

# DEMENTIA THE FAQS



**JEWISH CARE**

We believe that as a community we need to both understand dementia better and ensuring we are working together to support each and every one of us effected by it.

It is inevitable that dementia will touch us all at some time in our lives.

Our vision is for the Jewish community to be a 'dementia friendly community'. This is defined by the Alzheimer's Society as a community that shows a high level of public awareness and understanding so that people living with dementia and their carers are encouraged to seek help and are supported by their community.

This isn't something we at Jewish Care can do alone. We are building partnerships with a range of communal organisations from synagogues to friendship groups and are working together, with the tremendous support of volunteers, to improve the lives of people living with dementia.

We hope with an increased understanding and support from across the community those living with dementia will live well and enjoy life to the full.

If you have further questions about dementia or our work please do get in contact, you will find all the numbers you need at the end of this booklet.

A handwritten signature in black ink, appearing to read 'Daniel Carmel-Brown', with a long horizontal flourish extending to the right.

**Daniel Carmel-Brown**

Chief Executive

# 1. WHAT IS DEMENTIA?

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own individual way. It is often the case that the person's family and friends are more concerned about the symptoms than the person may be themselves.

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- Mood changes – people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.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 problems finding the right words for things, for example describing the function of an item instead of naming it.

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

## 2. WHAT CAUSES DEMENTIA?

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

- Alzheimer's disease – The most common cause of dementia. 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.
- 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.
- 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.
- Fronto-temporal dementia (including Pick's disease) – In front-temporal dementia, damage is usually focused in the front part of the brain. Because the frontal lobes control judgement and social behaviour, personality and behavioural changes are the most obvious signs, rather than memory loss.

## 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.

## 3. WHO CAN GET DEMENTIA?

- There are about 750,000 people in the UK with dementia.
- Dementia mainly affects people over the age of 65 and the likelihood increases with age. However, it can affect younger people: there are over 16,000 people in the UK under the age of 65 who have dementia.
- Dementia can affect men and women.
- Scientists are investigating the genetic background to dementia. It does appear that in a few rare cases the diseases that cause dementia can be inherited. Some people with a particular genetic make-up have a higher risk than others of developing dementia.

## 4. 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 or stabilise some of the symptoms in the early to middle stages, for some forms of dementia.

- Aricept
- Exelon
- Reminyl

## 5. HOW CAN I TELL IF I HAVE DEMENTIA?

Many people fear they have dementia, particularly if they think that their memory is getting worse or if they have known someone who has had the illness. Becoming forgetful 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, depression and in rare cases dementia-like symptoms may be caused by vitamin deficiencies and or a brain tumour.

The early signs of dementia can be subtle and vague and may not be immediately obvious.

Some common symptoms may include:

- Progressive and frequent memory loss
- Confusion
- Personality change

- Apathy and withdrawal
- Loss of ability to perform everyday tasks.

If you are worried about yourself, or someone close to you, it is worth discussing your concerns with your GP.

## **6. HOW DO I GO ABOUT DIAGNOSING DEMENTIA?**

It is very important to get a proper diagnosis. A diagnosis will help the doctor rule out any illnesses that might have similar symptoms to dementia, including depression. Having a diagnosis may also mean it is possible to be prescribed drugs for Alzheimer's disease. Whether you are someone with dementia or a carer, a diagnosis can help with preparing and planning for the future.

Dementia can be diagnosed by a doctor - either a GP or a 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 to check basic thinking processes and the ability to perform daily tasks. They may request further tests, such as a brain scan or a more in-depth assessment of memory, concentration and thinking skills.

## 7. CAN DEMENTIA BE PREVENTED?

At present, it is not clear what causes most of the diseases that lead to dementia. It is not clear what can be done to prevent dementia itself but 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.

## 8. WHAT IS THE DIFFERENCE BETWEEN ALZHEIMER'S DISEASE AND DEMENTIA

Dementia is an umbrella term resulting in loss of cognitive brain function. Possible causes are:



## 9. WHAT ARE THE SYMPTOMS OF THE DIFFERENT TYPES OF DEMENTIA?

Dementia is a very individual condition and not everyone will experience it in the same way. Some people may live with multiple (mixed) dementias.

### ALZHEIMER'S DISEASE

Alzheimer's is a degenerative disease when cells die and cause a breakdown of connections in the brain. This may lead to the following symptoms:

- Forgetful of recent memory, names and events
- Repetitive questioning
- Misplacing items, or putting them in odd places
- Confusion around day-time and night-time, time and seasons
- Disorientation in previously familiar surroundings
- Getting lost
- Problems finding the right words
- Mood, personality or behaviour changes
- Problems with going to the toilet
- Inability to learn new tasks

## VASCULAR DEMENTIA

This develops when brain cells are deprived of oxygen and die after a major stroke or a series of smaller strokes. This may lead to the following symptoms:

- Memory problems
- Disorientation
- Communication problems
- Becoming slower in thinking
- Personality changes including depression and apathy
- Becoming more emotional
- Difficulty walking
- Frequent urge to go to the toilet or other bladder symptoms

## DEMENTIA WITH LEWY BODIES

DLB is a progressive condition which worsens over time, caused by small round clumps of proteins which build up inside the nerve cells in the brain. This may lead to the following symptoms:

- Variations in attention, alertness and confusion. Fluctuations noticeable day to day or hour by hour
- Parkinson's like symptoms e.g Slowness in walking, stiffness in limbs, sometimes tremors
- Fainting and falls

- Visual hallucinations, often seeing animals or people who aren't really there
- Movements during sleep and vivid dreams
- Symptoms very similar to Alzheimer's Disease such as memory loss and disorientation

## **POSTERIOR CORTICAL ATROPHY**

Posterior cortical atrophy (PCA) refers to gradual and progressive degeneration of the outer layer of the brain (the cortex) in the part of the brain located in the back of the head (posterior). The symptoms of PCA vary from one person to the next and can change as the condition progresses. This may lead to the following symptoms:

- Difficulties with visual tasks such as reading a line of text
- Judging distances, distinguishing between moving and stationary objects
- Inability to perceive more than one object at a time
- Difficulty identifying and using tools or common objects
- Hallucinations
- Difficulty performing mathematical calculations or spelling
- Anxiety
- Hallucinations
- Disorientation

## FRONTOTEMPORAL DEMENTIA

Frontotemporal dementia (FTD) or frontotemporal degeneration refers to a group of disorders caused by progressive nerve cell loss in the brain's frontal lobes (the areas behind your forehead) or its temporal lobes (the regions behind your ears). This may lead to the following symptoms:

- Loss of inhibitions
- Loss of motivation
- Inappropriate behaviours
- Loss of sympathy or empathy – becoming less responsive to the needs of others
- Development of repetitive, compulsive or ritualised behaviours
- Craving sweet or fatty foods, loss of table etiquette, or binging on 'junk' foods, alcohol or cigarettes
- Personality and behavioural changes

## RARER FORMS OF DEMENTIA

- Creutzfeldt-Jakob disease (CJD)
- HIV-associated neurocognitive disorder (HAND)
- Huntington's Disease
- Multiple Sclerosis (MS)
- Niemann-Pick disease type C
- Parkinson's Disease dementia (PDD)

- Progressive Supranuclear Palsy
- Corticalbasal Degeneration
- Visual Variant dementia

## **10. CAN A PERSON WITH DEMENTIA STILL DRIVE?**

Someone who is diagnosed with dementia may be able to continue driving for some time. What matters from a legal and practical point of view, is whether the person is still able to drive safely. They must fulfil certain legal requirements which include informing the DVLA of their diagnosis and their car insurance company.

The DVLA will take up medical enquiries and then make the decision as to whether the person can continue to drive, they will then issue a new driving licence which will be valid for one year up to a maximum of three years with regular reviews.

As a person's dementia progresses, they will lose the ability to drive. The stage at which this happens will be different for each person but, according to research, most people stop driving within three years after the first signs of the disease.

## **11. SHOULD A PERSON TELL FRIENDS AND FAMILY THAT THEY HAVE BEEN DIAGNOSED WITH DEMENTIA?**

People with dementia will need support and assistance from others as they experience changes brought on by the disease. While telling friends and family may cause some emotional stress, it is important to tell people early on so that an effective and caring support network of family and friends can be established.

# **JEWISH CARE SERVICES**

**DEMENTIA IS A JOURNEY AND JEWISH CARE IS HERE TO HELP SUPPORT YOU AND YOUR FAMILY THROUGHOUT THE VARIOUS STAGES, WITH A RANGE OF SERVICES INCLUDING**

## **HOME CARE**

Our flexible home care service offers a personal approach from accompanying a client to a wedding or party, to full personal care. High quality care is available 24 hours a day, 365 days a year.

## **BENEFITS ADVICE**

Benefit Advisors are available either at the end of the phone or in person, to give practical advice on the UK benefits system and eligibility criteria.

## **COMMUNITY SUPPORT AND SOCIAL WORKERS TEAM**

The team is here to help enable you to find the right support and services to meet your needs, however small or complex they may be. They can also work with external bodies such as your local authority, doctors or hospitals and can act as an advocate on your behalf.

## **FAMILY CARERS**

For those looking after a relative or family members who are affected by dementia, the family carers team offers a confidential and empathetic support network.

## ACTIVITY GROUPS

We currently have two popular Memory Cafes in Golders Green and Redbridge and a Singing for the Brain group in partnership with the Alzheimers Society. All of these groups are designed for both the person living with dementia and their partner to share experiences and have fun.

## CENTRES FOR PEOPLE LIVING WITH DEMENTIA

These centres offer a fun and stimulating environment offering a much needed respite for carers and families. The highly trained team ensures their clients feel supported and cared for whilst helping to enhance their ability to continue to live in their own homes.

## CARE HOMES

Jewish Care offers the best in dementia residential and dementia nursing care in several homes throughout London, Essex and Brighton. Our care teams receive ongoing dementia training and deliver care with respect, patience and love.

**IF YOU WOULD LIKE TO FIND OUT MORE ON ANY OF THESE SERVICES, PLEASE CONTACT JEWISH CARE DIRECT OUR CONFIDENTIAL HELPLINE ON 020 8922 2222 OR EMAIL THEM ON [HELPLINE@JCARE.ORG](mailto:HELPLINE@JCARE.ORG) OR FIND OUT MORE ABOUT OUR SERVICES BY VISITING [WWW.JEWISHCARE.ORG](http://WWW.JEWISHCARE.ORG)**

**JEWISH CARE WORKS IN COLLABORATION WITH A NUMBER OF ORGANISATIONS, CHARITIES AND INDIVIDUALS TO ENHANCE THE QUALITY OF LIFE FOR THEIR CLIENTS LIVING WITH DEMENTIA. THESE INCLUDE:**

- Music for Life (Wigmore Hall and Dementia UK)
- Singing for Memory
- The Eden Alternative
- The Dementia Action Alliance
- Mobility London
- Community Focus (Barnet Arts Depot)
- Gardening Projects
- Choirs and singing groups
- Dance movement therapy
- Visual Arts
- Salmagundi Films-digital arts and animation
- World music percussion
- Story telling
- Textile Art
- Intergenerational Arts Work
- Reminiscence and Storytelling-Oral History Groups
- Musical theatre workshops
- Drama therapy
- Puppetry