the feelings that are expressed. When disoriented elderly can express the things that have often been suppressed for many years, the intensity of the feelings lessen, people communicate more and are less likely to withdraw into further stages of disorientation.



Validation has three basic components

1. Validation is a theory that very old people struggle to resolve unfinished life issues before death. Their behaviour is age-specific. Their movements reflect human needs. Validation is a way of classifying their behaviours into four progressive stages:

- Malorientation- Expressing past conflicts in disguised forms.
- Time confusion- No longer holding onto reality; retreating inward.
- Repetitive motion- Movements replace words and are used to work through unresolved conflicts.
- Vegetation- Shuts out world completely and gives up trying to resolve living issues.

Each phase has specific physical and psycho-social characteristics.

2. Validation is based on a basic, empathetic attitude that respects and values very old people without judgment.

3. Validation includes specific techniques for individual as well as group work, based on the needs of the individual and their phase of resolution.

Watch this video by Naomi Feil, the person behind the Validation therapy principles to get an initial idea about Validation Therapy. <https://www.youtube.com/watch?v=NPstZUTqUFw>

Validation principles

Principles were created by Naomi Feil, apply to maloriented and disoriented elderly often suffering from dementia; they help guide our actions and determine the Validating Attitude. Theoretical assumptions/bases are created by other theorists, apply to the general population (not specific to disoriented elderly) and are useful in supporting Validation Principles when challenged by scientists or academics. Our Actions/behaviour flow out of the Principles and support the Validation techniques.

1. All very old people are unique and worthwhile.

Example: A 90 year old woman lives in a nursing home. The caregiver calls her “sweetie” or mama or grandma.” Validation: Caregivers address her as “Mrs. Smith.”

Validation Worker (V/W) action: we address older people in a respectful way and treat each person as an individual.

Theory: from Humanistic psychology (Maslow, Rogers, etc.): know your client as a unique individual.

2. People with dementia should be accepted as they are: we should not try to change them.

Example: a 90 year old woman demands her breakfast after she has just eaten. The nurse does not say: “Honey, its 8 o’clock. You just finished all your breakfast. You can’t be hungry”.

Validation: we know that this woman is perhaps psychologically hungry for her family, for love. We ask, ‘what fills you up?’



V/W action: we do not try to change the person's behaviour; we accept it and try to help the individual fulfil the needs that are being expressed.

Theory: from Humanistic psychology (Rogers, Maslow, etc.): accept your client without judgment. Additionally, Freud said that the therapist cannot give insight or change behaviour if the client is not ready to change or does not have the cognitive capacity for insight.

3. Listening with empathy builds trust, reduces anxiety and restores dignity.

Example: A woman angrily declares that the caregiver threw a basin of water over her clothes and now she's all wet. The trusted, familiar Validation caregiver rephrases, asks, "Does that happen every morning?" "Yes, every morning." "Is there a morning when she doesn't throw water over you?" "Well, only when the very, nice, young lady comes to look in on me in the night. She asks if I need to go to the toilet. You see, I'm getting older now and I have a problem sometimes with pee-pee."

V/W action: we understand that this woman is ashamed of being incontinent and empathize with the feelings of the older person without concentrating on the "truth" of the facts.

Theory: from Humanistic psychology, most especially Rogers who focused his client-centred approach on using empathy.

4. Painful feelings that are expressed, acknowledged and validated by a trusted listener will diminish. Painful feelings that are ignored or suppressed will gain in strength

Example: An old woman gets up at 3.30 every afternoon to go home to her children. When staff says, "Sit down. Everything's OK." She gets more and more nervous and upset. When staff asks, "What is the worst thing that can happen to your children?" The old woman expresses her vivid memory of having left her children alone. Her fears are expressed to a validating caregiver and the old woman feels relieved.

V/W action: we are open to all feelings that are expressed by older people. Through empathy we share these feelings and encourage expression. We acknowledge that disoriented older people freely express emotions in order to heal themselves.

Theory: from Psychoanalytical psychology (Freud, Jung, etc.): "the cat ignored becomes a tiger"

5. There is a reason behind the behaviour of people with dementia.

Example: A woman accuses the cook of poisoning the food. The nurse does not say, "We have the best cook from Paris." The nurse knows the old woman may have been overfed by her mother (instead of loved), and now she expresses anger against the cook. The validating caregiver asks, "What does she put into the soup?"

Example: An old woman refuses to eat soup and vomits each time she is forced to do so. As a Jewish woman during WWII, she hid her identity papers in the soup tureen during a raid at her home.

V/W action: although we do not always know why the person behaves in a certain way, we help him or her express emotions to resolve unfinished business.



Theory: The brain is not the exclusive regulator of behaviour in very old age. Behaviour is a combination of physical, social and intrapsychic changes that happen during the life span. (Adrian Verwoerd is the original source for this, but this idea has been generally accepted by most geriatricians.)

6. The reasons that underlie the behaviour of dementia sufferers can be one or more of the following basic human needs:

Resolution of unfinished issues, in order to die in peace

- To live in peace
- Need to restore a sense of equilibrium when eyesight, hearing, mobility and memory fail.
- Need to make sense out of an unbearable reality: to find a place that feels comfortable, where one feels in order or in harmony and where relationships are familiar.
- Need for recognition, status, identity and self-worth
- Need to be useful and productive
- Need to be listened to and respected.
- Need to express feelings and be heard.
- Need to be loved and to belong: need for human contact
- Need to be nurtured, feel safe and secure, rather than immobilized and restrained.
- Need for sensory stimulation: tactile, visual, auditory, olfactory, gustatory, as well as sexual expression
- Need to reduce pain and discomfort.

And so they are drawn to the past or are pushed from the present in order to satisfy their needs. They: resolve, retreat, relieve, relive, express.

Example: A much disoriented woman kisses her hand. The hand is a symbol of her baby. The woman had an abortion, and now needs to express her guilt. She may not be able to see her hand or be aware of her body's position in space. Her hand feels soft, as if it were her baby. She sees her baby with her mind's eye to resolve her guilt and restore her identity as a good mother.

Example: An old woman moves her fingers like she used to use her typewriter, to maintain her dignity and identity as a typist. She cannot bear being old without a job. To restore balance, she works. A validating caregiver asks, "You certainly did a lot of typing in your life, didn't you?"

V/W action: We accept that very old people are in the final life stage, "Resolution"; we accompany them in the process; we accept that they are often in a personal reality and see this as a wise and healing response to an unbearable present reality.

Theory: several theories back up this principle:

Maslow's hierarchy of needs

Erikson's life task theory

From Humanistic psychology: human beings struggle for balance/ homeostasis, and are motivated to heal themselves (Rogers particularly)



7. Early learned behaviours return when verbal ability and recent memory fails:

Example: movement of tongue, teeth and lips create new word combinations – it is often an expression of basic human needs; an old woman sucks on her fingers to feel safe and pleasure (like she felt as a baby) and it is self-stimulating – she is alive.

Early learned movement can replace speech when verbal ability fails.

A woman moans: HEALVEN. She tells the worker she needs help from heaven. Her mother is in heaven. She combines images and sounds to form, HEALVEN. The worker asks, “You really miss your mother. Was she always with you when you needed help?”

V/W action: We calibrate the breathing, movements, gestures, body tension, mirror movements and sounds. That allows us to get onto the same wavelength as the old person and meet them where they are in that moment, even if we can’t explain their behaviour logically.

Theory: Piaget’s theory: movement comes before speech in human cognitive development.

8. Personal symbols used by elderly with dementia are people or things (in present time) that represent people, things or concepts from the past that are laden with emotion.

Example:

Person: An old man who has been oppressed by his father, accuses the administrator of tying him up at night; a doll is treated like a baby.

Concept: A wedding ring can represent love, a handbag, the identity or self.

Object: An institutional hall can become a street, a wheelchair can become an auto, an old man who used to be a car mechanic gets under his bed every day to repair a car.

V/W action: we accept that symbols are used to express needs and feelings; we try to explore and react with empathy.

Theory: Freud and Jung wrote extensively about symbols, describing them as representations.

9. People with dementia live on several levels of awareness, often at the same time.

Example: An old woman runs out of the nursing home calling, “mama’; she needs to find her mother. When asked, “Where is your mother?’ the old woman says, “My mother is with the dear Lord.”

V/W action: we never lie to older people because we know that on some level they know what the truth is.

Theory: Freud, preconscious, conscious and unconscious

10. When the 5 senses fail, dementia sufferers stimulate and use their “inner senses’. They see with their “mind’s eye’ and hear sounds from the past.

Example: A mother hears her children calling her – she wants to be a good mother to her children. The validating caregiver asks, “How many children do you have?”



Example: An old mother hears her daughter crying next door. This happens every night. Her 17 year old daughter died and the mother never had enough time to grieve. She wants to express her guilt. The caregiver asks, "What do you miss the most?"

V/W action: when older people see or hear things that we do not, we accept those as being part of their personal reality and understand that they are trying to meet their human needs.

Theory: Wilder Penfield: Human beings can stimulate their brains to recreate vivid visual, auditory and kinaesthetic memories.

11. Events, emotions, colours, sounds, smells, tastes and images create emotions, which in turn trigger similar emotions experienced in the past. Old people react in present time, the same way they did in the past.

Example: A woman hides behind the sofa scared to death each time the meal cart clatters onto the department. She feels the same fear she felt when tanks clattered through the streets of her hometown and bombed her home when she was 4 years old. The worker asks, "Did something terrible happen?"

V/W action: we accept and acknowledge that experiences from the past can be triggered and explore the feelings without judgment and with empathy.

Theory: Early, well-established emotional memories survive to very old age. Schettler & Boyd. Proust Was a Neuroscientist, by Jonah Lehrer, 2007, published by Houghton Mifflin Co., NY

M.1.2.2 Use of language

Great emphasis is put on the use of appropriate language, when dealing with dementia sufferers. In addition to the principles outlined in the previous section about Validation therapy, when faced with uncertain future developments and possibilities, carers should always put the focus on the most promising.

Establishing contact

- eye-contact: establish eye-contact before speaking, avoid speaking from behind or above as the sufferer's eye-sight is reduced to a limited tunnel-like vision. When approaching them or serving them something, make sure it's within this tunnel just in front of them.
- touch: touch lightly, observe (non-)verbal reactions, don't touch and slowly pull back when the patient signals discomfort. The sufferer needs to see where the touch is coming from.
- trigger: use certain signals or rituals to mark the beginning of communication in accordance with the patient's personal profile
- appreciation: avoid showing your own negative emotions
- end of contact: leave the contact situation explicitly and slowly, by increasing spatial distance underlined verbally

Understanding



- signals: are to be perceived as messages not as “strange” behaviour. Physical and verbal aggression can be the last remaining part of ways of communicating, so carers mustn’t take the meaning of words literally. The register of swear words, prayers and singing is the last part of the brain to be affected.
- personal profile: has to be done and documented thoroughly to be used by all carers of a certain patient
- nonverbal communication: nonverbal or paraverbal signals have to be observed and respected
- emotions: have to be taken seriously
- joining in: join in movements and actions in order to understand and signal understanding
- looking for words: help with finding words after a certain amount of time

Impairment

- attention: make sure that you have patient’s attention
- level of speech: try sending signals on several levels of speech, i.e. underlining speech by corresponding nonverbal communication
- register, pitch: find out which register and pitch are preferred by the patient and use it correspondingly
- short sentences: send only one message per sentence but on several speech levels
- closed questions: use closed questions to avoid confronting the patients with their decreasing mental abilities
- concrete topics: try avoiding abstract topics

M.1.2.3 Decatastrophising

Research suggests that between 38 and 72% of people with dementia may suffer with anxiety, especially in early stages of dementia. It has a negative impact on cognitive impairment and is associated with agitation and poor quality of life. The presence of excessive anxiety can be difficult to establish in people with dementia, especially when expressive or receptive speech is impaired. Unfortunately, there is a lack of research on the treatment of anxiety in dementia, and also on the wider issue of the management of anxiety disorders in old age.

There is, however, a commonly used technique called Decatastrophising based on the Cognitive Behaviour Therapy (CBT). The basic cognitive model of anxiety assumes that it generally involves a tendency to over-estimate the severity and probability of danger and to under-estimate one’s ability to cope well with adversity. Our greatest hopes and worst fears are seldom realised, as the saying goes. Decatastrophising is the term for a strategy commonly used in CBT to help people suffering from worry to re-appraise the things they’re anxious about. It can be broken down into the following steps:

- Identify and elaborate the feared worst-case scenario, and rate its severity 0-100%, probability 0-100% and your ability to cope 0-100%.
- Optionally, identify and elaborate the best-case scenario, and rate its severity, probability and your ability to cope.



- Identify and elaborate the most-likely scenario, and rate its severity, probability and your ability to cope.
- Develop a detailed and comprehensive coping plan, and finally re-rate the severity and probability of the feared outcome and your ability to cope.

When people rate the “severity” of a situation, or how “bad” or upsetting it seems, the first number they come up with is usually 100% or maybe slightly lower. However, if you rate your problems at the top end of the scale, it can encourage you to magnify how bad they are. A helpful tip is to imagine the worst catastrophe that could actually befall you in life, something horrendous like all of your family being kidnapped and tortured, etc. Think of 100% severity as representing absolutely the most upsetting thing that you could imagine. Now pause for thought and reconsider how severe or upsetting the problems you’re currently facing actually are by comparison. They’re probably not really 100%, relatively speaking, but fall a bit lower on the severity scale. Keep that in mind because it will help you to adopt a more balanced perspective throughout the whole exercise.

Here is a short list of questions a carer can use with a dementia sufferer to “decatastrophise” the situation that the patient seems to be anxious about.

What is the catastrophe that you are worried about?

Phrase as precisely/concretely as possible. Rephrase all what if – questions into clear predictions and statements about what it is, that you’re afraid of or what’s going to happen.

What exactly are you afraid of? What do you predict is going to happen?

In the worst case, how would you be able to cope?

Who could you ask for advice? Who could you speak to about your fears? Which resources, abilities or skills could be helpful for you?

What would you say to yourself about the catastrophe?

What would you like to hear to calm yourself? In what pitch of voice would you like to hear this?

M.1.3 Role of the professionals

Along with aging population come increased numbers of dementia sufferers, so European governments, local authorities and national health services have put in place care systems to address the increasing need for support.

M.1.3.1 Medical support and forms of therapies

SECTION M.1.3.1 NEEDS LOCALISING DEPENDING ON THE SITUATION IN EACH PARTNER COUNTRY!!!

A dementia diagnosis can come as a shock to the person with the condition and those around them. However, there are sources of help and support for everyone involved. In the UK the National Health Service coordinates the different providers of care.

Patient’s care plan



Following a diagnosis of dementia, a patient should have a care plan. This should set out what sort of care the patient and people who care for them might need. It's not the same as a needs assessment.

The care plan should include:

- how the patient can keep doing the things that are important to them for as long as possible
- information about services that can help them and how to access them
- any health conditions the patient has that need regular monitoring
- the name of a health or social care person who will coordinate the different kinds of support the patient may need

The care plan should be reviewed at least once a year. A memory assessment service, the social services department of the local council or the GP will help develop the care plan, together with the patient's carer, if they have one, and other family members.

A needs assessment

If the patient finds they need help to manage everyday tasks like washing, dressing or cooking, it's advisable to get a needs assessment from the social services department of the local council. Ideally, this assessment should take place face to face. It's a good idea to have a relative or friend with the patient if they're not confident explaining their situation. They can also take notes for the patient.

If the needs assessment identifies the patient needs help such as a carer to help with personal care (washing and dressing), meals delivered to their home (meals on wheels), or a personal alarm, they will then have a financial assessment (means test) to see how much the patient will contribute to the cost of their care.

The carer of a dementia sufferer may also be eligible for Carer's Allowance and support from their local council. Before the carer receives any help from their local council, they should ask for a carer's assessment.

If a person with dementia has care needs that relate mainly to their health, they may qualify for free NHS continuing care, which will be assessed by NHS staff.

Care options for people with dementia

Living in their own home

Many people with mild-to-moderate dementia are able to stay in their own home and live well if they have adequate support. Being in familiar surroundings can help people cope better with their condition. Their home can be made dementia friendly.

Moving into a care home

As the symptoms of dementia will get worse over time, many people eventually require support in a care home. Depending on their needs, this could be a residential care home or a nursing home that offers services for people with dementia. If the carer has been caring for a partner or relative with dementia, this can be a difficult decision to take. They should talk through their concerns with friends and family. The carer will still be involved in the care and support of the person with dementia after



they move to a care home. The carer may be able to arrange a trial period in a care home for the person they care for. The local council will have to carry out another needs assessment to confirm the need to go into a care home and a financial assessment to decide how much the person will have to pay towards their care home fees. Residential and nursing homes are inspected by the Care Quality Commission (CQC).

Admiral Nurses

Admiral Nurses are registered nurses and experts in dementia care. They give practical, clinical and emotional support to families living with dementia to improve their quality of life and help them cope. Admiral Nurses work in the community, care homes, hospitals and hospices. They also run a helpline for carers, people with dementia, and health and social care professionals.

Charities for people with dementia

There are several dementia charities that offer advice and support. One of the main dementia charities is **Alzheimer's Society**. Its website has information on all diseases that cause dementia, not just Alzheimer's disease, including how to live well with dementia and how to find help and support near you. It also runs the National Dementia Helpline on for information and advice about dementia.

Dementia UK is a national charity that aims to improve the quality of life for people with dementia. It offers advice and support to families who are living with dementia through its Admiral Nurses, who are registered nurses and dementia experts.

Alzheimer's Research UK carries out dementia research but also answers questions about dementia and dementia research, including how the patient and their family and friends can get involved. The charity's infoline can provide help and guidance.

Age UK has advice on a range of topics, including advance care planning, benefits and choosing a care home, as well as information on local activities and services for those with dementia. It also runs a free national helpline.

The Carers Trust provides information and advice on its website for carers, including how to get support for themselves.

Carers UK is a national charity for carers, providing information and advice from benefits to practical support.

Join a forum

Online forums are a good way to share experiences of living with dementia or caring for someone with dementia, as well as reading what others are going through.

Talking Point is the Alzheimer's Society's forum. It has people with dementia sharing their information and advice, and supporting each other. Carers can also turn to online communities on the **Carers UK forum**.

Dementia books on prescription



Reading Well Books on Prescription for dementia offers support for people diagnosed with dementia, their relatives and carers, or for people who would just like to find out more about the condition. GPs and other health professionals can recommend titles from a list of 37 books on dementia. The books are available for anyone to borrow free from their local library.

M.1.3.2 Reality oriented therapy (Reality Orientation)

What Is Reality Orientation?

Reality orientation has its roots in a technique used with disabled veterans to help them engage in, and connect with, their surroundings. It's an approach where the environment, including dates, locations, and current surroundings, is frequently pointed out and woven into the conversations with the person. Reality orientation, when used appropriately and with compassion, can also benefit those living with dementia

Is Reality Orientation Helpful in Dementia?

Multiple studies have demonstrated that the use of reality orientation has improved cognitive functioning for people living with dementia when compared to control groups who did not receive it. Reality orientation also has been shown to improve cognition when accompanied by medication. According to the British Journal of Psychiatry, the use of reality orientation by trained family members when coupled with medication (donepezil) demonstrated an improvement in cognitive functioning, although it did not affect mood or behaviour. One study found that the use of reality orientation may delay nursing home placement by slowing cognitive decline.

Furthermore, after reviewing six randomized controlled trials, a study in the Cochrane Library concluded that there may be some benefit for not only cognition, but also in the challenging behaviour of some people with dementia. Challenging behaviours in dementia often reduce quality of life and may precipitate nursing home placement.

Strategies for Reality Orientation

- Talk about orientation, including the time of day, the date, and the season
- Use the person's name frequently
- Discuss current events
- Refer to clocks and calendars
- Place signs and labels on doors and cupboards
- Ask questions about photos or other decorations

How Does Reality Orientation Contrast with Validation Therapy?

Reality orientation has, until more recently, experienced a decline in popularity over the years, especially in comparison to validation therapy. This is due, in large part, to a concern of people applying the reality orientation broadly without taking into account the person's emotions and mental health.

In contrast to reality orientation, validation therapy emphasizes the feelings behind the behaviours or statements. It encourages the person to talk about the reality they're in (rather than the one we know to be true), and believes that by processing some perhaps unresolved issues, they'll eventually be able to be more at peace.

Strict reality orientation could result in a harsh imposition of the "real" reality and a heartless response to the question, "Where is my mother?" Someone using pure reality orientation would



respond, "She died a long time ago. You're 92 and your mother couldn't possibly be alive today." Validation therapy, meanwhile, would acknowledge the person's feelings, ask questions about the person's mother, and ask what you missed most about her.

Cautions about Reality Orientation

As seen above, reality orientation must be mixed with compassion and used appropriately to benefit someone living with the confusion of dementia. Applying it, without evaluating, if it might cause emotional distress to the individual, would not be appropriate.

In many situations such as casual daily conversations, reality orientation can be used to help cue the person as to the setting around them. However, if the person to whom you're talking becomes more upset instead of less so, it's a safe bet that you should back off your attempts to orient and let compassion drive your conversation by joining their reality.

Clearly, those who use reality orientation must apply sensitivity and wisdom. In clinical and home settings, an understanding of both validation therapy and reality orientation is beneficial. Depending on the person's emotional state, personality and situation, the response that is most beneficial to the individual can then be used.

M.1.3.3 Cognitive stimulation therapy

There are a number of interventions or approaches to help people with dementia improve their memory and thinking skills to enable them to cope better with memory loss. One of the interventions for which there is most evidence in terms of clinical and cost-effectiveness is Cognitive Stimulation Therapy (CST).

Key points:

- CST has been found to help the memory and thinking skills of people with mild to moderate dementia. Studies have mainly been conducted with people with Alzheimer's disease or mixed dementia, but CST would be relevant to all.
- People with dementia who took part in the therapy group reported improved quality of life
- CST was found to be a cost-effective intervention and offers value for money
- National Institute for Health and Care Excellence (NICE) and Social Care Institute for Excellence (SCIE) guidance (2006) recommend that people with mild to moderate dementia should be given the opportunity to take part in a CST programme.

What is CST?

In the United Kingdom CST involves 14 sessions of structured 45-minute group therapy sessions. Sessions run twice a week over 7 weeks and each one covers a different theme. To make sure that there is continuity between the sessions they include the same structure, such as the warm-up activity, a song and a 'reality orientation board' at the beginning of every session which has information on the group, details including date, time, place, weather. Members give their group a name and sessions cover a range of activities to stimulate thinking, memory and to connect with others such as by:

- discussing current news stories
- listening to music or singing



- playing word games
- doing a practical activity such as baking which involves measuring ingredients and following a recipe.

The sessions are intended for people with mild to moderate dementia. They are designed to be relaxed, fun and to create opportunities for people to learn, express their views and work with others in a sociable setting. A training manual and DVD have been developed with guidance on how to plan and run the sessions and different ways to check progress. The manual has been translated and adapted for other cultures and countries.

There is a maintenance programme of CST that can be followed after the initial seven weeks of the CST programme. Maintenance CST (MCST) consists of an additional 24 weekly sessions that follow the same structure and principles as the CST programme, with a specific theme including orientation-based activity, refreshments and a group song.

Is CST effective?

CST has been found to benefit the memory and thinking skills of people with mild to moderate dementia. People with dementia who took part in the therapy programme reported improved quality of life. Some carers and relatives reported an improvement in language and the willingness of people with dementia to join in conversations.

In the original randomised controlled trial (RCT) most of the people with dementia were living in care homes and in a second study half were living in the community and half in care homes. The first trial found that CST worked as well as standard anti-dementia medication and the second study found that CST had benefits for people in addition to those from the anti-dementia medication they were taking.

Maintenance CST has also been evaluated in an RCT in which 236 people with dementia, who had previously completed 14 sessions of standard CST, took part. MCST helped improve the quality of life of those taking part: this was observed from self-reports by people with dementia at 6 months, and also from reports by their family or other carers at 3 months.

However, there was no difference in cognition between those who only took part in the original CST programme and those who continued with the MCST sessions. This may be due to the potential for improvements in cognition already having been achieved by CST.

Some of the people in the MCST trial were taking anti-Alzheimer medication, usually donepezil. The combination of medication and MCST resulted in better cognition than either of these treatments alone.

CST is now offered to people with dementia in NHS trusts and through memory clinics, with approximately 80% of UK memory services currently offering CST to some patients.