



20 THINGS EVERY DEMENTIA CARER SHOULD KNOW

A note from the Editor...

Caring for a person with dementia is not an easy task. Unexpected situations can arise, and you never quite know how the person will be feeling from one day to the next. It's also a great responsibility, as you will eventually reach a point where you will become the person making important decisions about ongoing care and support, and acting in the person's best interests. And you may be the only person they can rely on to make those choices.

You've probably already realised that being a good carer requires enormous patience and an endless amount of stamina. It also requires an understanding of dementia and how it affects a person's mind. The more you understand about dementia, the better in my view.

When my mother was first diagnosed with vascular dementia, I wrongly assumed the condition was mostly about memory loss. I didn't realise the impact it would have on mum's behaviour, her state of mind and her ability to cope with everyday situations that the rest of us take for granted. Many times I thought she was being unreasonable or irrational, but she was simply trying to make sense of the world around

her. I am sure I would have been a better carer had I understood more about dementia early on. So many seemingly strange and random events would have made sense.

This guide contains 20 useful things every carer should know about dementia – which I hope you will find a useful resource when providing care for a loved one. That said, dementia is a complex topic, so we've only had time to scratch the surface here – for more detailed information and support, we highly recommend you come along to The Alzheimer's Show on 5-6 June at London's Olympia. It's your exclusive gateway to access some of the country's most experienced care providers and leading dementia experts, all of whom can provide you with advice and support on many different aspects of being a carer. To book tickets, visit <http://alzheimersshow.co.uk>

1 A person with dementia may be subject to sudden mood swings, often without warning. They can be happy one minute, and tearful or angry the next. Coping with unpredictable moods can be a challenge for carers. If a person is in pain, they may display challenging behaviour so it's important to get to the root cause of the problem and arrange for them to see their GP.

2 A person with dementia should make a Lasting Power of Attorney as soon as they have been diagnosed with dementia, as it's hugely important to get their affairs in order while they still have capacity. There are two different types – Lasting Power of Attorney for Property & Finance and Lasting Power of Attorney for Health & Welfare.



3 A person with dementia may lose track of time and confuse day with night, especially during the summer months when it gets lighter earlier. It's not unusual for a person to confuse 5am with 5pm for instance. If the person with dementia lives alone, be prepared for occasional phone calls at unsociable hours and be patient.

4 It can be difficult for a person with dementia to get to grips with domestic appliances and they may forget how

to use everyday items like their microwave or washing machine, even if they have used them



for years. If a domestic appliance breaks down and needs replacing, it may be difficult for them to learn how to use a new one. You may be tempted to leave a note near the device with clear instructions on how to use it, but this may not work. You may need to be prepared to make other arrangements, such as arranging for someone to come in and prepare meals for the person, or arrange for them to have Meals On Wheels. If the person is struggling to use the phone or the TV remote control, Assistive Technology products – designed to be deliberately easy to use – may be the solution.

5 In the early stages, a person with dementia may be safe living on their own with occasional help and support from family and friends. However, it's worth planning for the future, as there will come a time when the person can no longer be left alone. It's worth discussing the future with them while they still have capacity and talking to them about what they would like to happen as their needs change. You might also want to look at home care agencies that can provide additional help, and in the long-term, a residential care home or nursing home may be a good solution. The person may want to stay in their own home permanently,

or as long as is reasonably possible. Discuss these scenarios now so that you know what the person would like to happen in future. You may also want to suggest that they make an Advance Directive, also known as an Advance Decision – a document they can prepare that describes what care they would like or not like to receive in future. For more information on an Advance Directive, visit <http://alzheimersshow.co.uk/making-an-advance-decision/>

6 When you care for a person with dementia, it can seem like a lonely and often isolating experience. Your friends may appear to be getting on with their lives, going out and socialising, while you may be spending most of your time being a carer. Fortunately, you're not completely isolated, as others are in the same situation. Talking to others and sharing similar experiences can help to ease the burden. Knowing that others are going through the same thing can make you feel less isolated.



7 Don't contradict or argue with a person with dementia, as this is likely to make them angry or frustrated. A person with

dementia has to work much harder than you to process information, follow a conversation and formulate a response to a comment you've made. So if they work very hard to understand what you've said and respond to you, it's not helpful to contradict their response.

8 A person with dementia may refuse to admit they need help, or may genuinely think they don't need any help. They may not be trying to deliberately mislead you, but it's important to listen

to your own instincts and take note of what you see. If the person looks unkempt, or the house is messy, then you may need to arrange some help.



Don't rely solely on the person with dementia to tell you when they need help or ask for it, as they may not think they need it. My mother used to assure social workers and nurses that she was doing all of her own washing, cleaning, ironing and cooking, and was perfectly capable of doing so. This simply wasn't true, as many of these tasks weren't getting done. She appeared to be living in the past and assumed she was still doing them. However, as I slowly and gradually introduced extra help and resources to help her cope, she began to grudgingly accept the help and in time, began to embrace it. Take note of what you see and be observant. If you see the person struggling, gently persuade them to accept a bit of support.

9 A person with dementia is at an increased risk of being a victim of financial abuse. According to a Financial Abuse Review published by Age UK in November 2015, those

with dementia or reduced cognitive function are most at risk. Even family members can take advantage. Some 50 per cent of financial abuse in the UK is by 'adult children', i.e. grown-up sons or daughters. If something doesn't feel right or someone in your family is being overly secretive or acting suspiciously, then listen to your instincts and confront them.

10 If you are caring for a person with dementia, you may be entitled to Carer's Allowance if you are providing care for someone for at least 35 hours a week and are earning £110 per week (after deductions) or less.

11 Even if you are not a full-time carer, you are entitled to request flexible working hours from your employer. Your employer doesn't have to agree, but they are obliged to consider your request and give a justifiable reason if they refuse. You also have the right to take time off in the event of an emergency, though this may be unpaid.

12 Your local authority is obliged to conduct a needs assessment of the person with dementia, and an assessment of your needs as a carer. From the very beginning, they must provide you with access to useful information and resources.

13 The person with dementia may be entitled to financial help. Attendance Allowance is not means-tested and is tax-free. It is available to those aged 65 and over who need help with personal care. In addition, the person may also be entitled to NHS Continuing Care, which is funded care provided by the NHS. This can be applied for if the person is living at home or in a

registered nursing home. Navigating the system and understanding what support is available and how to apply can be complex and time consuming, so come along to The Alzheimer's Show and speak to those who understand the process.

14 On a practical level, it's worth taking a careful look at the person's home environment. A person with dementia may be confused by patterned carpets or elaborate floor tiles and may



think the floor tiles are raised, or the patterns are obstacles. Clearing the house of patterns or rugs with elaborate designs may avoid confusion. It's also worth removing hazards such as worn or loose carpets or furniture in awkward places, to help reduce the risk of falls.

15 Lock medication away and don't rely on the person to take it unsupervised. My mother used to need a quick phone call at first to prompt her to take her medication, but as time went on, she became more confused about her tablets and could only take them safely under supervision. I installed a portable safe in



her kitchen to store her tablets that only her care workers and myself could access. This prevented her from taking too many or taking the wrong ones.

16 A change of routine or environment may sound like a good idea for a person with dementia, but it can cause confusion and unsettle the person. Taking the person away on holiday so that they wake up in a strange room and don't know where they are may cause distress. Experiment at first with a short break to see how they cope.

17 Regular exercise can help to offset some of the symptoms of dementia, and will also boost the person's mood, making them happier. A brisk walk, a bike ride, jogging or swimming are all good choices. Regular exercise can also reduce stress levels for you as a carer and improve your mental wellbeing.

18 A person with dementia may become confused about their age and what stage of life they are at, and may forget that a relative or loved one has died. My mother sometimes forgets



that her husband and her parents passed away some years ago and will occasionally ask where they are. While it may sound strange, it's best not to remind the person that a loved one has died. It's better to deflect the question and in my personal opinion, an occasional white lie can be a good thing. I learned this the hard way after once reminding my mother my father had died and listening to her grieve all over again. It was heartbreaking and very distressing for her as she was also concerned that she couldn't remember going to his funeral. Now if she asks for my father, I will say he is at work and then offer her a cup of tea. A simple distraction technique like this will usually work. Minutes later, the conversation has moved on to another topic.

19 Patience truly is a virtue. Be prepared to hear the same stories and repeat the same information time and time again. But try to keep it simple. Make answers short and to the point, and keep conversations concise. Don't offer lots of different choices when asking what a person would like to eat or do. Make it easy for the person to answer your questions and if you have to repeat the same information, do it patiently. If you are frustrated or impatient, the person may not understand why, but will pick up on your frustration.

20 Finally, looking after yourself and your own health is essential and will make you a better carer. If you don't look after yourself, you won't be able to care for the person with dementia. Getting help from a local support group can make a difference and having the chance to talk to others in a similar situation, who truly understand and appreciate the challenges you are facing, can really help. Now and then, take time to do something for yourself, and don't feel guilty about it. Think of it as recharging your batteries to enable you to provide the best possible care.

MORE INFORMATION

All the help and support you need when caring for a loved one with dementia is on hand at The Alzheimer's Show, the UK's only event that brings the entire dementia community together to provide you with information, knowledge and support. Many of the topics covered in this guide, such as Lasting Power of Attorney, challenging behaviour and understanding the mindset of a person with dementia, will be covered at the Show. Visit www.alzheimersshow.co.uk to order tickets.



Come to The Alzheimer's Show and meet our experts in person!

The Alzheimer's Show takes place at London's Olympia on 5-6 June 2020 and brings the dementia community together under one roof, offering support, information and practical advice for families, carers and healthcare professionals. Come along and meet our team of experts, take part in practical workshops, ask Admiral Nurses for advice on coping with dementia and learn more about how you can best care for your loved ones.

To book tickets visit www.alzheimersshow.co.uk