Dementia Care

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DEMENTIA CARE

A GUIDE

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Note to the reader

This book is not intended to be a substitute for medical advice. All information is correct at the time of going to press.

Introduction

My mother was diagnosed with vascular dementia in 2009. Looking back, the warning signs were there a year or so before Mum's diagnosis. She started forgetting things and repeating questions. She got confused while carrying out routine tasks and began putting things in strange places. One day she got lost driving to the vet's, which was a very familiar journey for her. One morning, my father found the kettle in the fridge. She had increasingly frequent moments of confusion.

At the time, Mum was caring for my father, who was seriously ill, so it was easy to blame her confusion on the stress of being a full-time carer. When my father died, her problems became more apparent. This is not uncommon in a person with dementia after a bereavement. It could be because the person who died might have helped the person with dementia, so that the full impact of the illness was less apparent to others, or it could be that caring for a loved one gave the person with dementia a focus.

My mother knew that her memory was letting her down, but was reluctant to seek help. Eventually I persuaded her to visit the GP, who conducted a short memory test and then referred her for a blood test and a brain scan. The diagnosis was confirmed by the results of the scan but I don't think Mum quite understood what it meant and she had forgotten about it a few days later.

And so began a challenging journey of caring for Mum that still continues to this day.

I wish I'd known then what I know now – I'm sure if I'd understood more about dementia at the time I would have been more patient and understanding during some of the more difficult moments. Like a lot of people, I wrongly assumed that it only affected the memory, but it can also have a significant effect on moods and behaviour.

I'm not a medical expert and there are many good books that explore the physical effects of dementia. This book is written from hands-on, personal experience. It's the book I wish I'd been able to read back in 2009, when I knew very little. It wouldn't have solved

every problem, but knowledge is power, and it would certainly have helped.

Each situation and person is unique, and it's impossible to predict every scenario you may experience. But I hope that some of my personal insights will help you to cope and also feel that someone else understands what you are experiencing. Even though you may feel isolated at times, I'd like to stress that you're not alone. There are organizations you can contact for help. Their details are at the back of this book.

Good luck with the journey ahead – you will learn much and hopefully this book will go some way to helping you cope and provide the best possible care for your parent or loved one. And if you'd like to get in touch and share your experiences, you can message me on Twitter @writefitchris.

Christina Macdonald

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What is dementia?

If your parent or other loved one has just been diagnosed with dementia, you may have some knowledge of the symptoms. Most likely you've noticed him or her having memory problems. However, dementia is about more than just memory loss. The more you understand about it, the better placed you will be to cope with the challenges ahead.

The word 'dementia' is not a diagnosis. Rather, it's an umbrella term describing a set of symptoms such as memory loss, difficulties with language, thinking and solving problems. These symptoms occur when certain diseases or conditions affect the brain. Dementia is not a natural part of ageing, although the risk of developing it increases with age. At the time of writing, Alzheimer's Society estimates that there are 850,000 people in the UK living with dementia, most of them over 65, but there are more than 40,000 people with young onset dementia under this age.

Unfortunately, dementia is progressive and there is no cure. This means that a person's ability to remember things, communicate and understand will gradually decline. Over time, people will gradually lose their independence.

Dementia is on the increase. According to an Alzheimer's Society 2014 report, there will be one million people with dementia in the UK by 2025. The cost is significant. Alzheimer's Society says there are 670,000 carers in the UK for people with dementia and it is estimated to cost the UK economy £26 billion per year. Yet getting a diagnosis can be difficult. According to the Health and Social Care Information Centre, only 67.2 per cent of people in England receive a diagnosis. In Scotland, only 64 per cent are diagnosed according to Alzheimer's Scotland, 43.4 per cent in Wales according to Alzheimer's Society and 64.8 per cent in Northern Ireland according to the Department of Health, Social Services and Public Safety.

The main types of dementia include:

Alzheimer's disease This is the most common cause of dementia. According to Alzheimer's Society, there are more than 520,000 people in the UK with Alzheimer's disease. It is named after a German psychiatrist called Alois Alzheimer, who first noticed the condition in the early 1900s in a 51-year-old female patient called Auguste Deter, who was suffering from short-term memory loss. During her autopsy in 1906, it was discovered that she had shrinkage of the cortex (the largest part of the brain) and abnormal deposits in and around nerve cells.

Proteins that build up in the brain to form structures called plaques and tangles are the cause, as they affect connections between nerve cells, eventually causing them to die.

Alzheimer's disease has two forms, the rare early-onset disease, where symptoms first appear under the age of 65, and the more common late onset Alzheimer's where symptoms appear over this age.

Symptoms: memory loss, difficulty learning new skills or new information, repeating things, confusion, loss of concentration, depression and irritability.

Vascular dementia This is the second most common type of dementia and according to Alzheimer's Society it affects around 150,000 people in the UK. Vascular dementia is caused by a reduced blood flow to the brain that can be caused by a series of mini-strokes, or by small blood vessels deep in the brain becoming narrowed and hardened (atherosclerosis). Vascular dementia is more common in smokers, those with high blood pressure, Type 2 diabetes, obesity or heart problems. Age is also a strong risk factor.

Symptoms: confusion, problems with concentration, hallucinations, slower thought patterns, memory loss, language problems, depression, anxiety and rapid changes in mood.

Mixed dementia Alzheimer's Society estimates that around 10 per cent of those with dementia have more than one type. Most com-

monly, people will have a combination of Alzheimer's disease and vascular dementia.

Symptoms: these can vary, depending on the areas of the brain affected. Symptoms could be similar to or the same as symptoms of Alzheimer's disease.

Dementia with Lewy bodies This is estimated to affect around 10 per cent of those with dementia. It is named after Friedrich H. Lewy, a scientist who discovered the condition when researching Parkinson's disease in the early 1900s. Lewy bodies are lumps of protein that develop inside brain cells. Although more research is needed, it is believed that these proteins interfere with chemical messengers in the brain that regulate memory, mood and our ability to learn. Lewy bodies are the cause of several diseases that affect the brain and nervous system, including Parkinson's disease. A person with Parkinson's disease may eventually develop dementia.

Symptoms: fluctuating attention, problems with perception, hallucination, difficulty with balance and movement, disrupted sleep, feelings of being persecuted.

Frontotemporal dementia Also known as Pick's disease, this is a less common form of dementia whereby the two frontal lobes of the brain behind the forehead and the temporal lobes behind the ears are damaged. Brain tissue in the frontal and temporal lobes shrinks. It is often diagnosed in those aged between 45 and 65.

Symptoms: inappropriate behaviour, lack of motivation, cravings for sweet foods, difficulty with speech and difficulty recognizing others.

Getting a diagnosis

If you think your loved one has dementia, it may take some time to persuade him or her to visit the GP. The person may not think anything is wrong, or may blame the symptoms on stress or getting older (the NHS estimates that around 40 per cent of those over 65 will have some form of memory problem). If he or she refuses to

visit the GP, then you could talk to the doctor on your own. At least your concerns will be on record.

Getting a diagnosis may take some time. The GP will need to rule out other possible causes of memory loss. She may recommend blood tests to look at iron levels and levels of vitamin B1 and also screen the person for depression, which can cause memory issues. Other conditions that may have similar symptoms to dementia include urinary tract infections and thyroid deficiencies. It's also important to rule out confusion that may be caused by poor sight or hearing. If the tests come back negative, the GP will make a referral to a specialist. This could be a psychiatrist, geriatrician or neurologist. The person with dementia will probably undergo a Mini Mental State Examination (MMSE), which tests memory, thinking and language, and may also be referred for a brain scan.

If the diagnosis is confirmed, the person will be under the care of the local community mental health team – namely psychiatrists, psychologists and community psychiatric nurses. Medication may also be given.

Medication for dementia

There are four types of medication prescribed to treat symptoms of Alzheimer's disease. However, apart from for Alzheimer's, there are no dementia-specific drugs available. The person may also be given other drugs to treat underlying conditions, such as heart disease, a stroke in the case of vascular dementia, or symptoms, such as hallucinations suffered by a person who has dementia with Lewy bodies. A person with vascular dementia may be given drugs to treat high blood pressure, high cholesterol, diabetes or heart problems as these can be linked to the condition. Specialist drugs are only available for people with Alzheimer's disease.

Medication for Alzheimer's disease may slow down the progression of symptoms, but not the disease. They may help to reduce depression, aggression and anxiety, although the drugs will only work for some people. The current four types of medication used to treat Alzheimer's disease include:

- donepezil (Aricept)
- rivastigmine (Exelon)

- galantamine (Reminyl)
- memantine (Ebixa or Axura).

Donepezil, rivastigmine and galantamine are known as cholinesterase inhibitors and work by boosting levels of a chemical messenger called acetylcholine (ACh), which improves communication between the nerve cells. Side effects include vomiting and diarrhoea. These drugs may be beneficial for those with mild to moderate Alzheimer's disease. They are not a cure and the condition is still progressing, but they can treat symptoms in some people. They may not work for everyone.

Memantine is usually prescribed for those with severe Alzheimer's disease, or those with moderate Alzheimer's if cholinesterase inhibitors aren't suitable. It works by regulating activity of glutamate, a chemical messenger involved in brain functions that is released excessively when brain cells are damaged. Side effects can include dizziness, aggression, depression, headaches and sleepiness.

If you have any concerns about any medication prescribed – for example, if you notice any changes in behaviour or side effects – always discuss these immediately with the person's GP or mental health team.

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What to do when the person is first diagnosed

Even though you might have suspected the person has dementia, the diagnosis could still be a shock. Your parent may be confused and unable to process the news. She may understand the diagnosis, but could be in denial and may refuse any offers of help and support.

You both need some time to come to terms with the diagnosis, but keep talking. Reassure the person. Let her know she isn't alone and get her to talk about it if she wants to. Make it clear you'll be there for her.

But don't wait for too long. It's important for the person to get her affairs in order. Sit down with her and help her plan for the future.

Here's a brief checklist of things to organize as swiftly as possible:

Set up direct debits or standing orders for regular bills As her condition gets worse, she will be more likely to lose her post and may forget to pay bills. Having household bills debited automatically from her account every month will eliminate the risk of having gas or electricity disconnected.

Locate important documents Find out where she keeps other important documents like insurance policies for house and car insurance. If she doesn't object, take these documents home with you and keep a note of any important renewal dates in your diary. Otherwise, put them all in one marked file in a safe place.

File bank statements carefully Keep them in a clearly labelled folder. Again, if she is happy for you to keep hold of these items you can keep track of everything (or arrange online access to

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