# Information Sheet (1)

# Alzheimer's Disease

## Dementia and an Introduction to Alzheimer's Disease

Dementia is a broad category of brain disease, and it comes in numerous forms with different names and symptoms. Alzheimer's Disease (AD) is just one specific type of Dementia. All forms of dementia are irreversible, progressive brain disorders and can have a debilitating effect on the ability to perform Activities of Daily Living (ADL).

AD is the most common cause of dementia among older adults. The signs and symptoms of AD slowly destroy memory, thinking skills, perception and eventually, the ability to carry out the simplest task. In the majority of cases, symptoms first appear in the mid 60s to the late 70s. However, as life expectancy increases, more people in their 80s and 90s will be affected by AD and all other forms of dementia.

Up until fairly recently, there hasn't been a great deal of publicity surrounding dementia and AD. There has only been limited attention given or hard evidence and statistics published by mainstream health care agencies concerning AD specifically and dementia in general. It had been left mainly to the Alzheimer's Society to provide much of the data and information out there in the public domain. However, in 2012, David Cameron, the then Prime Minister, launched a national challenge to raise awareness and to fight dementia. The Alzheimer’s Society took up the challenge and launched its own nationwide Dementia Friends initiative. More recently, the new Conservative Government recognised the necessity to have a continued focus on this Challenge and set out a five-year program through the Dementia 2020 Strategy published on 21st February 2015 and through supporting the delivery of NHS Englands five year forward plan.

The Alzheimer’s Society estimates that over 982,000 people are living with dementia in the UK. What is perhaps more concerning is that there may be an equal number of people who are showing signs of some of the symptoms of Dementia but have yet to be diagnosed. To further complicate and confuse matters, it has recently been suggested in the USA that approximately 20% of diagnosed patients may, in fact, have been misdiagnosed and may have other conditions.

If we are to believe recent breaking news, it has been announced that dementia has overtaken both cancer and heart disease as the number one cause of death in the UK.

Dementia in its wider form is the loss of cognitive functioning; thinking, remembering, reasoning, personality changes and behavioural activities to such an extent that it interferes with a person's daily life and activities. Dementia ranges in severity from the mildest stage, when it is just beginning to affect the person's cognitive functioning, to the most severe stage, when the person living with the disease depends completely on caregivers for basic ADLs.

The brain is made up of four lobes; frontal lobe, the parietal lobe, the temporal lobe and the occipital lobe. The causes of dementia can vary depending on the area and type of brain changes that may be taking place.

One of the least common types of dementia is Frontotemporal dementia (FTD), and many people, including some health professionals, may not have heard of it. It is often referred to as Pick's disease after the Czech neurologist Arnold Pick. He first identified patients with personality change and language impairment associated with loss of brain cells in the frontal and temporal lobes in 1892. As the name FTD suggests, it is a progressive loss of cells in the frontal and temporal lobes of the brain. The two main subtypes of FTD are called behavioural variant FTD (bvFTD) and primary progressive aphasia (PPA). PPA can be further split into two main subtypes: semantic dementia (SD) and progressive nonfluent aphasia (PNFA). There is a third subtype, more recently identified and described as Logopenic aphasia (LPA). These three subtypes of FTD are sometimes referred to as a spa, nfvPPA and lvPPA, respectively.

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Dementia with Lewy bodies (DLB), sometimes referred to as Lewy body dementia (LBD), is another form of dementia. It is so called because it was first identified by Frederic Lewy in 1912.

The second most common form is Vascular Dementia, which is caused by reduced blood supply to the brain. There are several different types of vascular dementia. They differ on the cause of the damage and the part of the brain that is affected. Two well-known types of vascular dementia are stroke-related and subcortical dementia. There are two subtypes of post-stroke related dementia: single-infarct or multi-infarct dementia. If symptoms of the stroke last less than 24 hours, this is known as a mini-stroke or transient ischemic attack (TIA). Subcortical dementia is caused by diseases of the very small blood vessels that live deep in the brain.

It is common for people to have mixed dementia, which is a combination of two or more disorders. For example, some people can have both Alzheimer's Disease and Vascular Dementia or Parkinson's Disease Dementia (PDD).

## So what is Alzheimer's disease?

Alzheimer's disease is named after Dr Alois Alzheimer. In 1906, Dr Alzheimer noticed changes in the brain tissue of the woman who had died of an unusual mental illness. Her symptoms included memory loss, language problems and unpredictable behaviour. After she died, he examined her brain and found many abnormal clumps, which are now called amyloid plaques. He also found tangled bundles of fibres, now called neurofibrillary or tau tangles.

These plaques and tangles in the brain are still to this day considered some of the main features of AD, and worldwide research is being carried out in this area. Another feature is the loss of connections between neurons, the nerve cells in the brain. Neurons transmit messages between different parts of the brain and from the brain to the muscles and organs in the body.

## Changes in the Brain

Scientists continue to unravel the complex brain changes involved in the onset and progression of AD. It seems likely that damage to the brain starts a decade or more before memory and other cognitive problems appear. During this preclinical stage, people seem to be symptom-free, but toxic changes are progressively taking place in the brain. Abdominal deposits of proteins form amyloid plaques and tau tangles

throughout the brain. Once healthy neurons stop functioning and lose connections with other neurons, they begin to die.

The damage initially appears to take place in the hippocampus, the part of the brain essential in forming memories. As more neurons die, additional parts of the brain are affected, and they begin to shrink (atrophy). The next stage affects the amygdala, the part of the brain that plays a key role in our emotional feelings. By the final stage of AD, damage is widespread and brain volume has shrunk significantly.

## Signs and symptoms

Memory problems are typically one of the first signs of cognitive impairment related to AD. Some people with memory problems have a condition called 'mild cognitive impairment' (MCI). In MCI, people have more memory problems than normal for their age, but the symptoms do not interfere with their everyday lives. Movement difficulties and problems with our sense of smell have also been linked to MCI. Older people with MCI are at greater risk of developing AD, but not all do. Some may even go back to normal conditions.

The first symptoms of AD vary from person to person. For many, a decline in the non-memory aspects of cognition, such as word finding, visual and spatial issues, impaired reasoning and judgment, may signal the very early stages of AD. Researchers are studying biomarkers; biological signs of disease found in brain images, cerebrospinal fluid and blood.

These researchers are trying to detect any changes in the brains of people with MCI and in cognitively normal people who may be at greater risk of AD.
Studies indicate that such early detection may be possible, but more research is needed before these techniques can be relied upon to diagnose AD in everyday medical practice.

## Mild Alzheimer's disease

As AD progresses, people experience greater memory loss and other cognitive difficulties. It may be possible to continue to work and drive during the early stages of this phase, but this needs to be monitored and addressed by carers, healthcare professionals and well-informed sympathetic employers. Problems can include wandering and getting lost, trouble handling money and paying bills, repeating questions, sequencing, taking longer to complete ADLs, and personality and behaviour changes. People are often diagnosed at this later stage of the disease's progression.

## Moderate Alzheimer's disease

During this next stage, damage occurs in areas of the brain that control language, reasoning, sensory processing and conscious thought. Memory loss and confusion grow worse, and people begin to have problems recognising family and friends. They begin to have difficulty in performing ADLs and multistep tasks such as getting dressed, making a cup of tea or coping with a new situation. In addition, people at this stage may be unable to learn new things and may have hallucinations, delusions, paranoia, and may behave impulsively.

## Severe Alzheimer's disease

Ultimately, plaques and tangles spread throughout the brain, and the brain tissue shrinks significantly. People with severe AD cannot communicate and become completely dependent on others for their care. At some point during this stage, people living with severe AD usually become doubly incontinent. Near the end, the person may be in bed most or all of the time as the organs and the body in general begin to shut down.

## What causes Alzheimer's?

Scientists don't yet fully understand what causes AD. In people with early-onset AD, a genetic mutation is usually the cause. Late-onset AD arises from a complex series of brain changes that occur over decades. Causes probably include a combination of genetic, environmental and lifestyle factors. The importance of any one of these factors in increasing or decreasing the risk of developing AD differs from person to person.

## The basics of Alzheimer's

Scientists are conducting studies to learn more about plaques, tangles and other biological features of AD. Advances in brain imaging techniques allow researchers to see the development and spread of abnormal amyloid and tau proteins in the living brain as well as changes in the brain structure and function. Scientists are also exploring the very earliest steps in the disease process by studying changes in the brain and body fluids that can be detected years before AD symptoms appear. Findings from the studies will help in understanding the causes of AD and make diagnosis easier.

One of the great mysteries of AD is why it has largely struck older adults. Research on normal brain ageing is shedding light on this question. For example, scientists are learning how age-related changes in the brain may harm neurons and contribute to AD damage. These age-related changes include atrophy (shrinking) of certain parts of the brain, inflammation, production of unstable molecules called free radicals and mitochondrial dysfunction. Mitochondrial dysfunction is a breakdown of energy production within a cell.

## Genetics

Research is being carried out worldwide on the influence that genetics has on the development of AD. There are many theories and medical papers on the subject, and it’s far beyond the remit of this presentation to pursue this matter in depth.

What is useful to know is the correlation between certain genes and differing forms of Alzheimer's. Most people with AD have a late-onset form of the disease, in which symptoms can become apparent in their mid 60s and upwards. The apolipoprotein E (APOE) gene has been identified as being involved in this stage. It comes in several forms, and as mentioned above, intensive research is ongoing to establish the influence that APOE in all its forms may have on AD.

Also, scientists have identified a number of regions of interest in the genome (an organism’s complete set of DNA) that may increase a person’s risk for late-onset AD to varying degrees.

Early onset AD mostly occurs in people aged between 30 and 60 and represents less than 5% of all people with the disease. Most cases are caused by an inherited change in one of the three genes, resulting in a type known as early-onset Familial Alzheimer's Disease, commonly called FAD. For others, the disease appears to do that without any specifically known cause, much as it does for people with late-onset AD.

## Health, Environmental and Lifestyle Factors

Research suggests that a host of factors beyond genetics may play a role in the development of AD**.** There is a great deal of interest, for example, in the relationship between cognitive decline and vascular conditions such as heart disease, stroke and high blood pressure, as well as metabolic conditions such as diabetes and obesity. This ongoing research will help us understand how reducing risk factors for these conditions may also reduce the risk of the disease itself.

A nutritious diet, physical activity, mentally stimulating pursuits, and social and generational engagement have all been identified as helping people stay healthy as they age. These factors might also help reduce the risk of cognitive decline and AD. Clinical trials are testing some of these possibilities.

## Diagnosis of Alzheimer's Disease

Doctors use several methods and tools to help determine whether a person who is having memory problems may have Alzheimer's dementia or some other form of the disease.

To diagnose Alzheimer's, doctors may:

- Ask the person and their carers, be they family members or a friend, questions about overall health, past medical problems, ability to carry out ADL and change in behaviour and personality
- Conduct tests of memory, problem-solving, attention, numerical skills and language
- Carry out standard medical tests, such as blood and urine tests, to identify other possible causes of the symptoms
- Perform brain scans such as Computed Tomography (CT), Magnetic Resonance Imaging (MRI) or Positron Emission Tomography (PET) to eliminate other possible causes of the symptoms.

These tests may be repeated over time to give doctors sufficient information about how the person's memory and other cognitive functions change or develop. Only after death can AD be definitely diagnosed. This can be done by linking clinical measures with an examination of brain tissue in an autopsy.

People with memory and thinking concerns should talk to the doctor to find out whether the symptoms are due to AD or another cause, such as stroke, tumour, Parkinson's disease, sleep deprivation, side effects of medication, an infection or another type of dementia. Some of these conditions may be treatable and possibly reversible.

If the diagnosis is confirmed as AD, beginning treatment early in the disease’s progress may help preserve daily functioning for some time, even though the underlying disease processes cannot be stopped or reversed.

It is very important to obtain an early diagnosis, as it is essential that people living with dementia and their carers positively and proactively plan for the future. They should consider rearranging their financial, legal and health care matters in preparation for the inevitable loss of mental capacity. To assist those affected by dementia and their carers, there are now many gadgets and equipment designed to enable people to live well with dementia. These assisted living devices range from the very simple to sophisticated technological devices. They can help in supporting ADLs and can assist in living well with dementia. It is also important to address potential safety issues, give consideration to accommodation and living arrangements, and develop support networks.

It is highly recommended to enlist the services of a Later Lifestyle Advocate who specialises in this very complicated area. A Later Lifestyle Advocate will be able to assess needs and wants, and either will be able to assist directly or be able to signpost to other professionals working in this specialist area.

In addition, an early diagnosis gives people greater opportunities to participate in both medical, psychological and lifestyle clinical trials that are testing possible new treatments for AD or other research studies.

## Treatment of Alzheimer's Disease

There is currently no cure for AD. It is by nature a very complex condition, and it is unlikely that any one drug or other intervention will successfully treat it. Current approaches focus on helping people maintain mental function, manage behavioural symptoms and slow or even delay the symptoms and progression of the disease. Researchers hope to develop therapies targeting specific genetic, molecular, and cellular mechanisms so that the actual underlying cause of the disease can be delayed and even prevented. Scientists across the world are working on a cure for this dreadful disease, and hopefully, sometime in the future, a cure will be discovered.

## Mainstream Drugs and Managing Mental Function

There are many authorised drugs which can only be obtained by prescription. These drugs work by regulating neurotransmitters, the brain chemicals that transmit messages between neurons. They may help maintain thinking, memory, and communication skills. Further, they may even help with certain behavioural problems. However, AD is a progressive disease, so these drugs don't change the underlying disease symptoms or the eventual outcome. They are effective for some, but not all people and may help only for a limited time.

## Managing behavior

Common behavioural symptoms of AD include sleeplessness, wandering, agitation, anxiety and aggression. Scientists are learning why the symptoms occur and are studying new drug and non-drug treatments to manage them. Current research has shown that treating behavioural symptoms can make people living with AD more comfortable and can make things easier for their carers.

## Looking for new treatments

AD research has developed to a point where scientists can look beyond treating symptoms to think about addressing the underlying disease process. In ongoing clinical trials, scientists are developing and testing several possible interventions. These include immunisation, drug therapies, cognitive training, physical activity and treatments used for cardiovascular disease and diabetes.

In the meantime, experiments and work continue in the complementary health care sector.

This long-established, but fast growing Complimentary and Alternative Medicine (CAMs) sector, often frowned upon by some within the medical profession, are health care system, practices and products that originate outside of mainstream medicine. Reference has been made above to the benefits of cognitive rehabilitation therapies, music, art and generational interaction, but other examples relevant to dementia are: massage therapy, aromatherapy, nutritional dietary regimes (food for the brain), herbs and spices.

One such CAM is an Alkaloid called Galantamine. Galantamine is found in daffodils, and some farmers have turned over their fields to grow and harvest daffodils specifically for the treatment of AD and other memory impairments. Galantamine is in a class of medications called acetylcholine inhibitors. It is a chemical compound and works by increasing the amount of a certain natural substance in the brain that is needed for memory and thought. It may improve the ability to think and remember or even slow the progression of memory loss for people living with AD. However, Galantamine will not cure AD or prevent the inevitable loss of mental capacity at some point in the future.

## Support for Carers and Family Members

Caring for a person with AD can have a high physical, emotional and financial cost. The demands of day-to-day care, changes in family roles and decisions about placement in a residential care facility can be difficult. Several evidence-based approaches and programs can help. The Alzheimer's Society is continuing to look for new and better ways to support caregivers.

Becoming well-informed about AD is one important strategy. Programs that teach families about the various stages of AD, about ways to deal with difficult behavior and about other carers' challenges can be very helpful.

Having control over legal and financial matters is another very important strategy for carers to be able to manage and cope more efficiently and with less stress and trauma with the inevitable loss of mental capacity of their loved one. Good coping skills, a strong support network, and respite care are other ways that help carers handle the stress of caring for a loved one with AD. For example, staying physically and mentally active can provide physical and emotional benefits.

Some carers have found that joining a support group is a critical lifeline. There are numerous facilities springing up all over the UK. Dedicated day care centres, dementia meeting centres and dementia cafes are just some examples of these facilities. Unfortunately, these groups are usually charities or national social movements and are, therefore, difficult to find and rarely commissioned or recommended by mainstream health professionals. Only the Alzheimer’s Society, Macmillan and Admiral nurses, specialist Solicitors and Later Lifestyle Advocates seem to be aware of these groups and know signpost people affected by AD to these facilities. These support

groups, whilst benefiting the person living with dementia, also enable the caregivers to find respite, express concerns, share experiences, obtain tips and receive emotional comfort. They can even be a source for making new friendships. Further, many organisations sponsor person-to-person and online support groups, including groups for people with early-stage AD and their families.

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