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| **USEFUL ORGANISATIONS:**  **Admiral Nurse Dementia Helpline:** 0800 888 6678  **Age UK:** 01743 233123 [**www.ageukshropshireandtelford.org.uk**](http://www.ageukshropshireandtelford.org.uk)  **Alzheimer’s Society:** [**www.alzheimers.org.uk**](http://www.alzheimers.org.uk).Shropshire 01952 250392  **A4U** (Action, Advice, Advocacy) 0845 6025561 [**www.a4u.org.uk**](http://www.a4u.org.uk)  **British Heart Foundation** Help line: 0300 3303311 [**www.bhf.org.uk**](http://www.bhf.org.uk)  **Cancer Research:** 0808 8004040 [**www.cancerresearchuk.org**](http://www.cancerresearchuk.org)  **Carer Emergency Duty Team Shropshire Council** 03456 789040  **Carer Support:** 01743 253729 [community.services@shropshire-cc.gov.uk](mailto:community.services@shropshire-cc.gov.uk).  **Citizens Advice Bureau:** [**www.citizensadvice.org.uk**](http://www.citizensadvice.org.uk)  **Community Legal Advice:** **0845 3454345** [**www.communitylegaladvice.org.uk**](http://www.communitylegaladvice.org.uk)  **Community Nurse:** 01743 277709  **Crossroads Together:** [**www.crossroadstogether.org.uk**](http://www.crossroadstogether.org.uk)**.**  **Dementia Action Alliance:** [**www.dementiaaction.org.uk**](http://www.dementiaaction.org.uk)**.**  **Dementia Friendly Café Royal Shrewsbury Hospital**  **Dementia Help:** helping Carers to cope: [**www.dementiahelpuk.com**](http://www.dementiahelpuk.com)**.**  **Dementia Live Better With:** [**www.dementia.livebetterwith.com**](http://www.dementia.livebetterwith.com)**.**  **IMPACT:** 01743 245552 [**www.impactaas.co.uk**](http://www.impactaas.co.uk).  **Mental Health:** Help line 0800 1951700 weekdays 10-2, w/e 12-Midnight  **NHS:** [**www.nhs.direct.nhs.uk**](http://www.nhs.direct.nhs.uk)**.**  **Occupational Therapist:** 01743 264092  **Police:** Wandering or lost call 101. In emergency call 999  **St John’s Ambulance Brigade:** 01743 231280  **Self Help Shropshire:** [**www.shropshire.gov.uk/community.nsf**](http://www.shropshire.gov.uk/community.nsf)  **Shropshire Disability Network**: 01948 840726 [**www.shropshire-disability.net**](http://www.shropshire-disability.net)**.**  **Shropshire Link:** 03456 789068  **Social Services:** [**www.shropshire.gov.uk**](http://www.shropshire.gov.uk)**.**  **The Samaritans:** [**www.samaritans.org**](http://www.samaritans.org/)  **The Stroke Association:** Help line 0845 3033 100 [**www.stroke.org.uk**](http://www.stroke.org.uk) |  | Marden Medical PracticePatient Participation  *DEMENTIA* *Information Pamphlet* **The Patient Participation Group**  **Marden Medical Practice**  Sutton Road, Shrewsbury, Shropshire SY2 2DL  Telephone: 01743 241313  E-mail: [marden.marden@nhs.net](mailto:marden.marden@nhs.net)  Web site: [www.mardenpractice.gpsurgery.net](http://www.mardenpractice.gpsurgery.net)  divider_forgetmenot1[1]  **Forget Me Not**  Suggested changes to this pamphlet to Les Wilkinson c/o the above address  Edition 4 ~ 1st May 2021 |  | |
| Support For Carers of People Living with Dementia  Support for Carers of People living with Dementia is an increasingly important activity, for GPs, Social Services, Hospital staff, Carer groups and Patient Support Groups. It’s important that carers once identified are registered, with Medical Practices, Social Services, Carer Support agencies and Hospital staff.  The aim of this pamphlet is to give carers and newly diagnosed individuals, an idea of how dementia may affect some people, with tips and signposting. The information may be useful but it is neither exhaustive nor authoritative. It doesn’t replace any other publication or have any medical expertise and it doesn’t cover all possibilities, for example early onset dementia may be totally different.  People react differently to a dementia diagnosis, there are different types of dementia and it affects different people in different ways. Dementia is not just a memory problem; it is a brain disease and information doesn’t always register no matter how often it’s repeated. Personality changes, anxiety, moods, anger, frustration and stress are often difficult for the carer to understand and come to terms with. The fact is it’s not the person; it’s the disease distorting that individual’s behaviour. If the person seems snappy, they may be out of their comfort zone, worried or concerned but can’t express it. Understanding and compassion must be the cornerstone of any approach as disagreeing, arguing, trying to reason with the person or reminding them they’ve already been told something, will not work and will create real difficulties in the relationship between the carer and their loved one. This is by no means easy.  As a carer, you can only do your best, you can’t do everything and you must be careful not to burn yourself out. You will be faced with new challenges and changes which may seem beyond your ability to cope, or drawn low emotionally, physically, mentally and spiritually. It can be equally difficult for the person cared for, they don’t understand what’s happening, they’ve lost independence, self-confidence and may be agitated, angry and frightened. Somehow, you’ll find the strength and love to spring back despite the difficulties. You must help the person with dementia to cope and you will both develop a stronger bond. No one knows it all and the carer is usually best placed to understand and advise on behalf of the person they care for. It may be difficult to plan or look ahead, so live in the moment, try to keep things in perspective and don’t fret over the future or over trivia. If you can’t control it don’t try, let it wash over you.  Listen to advice, research and read what you can on dementia. It’s been said that ‘Someone living with dementia can have a full life’ but be in no doubt, dementia is a life changing disease for both the individual diagnosed and the carer. |  | **USEFUL PUBLICATIONS**:  **A–Z Shropshire County Council Services** ~ [www.shropshire.gov.uk](http://www.shropshire.gov.uk) has details of available services e.g. health, disability, care, respite care and many more.  **Age UK** provides a wide range of services and leaflets on Dementia and other topics e.g.: Advocacy, Befriending at home, Benefits, Counselling, Day Centres, Help at Home, Home from Hospital, Telephone Buddy Service and many more.  **Alzheimer’s Society** provides fact sheet, advice and support for people with dementia and runs a Carer Peer Group once a month  **A4U** provides free, confidential information, advice and support to people with long term disabilities and/or long-term medical conditions, their families and carers and leaflets covering their services.  **Bereavement A Helpful Guide** is produced by IMPACT Marketing with input from the National Association of Funeral Directors.  **British Heart Foundation** has a number of publications including ‘Keep your heart healthy’ and Reducing your blood cholesterol’  **Community Legal Advice Service Partnership** (CLASP) is a partnership of the voluntary sector and voluntary organisations may refer their clients on a number of legal matters including Community Care.  **Community Legal Advice (CLA)** provides pamphlets on a variety of services such as ‘Community Care’, ‘Mental Health Laws’ and ‘Dealing with a will’.  **Crossroads Together: (previously Carer Trust4All)** Provides support to carers.  **Dementia Care.** [**www.dementiacare.org.uk**](http://www.dementiacare.org.uk)  **Shropshire Disability Network** work with people and organisations for the benefit of individuals with disability their families and carers.  **Shropshire Libraries**, Shared Memory Bags [**libraries@shropshire.gov.uk**](mailto:libraries@shropshire.gov.uk)**.**  **Tell Us Once.** Government service, to make it simpler to notify all departments of a death, by giving information only once. [**www.direct.gov.uk/death-tellusonce**](http://www.direct.gov.uk/death-tellusonce)**.**  **The Stroke Association** has an informative booklet ‘What is a stroke?’ in addition to information leaflets such as ‘Know Your Blood Pressure’ and a number of fact sheets e.g. ‘Haemorrhagic stroke’, ‘Diabetes and stroke’.  **The World Wide Web** can be surfed for more detailed information on dementia. | |
| **Singing for the Brain.** [**www.alzheimers.org.uk**](http://www.alzheimers.org.uk)**. Social Services Safeguarding**, for concerns over unreasonable behaviour.  **Telephone, Mobile**, consider large digit and simple to turn on/off  **Travel Packing List** is a useful timesaver and memory aid  **TV and wall pictures** may be seen as people in the room  **POSSIBLE PERSONALITY CHANGES**  **Dementia Stages**: there are various types and stages of dementia.  **Difficulties in crowds** or groups, the person my feel insecure.  **Distrusting and Accusative**: There may be accusations of moving, stealing or getting rid of various things e.g. clothes, jewellery, cash  **Going Home**: the individual may express a wish to ‘go home’ despite having lived in the same place for many years. This may be a wish to return to the independence and security that existed prior to the disease.  **Hallucinations & delusion:** these will seem real to the person, go with their reality e.g. a black mat may seem like a hole in the ground  **Inability to use gadgets**: TV, DVD, remote controls, operating telephones  **Keeping warm.** Electric Blanket, put day clothes on radiator overnight  **Mixing names and people**, getting relationships or names wrong  **Personal Hygiene**: Toilet, Towels, Finger nails, hand washing, bathing  **Reading skills**: these may decline and pages of a book may be re-read many times or the ability to read may diminish  **Visiting Mum**, or other deceased family members may be an expressed wish and talk of a sister may in fact be a daughter.  **Writing skills** may decline significantly, signatures may be problematic  **ADDITIONAL**  **Carers** must look after their own health and well-being, try to use family and friends to help with care and support and consider a period of Respite.  **Don’t be embarrassed** about a dementia diagnosis, it’s brain failure ~ Heart, Kidney, Liver and Lung Failure are without stigma.  **Include** people with dementia in conversations and decisions; don’t let people assume someone with dementia is unintelligent or dull. The person may take 30 seconds longer to process information and they are still ‘in there’. Revive previous hobbies, introduce interests, read to them and perhaps create a Memory Book or Memory Room. Think about having family or friends’ photos displayed, perhaps on the stairs.  **Exercise** if possible (walking, dancing etc) and go out together frequently.  **FOOD, DIET ETC**  **Appetite** will vary and may be lost so that little is eaten for some time. Taste or reaction to food texture may change; food may taste different, have no taste or may just be unpalatable. Once favourite foods may no longer be so and tastes or appetite may change again or improve later. Try different and new foods, in small quantities or those that can be eaten with fingers. Mix a little Ensure’ Cremes with ice cream  **Difficulty swallowing** may be apparent with problems taking medication  **Sweet foods**, including biscuits, chocolate, ice cream, puddings and sweets may be preferred or the only things eaten.  **Lack of balanced diet,** i.e. lack of greens may lead to severe constipation  **Fluids and Drinks** are important and can include custard, ice cream, ice lollies etc. Mix a little Ensure pure juice with preferred soft drinks.  **Eyesight** may mean that food cannot easily be seen on the plate e.g. mashed potato on a white plate or ice cream in a white bowl. Lightly patterned crockery has a similar effect. Dark coloured plates (e.g. dark blue) are recommended for this reason.  **Loss of recognition** of rooms, places, people, clothes, colours, food etc may result in confusion. Difficulty finding (seeing) things in cupboards, refrigerator, wardrobes or the route around the house e.g. the way to the toilet, may be problematic. Difficulty finding the door out of the bedroom at night may result in toileting accidents.  **BOOKS**, **BOOKLETS, and OTHER INFORMATION**  **Alzheimer’s Fact Sheets** are comprehensive and accessible on line  **Alzheimer’s ~ The Dementia Guide**, living well after diagnosis  **Amazon** have many free or low-price books on Dementia  **Berkshire NHS Health Foundation** see Online Dementia Handbook  **CogniCare App** for mobile phone etc, to help with dementia care  **Contented Dementia** by Oliver James  **Dementia: The One Stop Guide** by June Andrews  **Teepa Snow** has a series of very informative You Tube videos on understanding and supporting someone with dementia  **The End of Alzheimer’s** by Dr Dale Breseden  **The Grief Recovery Handbook** by John W James and Russell Friedman |  | **MEDICATION, Medical and Other Points**  **The Memory Clinic** will make the diagnosis, arrange follow up visits, prescriptions and monitor reaction to medication. Prescription is then undertaken by the person’s GP.  **Pills,** Tablets and Patches vary for dementia and medication is available to control or help with Mood, Anger, Frustration, Stress, Sleep, Anxiety, Insecurity, Feeling Frightened and Hallucinations. Read medication instructions and side effects, Monitor medication and side effects  **Behaviour changes/concerns** discuss these with the Memory Clinic Nurse.  **Administering medication** if difficult or refused, be inventive (with syrup?) but check with GP or Memory Clinic before splitting or crushing tablets.  **The Occupational Therapist** can arrange such things as Bath Seats  **Constipation:** GP may prescribe Cosmocol to encourage a motion, Lactulose as a stool softener or Senakot, Enemas, Suppository Gel etc.  **Constipation & Urinary Tract Infections** may exacerbate dementia symptoms, try to avoid or seek medical help.  **Eye, ear and oral health** are still important to maintain  **Hospital Dementia Care Team:** Important support on hospital admission  **Hospital & Surgery staff** should be informed that a person has dementia.  **Personal Hygiene** and toileting may need monitoring, help and support  **Toileting during night**/incontinence ~ It may be less stressful to wake the person during the night for a toilet visit than to deal with ‘an accident’  **MONEY, BANKS and DOCUMENTS etc**  **Lasting Power of Attorney (LPA)**, both Finance and Health should be put in place whilst the person has capacity**.** [**www.gov.uk/power-of-attorney**](http://www.gov.uk/power-of-attorney).  **Record** Bank Account, Insurance, Club Card or Membership details.  **PINs**, Access to accounts may be forgotten, Joint Accounts may be frozen  **Cash** recognition of denominations may be problematic. Cash may be hoarded or hidden and those close may not be trusted (this may have an effect on securing LPA). The person may be concerned about their difficulty in accessing bank accounts etc independently. Getting a small Digital Safe for the house to keep some cash in may ease cash concerns.  **Driving Licence** may be revoked by DVLA  **Signatures** on forms may be difficult, a box cut through a coloured cardboard overlay may help to pin point where to sign.  **Wills** if not already in place should be written whist the person has capacity  **THINGS TO CONSIDER OR IDEAS TO HELP**  **Age UK Support Groups** (Various) **& Respite Day Centre** (Withywood)  **Age UK Help at Home** for help with cleaning, gardening etc  **Alzheimer’s Carer Peer Group** These meet locally, check for details  **Alzheimer’s ‘This is Me’** to record the person’s details  **Assisted Living Allowance** for people with dementia ~ not means tested.  **Blue Badge** for disabled parking is open to dementia patients from 2019.  **Cameras:** in rooms at home, linked to mobile phone  **Carers Allowance.** [**www.gov.uk/carers-allowance**](http://www.gov.uk/carers-allowance)**.**  **Carer Groups:** e.g. online dementia and support to professionals groups.  **Citizens Advice** [**www.cabshropshire.org.uk**](http://www.cabshropshire.org.uk)**. 03444991100**  **Council Tax reduction** can be claimed for someone with dementia  **DEEP Group:** Check with Dementia Action Alliance for details  **Carer Support:** Medical Practice PG Dementia Support and Local Church  **Dementia Friendly Café RSH** Gym Ward 21S ~ (Tuesdays)  **Dementia Friendly Forget Me Not Tea**, St Peter’s Hall, Monkmoor Road  **Diary, Days and times:** use white wall board divided into days, plus a large Day and Date display, Day Clock, Talking Watch.  **Diary:** number each medication and record when it’s administered  **Fiddle Box:** collection of household items to fiddle and occupy the person  **Herbert Protocol:** a ‘Safe & Found’ pre prepared description of someone as an aid should they go missing [**www.westmercia.police.uk**](http://www.westmercia.police.uk)**.**  **ID/Carer contact Card:** in Purse/wallet or as Mobile Phone Wallpaper  **Lights:** Under bed, Night or Rope Lights for Toilet, Stairs or limit roaming  **Live Better With Dementia:** [**www.careplace.org.uk**](http://www.careplace.org.uk) **(was Unforgettable)**  **Locator:** Consider GPS locator/tracker on Person or in Handbag etc  **Mirrors** and window reflections add to hallucinations, take down or cover  **Motion Alarm**: to alert for movement during the night  **Music** is important, collect DVDs on Music, Musicals, theatre shows, Humour, Situation Comedy etc. **CD Music** likewise.  **Professional Carers** vary or may not fully appreciate the implications and effects of dementia on the individual or full-time family carer.  **Radar Keys** for access to disabled toilets [**www.completecareshop.co.uk**](http://www.completecareshop.co.uk)  **Register as Carer** in Medical Practice and with Social Services.  **Shopping List** is a useful memory aid, also keep a stock of groceries  **Signs** for orto toilet, Living Room, Bedroom etc might be needed | |