

Dementia

by Sally Bundock

Dementia is a condition that will touch many of us during our lives. It is estimated that one in three people in England will care for a person with dementia in their lifetime. YouGov 2011 research reveals that people fear dementia more than any other disease. However, as with any other medical condition early diagnosis can pave the way to receiving appropriate treatment and support to maximise future quality of life.

So what exactly is dementia? Dementia is a syndrome that can be caused by a number of progressive disorders. It can affect memory, thinking, behaviour and the ability to perform everyday activities. Around 60% of people with dementia have the most common type, Alzheimer's, named after Dr. Alzheimer who in 1906 identified a build up of plaques and tangles of proteins forming in the brain. Around 20% have vascular dementia with many people having a mixture of the two. There are other less common forms of dementia, e.g. dementia with Lewy bodies and frontotemporal dementia.

Dementia mainly affects older people. People diagnosed with dementia under the age of 65 are often described as having 'early onset dementia', 'young-onset dementia', or 'working age dementia'. The symptoms of dementia may be similar regardless of a person's age, but younger people may have different needs, and require some different support. The likelihood of developing the condition after age 65 roughly doubles every 5

years. Although dementia is progressive and currently incurable, there is much that can be done to lessen symptoms.

Around 820,000 people in the UK currently have dementia with this number likely to double in the next 30 years. Currently costing £19 billion a year in England alone this figure will increase considerably in the future. Dementia is a global problem. By 2020 estimates indicate there will be nearly 70 million people with the condition. Much is being done to find new treatments and in December 2013 the UK hosted a G8 Summit on Dementia which produced positive plans for collaboration.

Currently only around half of those with dementia in England have a formal diagnosis or contact with specialist services. Diagnosis rates vary across the country from 75%-39%. Much is being done to rectify this situation. It is estimated 25% of hospital beds are occupied by people with dementia and a new initiative involves assessing patients over 75 who stay for more than 3 days for dementia. This is a real opportunity to detect and diagnose dementia and ensure appropriate care is received.

If someone is concerned about their memory it is advisable to discuss this with their GP. Similarly if there is concern about someone else then they should be encouraged to make that visit, preferably accompanied. Memory problems do not always mean dementia and can be caused by stress, drug side effects and

other health problems.

If the GP feels that dementia may be an issue then referral to a Memory Clinic is likely. Waiting times in England to be seen at a Clinic vary from a few weeks to a number of months. The waiting time for a diagnosis following assessment by a Clinic, similarly varies. Diagnosis of the condition is not an easy one to make. A number of tests usually need to be carried out and patients may see a specialist, perhaps a neurologist, a psychiatrist or a geriatrician. It is more important now than in the past to identify the type of dementia, as a wider range of drug treatments, is now available.

If a patient is not offered referral to a Memory Clinic or specialist by their GP and remains concerned the matter should be discussed fully again with the GP. If the matter remains unresolved an appeal may be made via the GP's complaints procedure. In the unlikely event of further dispute an appeal may be made to NHS England.

Once a diagnosis has been made patients should be provided with certain information:

- the type of dementia diagnosed – if this is not clear what further tests may be necessary
- details about symptoms and how the illness might develop
- treatments
- care and support services in the local area

- support groups and voluntary organisations for people with dementia and their family and carers
- advocacy services
- where financial and legal advice may be found

Once a person has been diagnosed they should be seen periodically by their GP. For some follow up appointments with a specialist will be appropriate.

Diagnosis is a good time to consider financial and personal affairs, in particular Lasting Power of Attorney (LPA). This replaced Enduring Power of Attorney and is a legal document which allows people to choose someone who can make decisions for them, if they become unable to do so for themselves. The Attorney is the person chosen to make decisions on their behalf.

There are 2 types of LPA which give the Attorney(s) the power to make decisions about:

Property and affairs – the person's financial and property matters, such as selling a house or managing a bank account

Personal welfare – the person's health and personal welfare, such as day-to-day care, medical treatment, or where they should live

You do not need to see a solicitor to set up an LPA unless there are complicated issues. A free form can be downloaded from www.gov.uk/lasting-power-of-attorney Once completed, it needs to be registered with the Office of the Public Guardian. The cost is £130 per LPA and so the cost for both would be £260.

If an LPA is not made and a person becomes unable to make certain decisions for themselves, there may be a time when no-one can do this for them, as no-one



will have the legal power to act on their behalf. This can make things like paying bills, including care fees, and decisions about future care difficult.

In this situation, someone may need to apply to the Court of Protection to become the person's Deputy. This can give them similar powers to that of an Attorney. A relative or friend can apply to be a Deputy, or a professional may be appointed. The process of becoming a Deputy is a lot more time-consuming and expensive than an LPA. There are also ongoing requirements that a Deputy must fulfil such as paying an annual fee and submitting an annual report, so it can be easier for someone to be an Attorney rather than a Deputy.

The Dementia Friendly Financial Services Charter is a new initiative led by the Alzheimer's Society (AS) and Lloyds Banking Group to help financial services organisations recognise, understand and respond to the needs of customers living with dementia and their carers. The charter lays out ways organisations can work towards becoming more dementia friendly, such as appointing a 'champion' to drive forward the initiative in each of their branches.

Most types of dementia are progressive and cannot be cured. However, there are some exceptions, for example dementia caused by thyroid hormone deficiencies, which can be treated by vitamin supplements. Some causes can be treated surgically for example some brain tumours. It is also important to ensure that any other health problems such as diabetes and depression are well managed.

For dementia that cannot be cured, medicines can be prescribed that may prevent symptoms getting worse for a period of time. These are generally prescribed to those in the early and middle stages of the disease. However research is ongoing and the DOMINO-AD trial demonstrated the value of continued drug treatment (Donepezil) for patients who have deteriorated beyond the point where the drug is usually recommended.

Antipsychotic drugs have been prescribed for patients with dementia for over 40 years, very often to treat challenging and disruptive behaviour. Current thinking is that these drugs should only be prescribed to people with dementia in exceptional circumstances and if prescribed, the person should be

reviewed on a regular basis. The National Dementia and Antipsychotic Prescribing Audit reported a reduction in the prescribing of antipsychotic medication nationally. Overprescribing is still a problem with wide regional variation. NHS and social care organisations are working together with their partners to reduce the use of this medication by two thirds.

Psychological treatments, such as cognitive stimulation, do not slow the disease progression but can help with coping with symptoms.

For many the most important type of treatment is care and support. Discussing options with all those concerned – family, the GP and the local authority are important. Every effort should be made to maintain memory, independence and function.

The Alzheimer's Society www.alzheimers.org.uk Helpline (support and information) 0300 222 1122 is an invaluable resource on all aspects of dementia. Their 80+ factsheets on a wide range of topics from Emotional and Practical Support and Genetics of Dementia to Financial and Legal Affairs can be downloaded from their website or sent out by post.

Comprehensive information on Symptoms and Diagnosis is available as well as sections on Living with Dementia, Caring for a Person with Dementia and Research. There is also an online forum (Talking Point) and a resource which allows you to put in your postcode to find local support services in your area such as Dementia Cafés. The The Dementia Guide produced by AS is a must have.

AS is very proactive in research and together with the Department of Health has developed a best practice guide for health and social care professionals.

It is currently estimated that there are 670,000 carers of people with dementia in the UK. They play a vital role and save the UK around £7 billion annually. Acquiring the necessary help and support to fulfil their role as well as looking after themselves can be extremely challenging. Surveys have shown that many carers feel they lack the necessary support and feel more should be done to help them. The Dementia Action Alliance launched a 'Carers Call to Action' in November 2013 setting out goals to bring about real change for carers. The Triangle of Care for dementia

Dementia UK www.dementiauk.org 0845 257 9406 provides Admiral Nurses, mental health nurses specialising in dementia care. They largely work within the NHS, providing psychological support and practical advice to help family carers. They also liaise with other professionals to deliver holistic support where needed. Their website will tell you if there is an Admiral Nurse in your area. If there is not, telephone help is available.

An estimated one third of people with dementia live in residential



guide was launched in Parliament in January 2014. The guide sets out 6 key standards to improve the care of people living with dementia by achieving better collaboration between them, the carer and the health professional. This guide could transform the lives of carers of people living with dementia.

Useful organisations for both information and on-line Forums are Carers UK www.carersuk.org 0808 808 7777 and Carers Trust www.carers.org 0844 800 4361. The Crossroads Care arm of the latter provides much information on carers breaks.

care with two thirds living at home. One third of those living at home live on their own often experiencing loneliness. This group often rely on support from home care agencies. AS's 'Support Stay Save' report found that 83% of people with dementia want to stay in their own home. Initiatives are now in place to improve training for home care staff to improve the services offered which in turn should help people stay at home, avoiding or delaying the need for hospitalisation or a move to a care home.

Hospital stays for those with dementia tend to be longer than

for non-sufferers and patients are more likely to be readmitted. Most hospitals now have 'dementia champions' and many hospitals have committed to becoming dementia friendly, working in partnership with their local Dementia Action Alliance.

There is no doubt that making hospitals and care homes more 'dementia friendly' can only improve the quality of life for sufferers. Improved care and support in care homes can help prevent hospital admissions. The Dementia Care and Support Compact was launched in March 2012 to encourage care homes and providers to improve the quality of dementia care. So far 150+ organisations have signed the compact representing around 3,000 services.

Selecting a care home for a dementia sufferer can be difficult. A good resource is NHS Choices website www.nhs.uk The site gives much information on dementia, care homes and care services. It also links through to Care Quality Commission assessments. Inputting your postcode will enable you to find information on care homes in your chosen area.

Currently too many people with dementia are not supported to have early discussions and to make plans for their end of life care. It is important that early discussions take place so that people can plan ahead for their future care, including palliative and end of life care. These are undoubtedly difficult discussions but ones that need to take place.

To help the growing problem of dementia and other diseases, the NHS Health Check programme for people aged 40-74 helps people to make changes to reduce the risk of future ill health. Vascular dementia results from problems with the blood supply to the brain. The effects of vascular

dementia can be minimised or prevented altogether through a healthy lifestyle. Smoking and obesity, for example, affect many types of dementia, particularly vascular dementia.

Health Education England (HEE) is responsible for overseeing education and training within the health and care system. The Government's Mandate to HEE states all NHS staff looking after patients with dementia will go through foundation dementia training, with HEE ensuring 100,000 staff have foundation level training by March 2014. Furthermore, the Government has accepted the recommendation to develop a care certificate made by the Independent Cavendish Review, carried out following the Francis Inquiry into the Mid-Staffs NHS Foundation. So much is now being done to improve education and training for those involved in the care of dementia patients.

In December 2012 AS launched the Dementia-Friendly Communities programme. This allows communities to be recognised for their work through a process which sets out expected criteria for communities who wish to be recognised as working to become dementia-friendly, such as involving people with dementia, raising awareness of dementia and setting achievable goals. Communities meeting the criteria can use the recognition symbol to identify those businesses or organisations committed to become dementia friendly. To date 25+ communities (from Falmouth to Bradford) have signed up with many more to follow.

Dementia Friends, launched in February 2013, is another initiative run by AS. Dementia Friends have developed a better understanding about what it is like to live with dementia and

have the knowledge, confidence and skill to engage with those with the condition. There are now 2,000+ Dementia Friends Champions who go out into the community working with dementia projects and delivering information sessions. Through these sessions nearly 35,000 Dementia Friends have been recruited to further the good work.

Britain is well placed to take a dominant role in dementia research with its well established life science industry, world leading universities and scientists and the NHS which as the main provider of healthcare is able to provide vast amounts of patient data. Since 2009/2010 government funded dementia research in England has almost doubled to £52.2million in 2012/13. Dementia research, with help from diagnosed individuals, is looking at all aspects of the condition including prevention, genetics and diagnosis.

Following on from the National Dementia Strategy (2009), in late 2012, a nationwide campaign raised dementia awareness by encouraging people to visit their doctor if they were worried or if they wanted more information to visit NHS Choices. This campaign reached over 27 million people. From 2013/14 GPs will be able to use a contract called an enhanced service to improve diagnosis by asking people in certain at risk groups e.g. those with cardiovascular risk factors, about their memory.

www.dementiachallenge.dh.gov.uk provides comprehensive information on David Cameron's initiative launched March 2012.

The establishment of a national Dementia Action Alliance in 2010 has acted as a catalyst for national action and collaboration on dementia. There are now 130+ members across England, drawn from charities, government

bodies, royal colleges etc. This initiative has coordinated action on cross cutting issues affecting people with dementia and has ensured members have committed to action plans around improving the lives of dementia sufferers. Similarly local Dementia Action Alliances, now in 50+ locations including Plymouth and London, are able to make real positive changes for dementia sufferers. Work in schools is raising awareness amongst young people.

In 2014/15 the government working with AS is launching a Dementia Movement aimed at further raising awareness and recruiting more people into the Dementia Friends programme and inviting communities and business to become dementia-friendly organisations.

Dementia will continue to be a challenging global issue but in 2014 in the UK we can be assured that much is being done to ensure more people get a diagnosis, more support for sufferers and training for professionals is becoming available and less antipsychotics are being prescribed. Valuable research is taking place and whilst there still remain some regional variations, the number of excellent dementia projects is growing. For current sufferers it must be remembered that diagnosis whilst upsetting is also a gateway to making informed choices about the future with the help of all the resources available.

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Reference

The Department of Health 'Dementia – A state of the nation report on dementia care and support in England' November 2013 was consulted in the writing of this article. Contains public sector information licensed under the Open Government Licence v2.0.

www.nationalarchives.gov.uk/doc/open-government-licence/