

DEMENTIA: A CARER'S GUIDE

(Written by the Reminiscence Learning Carers' Zoom Group,
Wellington, Somerset - Summer 2022)

What is Dementia?

Dementia is a progressive decline in the functioning of the brain. There are several forms and no two are identical. Common effects include memory loss, irritability, confusion, decline in the understanding and use of language. There is no cure for dementia though some drugs may slow the decline, others may moderate some of its effects.

For more information about dementia see the websites of the NHS, and the Alzheimers Society

<https://www.nhs.uk/conditions/dementia/> <https://www.alzheimers.org.uk/>

LEGAL ESSENTIALS

Lasting Power of Attorney (LPA)

A person with dementia will lose the ability to make informed decisions about their finances and welfare. As soon as possible you should assume legal responsibility for them by acquiring Lasting Power of Attorney. To do this you must:

- i. complete the relevant forms: one for finances, one for health and welfare
- ii. register the forms with the Office of the Public Guardian. In 2022 there is a registration fee of £82 per form (there are exemptions dependent upon income and receipt of certain welfare benefits). The forms are available online and you can complete them yourself. If you are unsure about completing the forms you will feel safer having them done by a solicitor or other professional with the relevant knowledge.

It is recommended you lodge a certified copy of the Health and Welfare LPA with your GP and any other medical/welfare team involved and also have a copy to hand to grab in an emergency eg hospital admission.

It is also advisable to arrange Lasting Power of Attorney for yourself.

Forms are available at: <https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney>

Wills

Writing a will is essential to ensure that, after death, the wealth and possessions of the person with dementia pass to the person(s) of their choice. You should do this too. To avoid errors it is wise to have wills written by a professional such as a solicitor or specialist will-writing service.

FINANCE

Attendance Allowance

A person with dementia is entitled to an attendance allowance, provided they and their carer are of state pension age or are both physically or mentally disabled. There are two levels, depending on the amount of care required.

OUT AND ABOUT

The financial burden of going out with a person with dementia will be eased by making use of concessions. Some examples:

Blue Badge

A person with a hidden disability such as dementia can apply for a Blue Badge to facilitate parking <https://www.somerset.gov.uk/roads-and-transport/apply-for-a-blue-badge-if-you-have-a-hidden-disability-a-non-visible-condition/>

RADAR Key

RADAR locks were fitted in 1981 to help keep accessible toilets free and clean for disabled people. Keys can be purchased online or locally at the Tourist Information Centre, Market House, Taunton.

CEA Cards

Carers obtain a free cinema ticket if they produce a CEA card when accompanying a person with dementia. CEA cards in 2022 cost £6 from <https://www.ceacard.co.uk/apply>

National Trust Companion Card

The National Trust issue a Companion Card, allowing a carer free entry to accompany someone with a disability (this includes dementia) <https://www.nationaltrust.org.uk/features/access-for-everyone>

English Heritage

English Heritage operate a similar scheme, <https://www.english-heritage.org.uk/about-us/contact-us/membership-faqs/>

Free Entry to Attractions

Attractions advertising free entry to an accompanying carer include the [Roman Baths](#) and [Longleat](#). Other attractions allow free entry for carers though they do not advertise it. Those we know of are [Somerset County Cricket Club](#) (to accompany a season ticket holder), [Hestercombe](#), the [Brewhouse](#) and the [West Somerset Railway](#). Other attractions may do the same. There is no harm in enquiring when planning a visit.

READING AND WATCHING

- Wendy Mitchell, who has dementia, writes of her experience in *What I Wish People Knew About Dementia* (published 2022).
- What it is like to be a carer is captured in Jane Grierson, *Knickers in the Fridge* (2008) and Marianne Talbot, *Keeping Mum* (2011).
- A person with dementia is the title character of the 2021 film *The Father*, played by Anthony Hopkins.
- Julianne Moore plays the title character who develops dementia in the 2014 film *Still Alice*, based on a novel of the same name by Lisa Genova issued in 2007.
- In 2021 the BBC showed four people and their families living with dementia. Spread over two programmes, *Dementia and Us* is on BBC iPlayer.

Attendance Allowance cont'd

The lower level (as of summer 2022) is £61.85 a week. The higher level, is £ 92.40 per week. Payments can be backdated from the day the form is received in the post or from the date it is ordered by phone (provided it is returned within six weeks).

Application forms can be downloaded from <https://www.gov.uk/attendance-allowance/how-to-claim> or ordered by phone on 0800 731 0122.

Forms are quite detailed so it is advisable to have help in completing them. Age UK provide a free service for this. Contact the Taunton branch at 01823 345613.

Council Tax

A person with dementia living with one other person (but only one) is entitled to a 25% discount of their council tax. The application form for West Somerset and Taunton Council area is available at https://my.somersetwestandtaunton.gov.uk/en/service/Council_tax_discount_or_exemption

Carer's Assessment

You are legally entitled to carer's assessment.. This may result in help such as home cleaning, paying for taxi fare if you don't drive, gym memberships to aid dealing with stress. There is no harm in having such an assessment but be aware that these budgets are tightly restricted so may not yield any benefits for you. Assessment are conducted by a social care worker from Somerset County Council. To arrange an assessment phone 0300 123 2224.

ADVICE HELPLINES

Dementia UK (run by Admiral Nurses, specialist dementia nurses), tel. 0800 888 6678.
Dementia Connect, run by the Alzheimers Society, tel.0333 150 3456. They also have an online forum called Dementia Talking Point.

Help in a Crisis

Locally operated, Intensive Dementia Support Service (IDSS, part of the NHS), 8.00-8.00 seven days a week. Tel. 01823 426240

INCONTINENCE

Over time a person with dementia may become incontinent. This cannot be cured but the NHS can help by supplying free materials such as incontinence pads. Your GP can arrange an appointment with a specialist Continence Nurse.

HELP IN THE HOME

Micro Providers are self employed and will look after a person with dementia while you go out as well as helping with personal care, house cleaning, ironing etc. Charges (as of summer 2022) start from £17 per hour weekdays, more at weekends. A list of Micro Providers is available at <https://somersetcommunityconnect.org.uk/community-directory/>

Businesses such as [Home Instead](https://www.homeinstead.co.uk/taunton-west-somerset/) provide similar services at a higher cost <https://www.homeinstead.co.uk/taunton-west-somerset/>

ME TIME

Your physical and emotional wellbeing, and your effectiveness as a carer depend upon having time to sustain your interests and relationships. Try to involve family members in caring responsibilities. Make use of respite opportunities (see below). You will gain strength from being part of a carers support group. This will help you to overcome the sense of isolation that comes with being a carer, form new friendships, share with and learn from the experience of others.

INFORM YOUR GP

Let your GP know that you are a Carer and ask for it to be noted on your medical record. Surgeries usually have a form for the purpose.

RESPITE

Reminiscence Learning run respite activity sessions Monday to Wednesday, 9.30-3.30. The current charge (summer 2022) is £49 per day, including a two course lunch. <https://www.reminiscencelearning.co.uk> Tel. 01823 668676.

The Filo Project host a small group in the provider's home. The charge, as of summer 2022, is £80 per day, including transport to and from the host's home as well as a cooked lunch. <https://www.thefiloproject.co.uk>. Tel. 0333 9398225.

Care Homes providing short-stay respite care include Oaktree Court and Wellington House, both in Wellington; Abbeyfield (Somerset) and Oake Meadows, both in Taunton.

THIS IS ME

Staying in a new environment such as a hospital or care home is challenge for people with dementia and their new carers. It will help meeting the needs of the person if their new carers are supplied with basic facts such as the names of family members, medication, disabilities etc. The Alzheimers Society produce a template to record this essential information https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/this_is_me.pdf

ACTIVITIES

A person with dementia will lose some of their interests and abilities but may develop some new ones. Some suggestions: singing and listening to music (particularly music which can prompt memories), walking, colouring ¹ painting, doing jigsaw puzzles ² looking at old photographs and family albums and writing a life story ³ . Women, in particular, may enjoy caring for a doll ⁴

¹ colouring books for adults are plentiful in shops like WH Smith

² as ability declines use puzzles with a smaller number of pieces. Relish produce a range of products to entertain person with dementias in addition to jigsaws <https://relish-life.com/>

³ for a template see <https://www.dementiauk.org/life-story-work/>

⁴ specially designed dementia/empathy dolls are sold by <https://www.alzproducts.co.uk/dementia-doll>