

ALZHEIMER'S DISEASE

WHAT IS ALZHEIMER'S DISEASE?

Dementia is a term used to describe a progressive, gradual loss of mental abilities. The most usual change is in a person's memory but other changes may also be noticed, for example being unable to hold a conversation or carry out every day tasks such as driving, cooking or managing money. Personality may also change and behaviour become unfamiliar.

There are a number of illnesses causing dementia, but Alzheimer's disease is the most common one.

HOW COMMON IS IT?

It is estimated that about 600,000 people in this country suffer from Alzheimer's disease. Under the age of 60 years the condition is rare but from then on it becomes increasingly common. As many as one in five of those over 80 years may be affected to some degree.

Because Alzheimer's disease becomes more common with increasing age and because the numbers of elderly people in the population as a whole are growing, the number of patients affected by the illness are steadily increasing.

WHAT HAPPENS TO THE BRAIN?

The changes, which occur in our brain, were first described early this century by a German doctor called Alzheimer. The disease causes a gradual death of individual nerve cells resulting in brain shrinkage or atrophy. There are other changes, that can be detected under the microscope, and it is also known that there are deficiencies of certain vital chemicals within the brain. Current medical knowledge now allows some new treatments to be tried out which attempt to temporarily correct the chemical imbalances.

WHY DOES IT DEVELOP?

The underlying cause of the disease is nearly always unknown. In only a few families the disease is directly inherited. However, even someone with a close relative with Alzheimer's disease is much more likely not to develop the illness than to do so. Because its onset may coincide with an event such as another illness, surgery or bereavement, relatives may see this as relevant. But these

events are usually coincidental and not the cause of the illness. Although much research is continuing to contributing factors such as exposure to aluminium, results are still not strongly conclusive.

HOW IS THE DIAGNOSIS MADE?

There is no simple test which can make the diagnosis of Alzheimer's disease with certainty. A post mortem after death can confirm the diagnosis by examining brain tissue under the microscope.

During life, the diagnosis is based on carefully noting the way symptoms develop and change over time, the results of psychological testing, blood tests and sometimes a CT brain scan. Relatives' observations and report of change are also crucial, as it is often those close to the patient who notice the very early changes in behaviour.

The uncertainty prior to receiving a diagnosis can be a worrying time for relatives and can prolong frustrations as behaviour changes. It is common for the symptoms to fluctuate from day to day and this can be very perplexing and lead to the false belief that the sufferer is aware of what they are doing. Practical advice and support can help carers to cope better with unexpected behaviour.

Confirmation of the diagnosis has significant practical implications for the future. Immediate concerns often involve issues such as driving and handling finance.

WHAT OF THE FUTURE?

Whilst there is no cure for Alzheimer's disease, there are currently good and bad approaches to treatment. A careful initial medical assessment and subsequent regular monitoring is needed. The course of the illness varies from individual to individual. In some patients deterioration can be very rapid, over months, but in most the decline occurs over several years.

The past few years have shown the emergence of medication which has been shown to slow the rate of decline in memory and ability to do everyday tasks seen in Alzheimer's disease, although they do not make any difference to the overall progression of the disease. At present, they can only be used where Alzheimer's disease is mild or moderate in severity. In Berkshire, it can only be started and controlled by a Doctor in Old Age Psychiatry.

BENEFITS

For people in later life who are experiencing various degrees of ill-health, the government provides a number of benefits both for the individual concerned or those who are helping to care for them. These include:-

1 Attendance Allowance

- 2 For all people aged 65 and over, who due to their ill-health, need help from another person to cope with daily tasks.

This is paid at two rates; a lower rate for people who only need help either during the day or night; a higher rate for people who need help both day and night.

This allowance is not means tested, i.e. is paid if you qualify, whether or not you have any savings.

Help with claiming this benefit is available through a Social Services Welfare Benefits Officer, or by contacting your local Citizens Advice Bureau (see useful contact sheet for the telephone numbers).

Disability Living Allowance

This is similar to Attendance Allowance but is for people who are not yet aged 65.

Carer's Allowance (formerly called Invalid Care Allowance)

If you are under state retirement age and caring for at least 35 hours per week for someone who is in receipt of Attendance Allowance or the middle/higher rate of the care component of the Disability Living Allowance, you may be entitled to claim this benefit, depending upon the level of your own earnings.

Paying for care at home as an alternative to residential accommodation

Social Services now offer a Direct Payment Scheme which allows you to do this. Please ask for the Age Concern Factsheet No. 24 on this if interested.

Council Tax Discount

Anyone who has been diagnosed as having Dementia is entitled to claim a reduction (25%) on their Council Tax.

Note: you must have already been granted Attendance Allowance before you can claim this discount.

To make a claim, contact your local council tax dept. and ask for form SM1.

3 Travel Benefits

Many local councils have schemes offering free bus and travel tokens to those over the state retirement age. Contact your local council for details.

Blue Badge Car Parking Scheme

This allows you to park in the disabled parking bays (often free of charge, but check first). To apply for this telephone your local Social Services Enquiry Line (see out & about sheet).

4 On a low income?

The **Pensions Credit Scheme** has now replaced income support to provide a guaranteed minimum weekly income. Contact the Pension Credit Helpline on 0800 991234 for details or speak to the Citizens Advice Bureau.

Housing Benefit may also be available to those on low incomes in rented accommodation. Contact the Housing Dept of your local council.

LOOKING AFTER YOURSELF THE CARERS PAGE

Many people caring for someone with Dementia wish to look after them as long as they can. You may feel that it is your responsibility or duty to look after the person and that you are strong enough to cope with every demand, however caring for someone with Dementia is often physically, mentally and emotionally draining. Whilst loyalty is important, it must not come at the cost of your wellbeing. If you do not take care of yourself, looking after the person with Dementia will become more difficult than it needs to be.

Some suggestions to ensure you remain well:

- Ensure you take as much care of your own physical health as you do over that of the person you are caring for. (take regular exercise, eat a balanced diet and get a good night's sleep) Overlooking your physical needs could lead to stress-related illness.
- Talk to someone you trust about your concerns, feelings, frustrations and dilemmas. It is normal to experience some difficult emotions e.g. fear, anger, guilt, loneliness etc. These emotions are quite natural and only harmful if they are denied or bottled up.
- Consider joining a Support Group where you can meet others who may share your worries about the future and identify with your situation. In addition to the emotional support provided by such groups, they can be a source of practical advice and new friendships.

Practical Help

- Contact Social Services to enquire about the availability of help with specific tasks such as providing personal care, (eg. washing, dressing or getting ready for bed) meal provision (Meals on Wheels), help with laundry, shopping, bathing, prompting to take medication etc.

Getting a break when you need it

Ensure you have regular breaks. It can be difficult to arrange time off from caring for someone, however it is essential that you have time for pleasure and relaxation such as social contact with friends or the pursuit of a hobby. Sometimes a few hours may be all that you need to enable you to meet friends or

pursue a hobby, but there will also be times when you will need a longer break. See information sheet regarding holidays (Out and About)

Day Centre

Ask Social Services about local Day Centres that the person with Dementia can attend one or more times each week. There is a small charge for this service, but it usually covers the cost of a meal, refreshments and transport. Whilst the person benefits from social stimulation and involvement in structured activities in a safe environment, you can try to make sure you prioritise this time to meet your own needs.

Care at Home

Alternatively care can be provided for the person within their own home. This can be arranged for a specific time each week or to enable you to attend a particular event. (e.g. a Wedding) In Berkshire, this is provided by Crossroads or St John Ambulance. (see Useful Contacts sheet for your local provider)

Away from Home

A Respite admission to a Nursing or Residential Home can be arranged through Social Services, to enable you to have a rest or go on holiday for one or two weeks. It is important to plan ahead as the available places get booked up very quickly. Every Carer is entitled to 4 weeks subsidised Respite per year. For further information, speak to your Care Manager.

Plan for the future.

Investigate what practical support and long-term provision is available before you need it. Keep a list of numbers of people who can help (see Useful Contacts sheet) by your telephone. This preparation could prevent you having to struggle on alone should you ever need additional help. In addition to the suggestions above, it is your right to ask Social Services for:

A Carer's Assessment
Benefits you are entitled to claim
Information about Nursing / Residential Homes

We regularly review and amend the contents of this Carer's Pack and welcome your suggestions on how to improve it and make it more useful to Carers. Please pass your comments to the person who provided you with this pack.

COMMUNICATION

Communication is about far more than passing on or understanding a message. The ability to communicate with others is a basic human need – it goes to the heart of who we are. Meaningful communication helps to preserve our sense of identity and is central to our quality of life.

HOW WE COMMUNICATE

Speaking (Verbal communication) - our most sophisticated means of communicating is by translating our thoughts into words.

Body Language (Non-verbal communication) - the messages we give without words, through our facial expression and eye contact, our tone of voice, how we stand and hold our bodies and our use of touch. Non-verbal communication is more subtle but is often more powerful than the words we speak.

Non-verbal communication becomes all the more important during the course of dementia as ideas become confused and as language skills diminish.

Examples:

- A blank or puzzled look on the part of the person with dementia may let you know that he / she has lost the thread of the conversation and that you need to simplify your language or slow down the pace of conversation.
- Restlessness on the part of someone with limited verbal skills may be their means of communicating a need (e.g. for purposeful occupation, or simply a need for the toilet)
- If your expression is habitually tense or frowning, someone with impaired understanding of verbal language might believe that you are angry with them even though your words do not express anger.

COMMUNICATION AND DEMENTIA – WHAT CAN GO WRONG

Even quite mild memory problems can be at the root of misunderstandings and of communication breakdown between families and friends.

Memory loss can result in:

- Asking the same question repeatedly
- Telling the same story over and over again.
- Saying things that are not true.
- Talking less (being unable to remember what there might be to talk about)
- Losing the train of thought mid-sentence.
- Referring to people or places from the past as if they were in the here and now.

In addition the person with dementia may experience **Speech and Language difficulties** (problems in understanding, and commonly in word finding). The extent of any language involvement varies according to the type of dementia. For

some people verbal communication at a simple level remains possible throughout the course of their illness, whilst for others language difficulties can be one of the first signs that anything is wrong.

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6 VISION AND HEARING

We all rely on both our eyesight (to interpret non-verbal messages), and on our hearing in order to communicate with one another.

It is important to remember that you may need to start to assist the person with dementia in keeping their glasses clean, and to prompt them to wear the right spectacles at the right times.

Sometimes what appears to be a problem with eyesight is actually to do with the brain having difficulty in interpreting what the eyes are seeing, but it is always a good idea to arrange for an eye check to see if there are any visual difficulties that can be improved upon.

Likewise it is important to request a hearing test if you have any doubts about the person's hearing.

Hearing aid use: Even long-term hearing aid users may start to have difficulty and need your help:

- In keeping their aid clean, free from wax and in good working order.
- In realising when their aid is not working properly e.g. when the battery needs replacing
- In remembering how to adjust their aid for different situations.

Discomfort caused by too much amplification, or reduced hearing resulting from a non-functioning aid acting effectively like an ear plug, can be at the root of a person's refusal to wear their hearing aids.

When you are speaking it helps to:

- Pronounce your words clearly (but take care not to exaggerate your mouth movements as this will make it harder to lip read because it changes the way words look). Make sure that the person can see your face and take care not to hide your mouth e.g. with your hand or by looking away.
- Take care not to speak too quickly.
- Raising your voice a little may help but take care not to shout as shouting distorts words and makes them harder to understand.

Noise sensitivity: Sounds that we take for granted can actually disturb some people with dementia. Many people with early stage dementia have said that they function best in a quiet environment.

7 TIPS TO HELP WITH COMMUNICATION

8 Gaining attention

- Try to minimise competing noises such as radio or TV or the conversations of other people.
- Make sure that you have the person's attention before you start to tell them something e.g. by making eye contact / by saying their name / by

- touching their arm or even holding onto their hand to keep them focussed on you if necessary.
- Try to position yourself so that the person can see you clearly, and maintain eye contact whilst conversing.

Listening

- Try to listen carefully to what the person is saying, and encourage them but at all costs do not patronise them. Most of us would react badly to being treated as if we were small children and people with dementia are no different in this respect.
- If the person with dementia is struggling to find a word, encourage them to relax and to tell you more about the word rather than concentrating too hard on remembering it. You might also ask them to try to show you what they mean in some other way (pointing / gesture pantomime etc). You may be able to guess the word with these additional clues.
- If the person's speech has become difficult to understand then use your knowledge of the person to interpret their meaning and check back with them to see if you have got it right.
- If the person's ability to concentrate is such that they are unable to follow a 'normal' conversation, then try to listen closely and respond to the person's remarks (adjusting the conversation to follow their train of thought). This can give them a sense of having had a 'proper conversation' and of having been listened to and involved.

9 Encourage spontaneity

- The ability to laugh together can be a tremendous safety valve. NB style of humour is important. Simple humour is best whereas a teasing approach, innuendo or play on words (even if this was once part of their style of communication) may well be misunderstood.
- If the person you care for is feeling sad they have a right to be allowed to express these emotions. All you can do is to show them that you care.

10 Ways in which people with dementia may try to communicate

- By talking about the past. Many people with memory impairment use accounts of their past lives in order to hold onto a sense of their own identity. It can be very beneficial to help them to put together a simple photographic 'life story' marking key points in their life from childhood to the present day. This can be very comforting when entering a new environment e.g. starting to attend a day centre or moving into a residential care setting.
- People with dementia may at times express themselves symbolically. It is often worthwhile to look for a deeper meaning before you dismiss their words as simply 'confused' e.g. "I've got to go to work" might mean "I need to feel useful" – so that simply reminding the person that they no longer go to work may not be the best way to respond. "You've stolen my money" may mean "I feel as if you're taking control of my life" and

sensitive reassurance rather than denial and argument might be the best approach.

NB. The ability to reason logically is often affected in dementia. As a general rule it is always better to **avoid confrontation** and either to distract or to give a non-committal response in order to avoid argument.

11 Body Language

- Try to find ways to relax yourself so that your body language communicates an unhurried calmness. This will convey to the person that you have time for them, whereas a tense expression may upset them and make communication more difficult.
- You can pick up clues as to how the person with dementia is feeling from their body language even if words fail them.

Even people with severe dementia remain able to communicate, but they are much more dependent on our ability to interpret their meaning, and to respond in ways that they are able to understand. Remember that the emotions behind failing words are far more important to understand than the words themselves and need to be validated (i.e. to be recognised and acknowledged). You can communicate your care and affection by the tone of your voice and the touch of your hand and the reassurance this can provide should never be underestimated.

12 Speaking

- Break down your sentences into less complex patterns. Aim to use short simple sentences but take care not to 'talk down' to your listener.
- Try to use familiar vocabulary. If the person has difficulty in understanding you, rather than repeating yourself, try to rephrase your sentence using different words.
- Be direct e.g. say "I'm busy at the moment", not "Do I look as though I have nothing to do"
- Be literal e.g. Say "It's raining hard", not "It's raining cats and dogs"
- The person may need more time to process information. Slow down the pace of conversation and give them time to think.
- Make use of gesture and pointing to help make your meaning clearer.
- If the person has difficulty in concentrating or in focussing on a topic it can be very helpful to use pictures photographs or objects to 'anchor' your conversation.

13 Asking Questions

- Try to avoid asking questions that tap into recent memory e.g. "What did you do yesterday" / "What did you have for lunch". Dementia most commonly features recent memory impairment making this type of question impossible to answer and causing the person to feel embarrassed or even defensive.

- Avoid asking open ended questions e.g. “What would you like to do this afternoon” (The person with dementia is likely to find it difficult to think of the options)
- Instead offer a choice of just two alternatives e.g. “Would you like to go out for a walk or would you prefer to stay at home”
- Alternatively ask questions that require only a Yes / No response e.g. “Would you like a cup of tea”

14 Showing Respect

- Do your best to include the person with dementia in conversations with others and try to avoid speaking for them or talking across them as if they were not present. People with a variety of disabilities complain of being treated in this way and it is a particular hazard for people with dementia.

15 Whose reality?

Present reality can become confused as dementia progresses. It used to be thought that the best approach was to correct time confused errors (Reality orientation)

e.g. by responding to the person who says “Where’s my mother” with “Your mother died twenty years ago”. However this kind of blunt response often causes reactions of shock, distress and sometimes disbelief.

It is often more helpful to try to identify the feelings behind a confused statement e.g. perhaps feelings of anxiety and a need for reassurance, and to let this insight guide your response (a Validation approach)

e.g. you might reply: “Are you worried about being on your own?– I’ll stay with you– shall we look at those photographs of your mother on her wedding day”.

16 Your own communication needs

Changes in a person’s ability to communicate inevitably brings about loss, both for the person with dementia, and in a different way for those who care for them. It is important as a carer, to realise that you will also need time for yourself to relax and to be able to spend time with family and friends without having to consider the communication needs of the person you care for.

It is also reassuring to hold onto the fact that however impaired a person’s speech and language may become throughout the course of their illness, that non-verbal channels of communication will continue to be an effective means of communication.

CONTINENCE

INCONTINENCE IS NOT AN INEVITABLE PART OF DEMENTIA

If 'accidents' begin to occur, it is important to rule out any treatable medical cause.

These could include for example:

- Diabetes
- Prostate problems (in men)
- Effects of certain medications (e.g. water tablets)
- Infections
- Even constipation may be the cause of incontinence

Constipation may be due to:

- Taking less exercise
- Not drinking enough
- Not eating enough fibre
- The side effects of certain medications

Please **seek advice from your doctor** in the first instance.

INCONTINENCE AND DEMENTIA

If a person with dementia begins to have 'accidents' these may be due to a variety of difficulties associated with the illness. It is important to understand these difficulties in order to know how to help.

Difficulties could relate to:

AWARENESS (recognising the need to go)

How to help:

- be alert for any early warning signs e.g. fidgeting / restlessness / starting to undo clothing.
- try to remind the person at regular intervals to use the toilet

COMMUNICATION (being unable to say that they need the toilet / or being unable to understand e.g. directions to the toilet or other prompting)

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18 How to help:

- again be alert to non-verbal signs (as above)
- keep any verbal instructions very clear and simple

RECOGNITION (difficulty in finding or in recognising the toilet)

How to help:

- paint the toilet door in a clearly contrasting colour so that it stands out.
- put an easy to read sign (or a picture symbol) on the toilet door to help to identify it
- make sure that the route is well lit and that the path is uncluttered
- paint the wall behind the toilet a darker colour so that the toilet pan stands out

ABILITY TO CO-ORDINATE THE MOVEMENTS REQUIRED (to remove clothing / to turn around and sit down etc)

How to help:

- make sure that clothing is easy to remove (elasticated waists / Velcro fastenings etc.)
- give simple step by step verbal prompts
- sometimes gentle positioning or even help with removing clothing may be necessary. (Try only to give as much help as is needed and aim to preserve the persons privacy and dignity at all times)

IF INCONTINENCE CANNOT BE AVOIDED ask your GP to put you in touch with your district nurse or local continence nurse to advise you about suitable aids and services. (see contacts sheet)

These could include:

- suitable pads and pants
- absorbent and waterproof covers to protect chairs, mattresses and pillows
- a commode if access to the toilet is difficult
- laundry services

Diet and Good Health

Proteins:- These are essential for tissue growth and repair especially muscles. They are comprised of amino acids, hormones, enzymes and other factors. Sources include: meat eggs, milk cheese, peas, beans & soya products (legumes), lentils, nuts and seeds with tiny amounts in rice and potatoes. The egg is the only one with all 8 amino acids.

Fats - Animal Fats:- the majority of these are saturated and considered more likely to be deposited on vessel walls especially if little fibre, vitamins and minerals are present in the diet. Increased risk of heart disease/ Alzheimer's. These are solid at room temperature.

Fish Oils – Salmon, mackerel, herring and sardines are considered very good sources of omega 3 essential fatty acids. Linseeds are another source. Omega 3 fatty acids are important in preventing hardening of the arteries, cancer, heart disease, depression, mental illness. Cod liver oil is a traditional supplement for vitamin A & D helpful for eyes, skin, bones and mucous membranes it relieves arthritis inflammation. There is evidence that intelligence depends on these and they could prevent degenerative disease.

Vegetable fats – these are from seeds and nuts and are best cold –pressed & unhydrogenated ie liquid. They can reduce the bad cholesterol in the blood and some monounsaturates such as olive, groundnut and rapeseed oils can increase the good cholesterol which acts as a scavenger cleaning the blood. When buying margarine look for brands that have no trans fat. Fats in processed foods tend to be the bad kinds - cakes and biscuits!

Fats are essential to life for energy and insulation against the cold. Vitamins A D E and K need fat to transport them round the body. Women need them to make oestrogen. Try to add the good sorts to your diet and leave out the bad sources.

Heating most fats causes dangerous changes. Try to add fats at the end of cooking where possible. Try softening onions etc in a little stock rather than frying them before adding other ingredients. Try occasionally roasting a joint on a rack over hot water or over a bed of potatoes and carrots without excess fat. Add olive oil to the finished stew instead of frying everything first. Even if you just change from the usual methods now and again it helps.

Carbohydrates - These are sugars and starches. There was a time when we were all urged to eat more bread and potatoes. No one has ever advocated eating more refined sugar. It has been called "sweet, white and deadly". Sucrose has had all its vitamins and minerals stripped from it in refining as has white flour though it, by law, has some elements put back in. It is increasingly written about as one of the chief causes of aging. To be digested starches and sugars need B Vitamins and magnesium. It is noted that we consume only three

of the eight types of sugar in any quantity. This is very unbalanced as some of these rarer sugars act as intracellular messengers.

Fruits, vegetables and cereals are good sources of carbohydrates. Sweets, biscuits, cakes, potatoes, carrots, bread, rice and cornflakes are absorbed very quickly and can lead to sudden rises in blood sugar levels and equally sudden drops in those levels. It helps to have a little fat or protein with these items to slow down absorption.

Fibre This is really a type of carbohydrate from the cell walls of plants – cellulose and is important for bulking out our stools helping to transport toxins and other wastes from the body. Wheat bran used to be the fibre everyone sought but it has been shown to prevent absorption of vitamins and minerals So oat bran, vegetable and fruit fibre is better able to bind with bad cholesterol and transport it out of the body. Salads and cereals linseeds and soya products add fibre as well.

Vitamins and minerals There are at least 15 vitamins, 15 minerals, 8–10 amino acids & some rarer sugars that all work together to keep a healthy body functioning well. It is very common even in rich western countries to have deficiencies in these. Our food at best travels far from where it was produced and cannot be said to be fresh. We have many pesticide and herbicide residues to eat with our food these days. There are high levels of preservatives and colourings, flavour enhancers, tenderisers added to processed foods. Our bodies were not designed to cope with such numerous all pervasive chemical additives. We have to work hard to find the food which will provide everything we need without too many unwanted additions. It can be expensive but fruits and vegetable nuts and seeds are wonderful sources of anti-oxidants proven to reduce Free-radical damage ie rusting of the body. Vitamins and minerals are best found in food sources but sometimes its difficult to get all you need especially if you have strong likes and dislikes which limit variety. Supplements are wise in such cases.

Water - 70-75 % of the body is water. We all need 1 and a ½ litres a day. Dehydration is very common causing confusion, constipation and continence problems and over a long period, slow poisoning. Water flushes out toxins and wastes which otherwise accumulate. Unfortunately our water quality is questionable sometimes polluted with pesticides, nitrates, oestrogen-like compounds which reduce fertility. Chlorine, ammonia and fluoride are commonly added as public health measures but they do have bad effects for some people and they make the tea taste horrible. Water on its own or with a little fresh lemon juice is very important. Its quite hard to realise you need water and not tea/coffee/juice/fizz/alcohol. It's one way of saving money for expensive organic vegetables and bread! It's especially important if you decide to increase your fibre intake.

19 Food as Medicine

Almond rich in protein ,B vits, potassium, zinc, phosphorus, almond milk-digestive

Apple rich in pectin which binds toxins, Vit C, digestive, good for rheumatic pain
Apricot rich in iron, beta-carotene, fights infection, ?cancer preventative

Avocado rich in Vit A, C, E, some B, potassium, monosaturated fats good for heart skin etc

Banana rich in potassium B6, Vit K, calcium ,folate, pectin fibre

Barley for inflammation constipation strength, digestion liver, stress fatigue, brain,Vit B E calcium

Basil natural tranquilliser, aids sleep

Beans fibre protein iron folate, slow digestion, steady blood sugar, reduces blood cholesterol

Berries Vit C and anti-oxidants

Beetroot digestion, cleanses the liver, strengthen the immune system

Black cumin seed negellin stimulates digestion, protects the heart, essential fatty acids, skin

Blackcurrant Vit C, and carotenes, flavenoids, anti-o, inflammation, heart, cataracts

Brazil nuts- rich in anti-o selenium, thyroid function, fertility

Broccoli iron,beta-caratene,vit c, folate , one of rarer sugars which fights cancer, joint problems

Brown rice fibre, B vits, Vit E, methionine helps produce anti-o enzyme

Brussels sprout carotene, helps liver cleanse body of Parkinson/Alzheimer toxins, C Folate

Cabbage Rich in ABCE, iron sulphur silica magnesium, chlorophyll tonic disinfectant for ulcers

Camomile for sleep, stomach trouble,IBS,period pain, migraines, headaches, muscle spasm

Cardamom digestive, respiratory disorders eases indigestion, flatulence and colic

Carrot VitsABC Calcium Iron Potassium, beta-caratene for eyes, cancer, skin, anti aging

Cauliflower folate, anti-o vit C, cancer fighting rarer sugar

Celerysodium potassium –lowers blood pressure & blood Cholesterol, reduces acidity, diuretic

Cinnamonantifungal antiviral,antibacterial for vomiting, stomach upsets, anti-spasmodic as tea

Chillies capsaicin which can relieve pain of shingles, induces sweating

Cloves toothache remedy relieves pain, antiseptic, germicidal

Cranberries antibacterial good for cystitis

Fenugreek soothing for inflammation of stomach and as poultice for boils/abcess not for pregnant

Garlic prevent cancer, heart disease,antiseptic, reduces risk of pre-eclampsia, liver cleanser

Ginger circulation, arthritis, rheumatism, digestion (flatulence),antiseptic, loosens mucous

Grape stress fatigue convalescence cleansing and strengthening stimulating regeneration

Horseradish digestive, diuretic

Lemon Balm treats anxiety, tension even mild depression

Lentils protein, cholesterol lowering fibre, iron,potassium magnesium, lignans which fight cancer
Mango Vit E ,iron Vit C very rich in Beta-carotene anti -O

Melon Cleansing, mildly stimulating for kidneys and bladder
Mushrooms Shiitake reduces blood cholesterol, B vit, iron protein, rare sugar immune enhancing

Nutmeg small amount help flatulence, nausea, vomiting, sleep and well-being too much is danger

Oats steadies blood sugar, lowers cholesterol, good for digestive troubles B, E calcium,magnesium

Oily Fish omega 3 fatty acids lower cholesterol, protect heart, skin, brain
Olive Oil mops up cholesterol, inhibits free radicals, for digestion & bowel movements, rheumatism

Onion lower heart,cancer,stroke risks, for arthritis,asthma,bronchitis,urinary problems,gout, ”

Orange Vit C, Beta-carotene, bio-flavenoids fights infection, strengthens capillary walls anti-O

Parsley anti-O, carotenes, vitC, potassium calcium,diuretic, expectorant, not if pregnant

Peppers Vit C, anti-O beta-carotene, especially red & yellow fight cancer heart disease

Peppermint antispasmodic digestive

Pineapple bromelain enzyme digestive , anti inflammatory ,speeds up healing

Prune twice as much anti-O than other fruit, high fibre, laxative

Pumpkin Seed for prostate trouble, anti-O, Vit B complex, calcium iron zinc magnesium

Radish small amounts good detox for liver

Raspberry Leaf good preparation for labour, also throat irritations & mouth ulcers

Rosemary strengthens muscles, hair, antibacterial ,antiseptic,antifungal for memory brain

Sage anti aging, good for eyes, immune system colds flu, brain stress not pregnant /epileptic

Sauerkraut promotes a healthy colon, eliminates toxins in gut, Vit C, Calcium, enzymes

Sesame Seed Protein,calcium,Vit E,zinc,essential fatty acids,amino acids vitality circulation

Soya Bean natural HRT,prevent breast/prostrate cancer,B

Vits,calcium,lethicin for brain nerves

Spinach Anti-O iron,potassium, eat raw/ lightly cooked protects eyes, reduced cancer risk

Sprouted seeds Cheap source of vits ACBE enzymes sprouting increases vit E 300%

Sunflower seedsBVits, good fat,protein, minerals good for irritability,fatigue, depression

Sweet potato antiO, VitE, minerals- lower risk of degenerative disease

Thyme antimicrobial good for chest infections asthma sore throats,cough, spasm

Tomato lycopene vit C iron potassium- might slow macrodegeneration, lower many cancer risks

Turmeric curcumin is antitumour anti-inflammatory helps liver, reduces wind when used with pulses

WatercressVits A,CB iron iodine calcium zinc for anaemia,infections,excema, degenerative disease and cancer

Ten top foods Almonds, Apples, Apricots, Avocados, Bananas

Beetroot, Berries, Broccoli, Cabbage, Carrots

Eat these too regularly Grapes, Melons, Oats, Oily Fish
Olive Oil, Pineapple, Soya Beans,

Watercress

DRIVING

Driving is a complicated skill requiring a high level of perception, co-ordination, alertness and decisiveness. Many relatively mild illnesses, disabilities and drugs can adversely affect driving ability, particularly in new or unexpected circumstances. Such changes may sometimes not be obvious until the driver is confronted with an unforeseen situation – and then it may be too late.

For a person with significant memory difficulties there may be associated problems with perception, co-ordination, alertness and decisiveness.

Some of the strengths and weaknesses highlighted by the psychologist's assessments will be directly related to the skills and abilities needed for safe driving.

Giving up driving may involve a significant loss of independence and self-esteem. The decision is seldom easy, but does eliminate any possibility of a costly and avoidable accident. It is worth remembering that the Automobile Association calculate that use of public transport and taxis is usually more economical than using a personal motor car for those who travel less than 4,000 miles per year!

The Law

All holders of a British Driving Licence are required by law to inform the Driver and Vehicle Licensing Authority (DVLA) in Swansea at once of they have any disability which may now, or in the new future, affect their fitness as a driver. The only exception to this rule is if the disability is not expected to last more than 3 months. Failure to inform the DVLA of a diagnosis of dementia is a criminal offence punishable by a fine of up to £1,000.

Most car insurance companies also expect to be told of any problem which potentially may influence driving skills or they will regard the insurance policy as invalid. Once informed they may refuse to continue insuring the driver or increase the premium. Different companies have different practices.

When to stop driving

If a person with dementia would like to continue driving they should request a medical investigation. The DVLA will then send a form, which gives permission for your doctors to release information. You may be asked to have a formal driving assessment. Based on this you may be issued a 1 year licence.

Whose responsibility?

It is the responsibility of the driver to inform the DVLA of any relevant medical problems or disabilities and for many family members to persuade him/her to do so. Doctors and other professionals are required to inform patients if they have any condition which may now or may in future interfere with fitness to drive. If the patient continues to drive without informing the DVLA then they do so illegally and further action may be necessary. If a person with dementia continues to drive against a doctor's advice the doctor may inform the DVLA. Family, a neighbour or police officer may also do so.

Encouragement to stop driving

Some people with dementia decide quite independently that they no longer want to drive. Others need a little or a lot of encouragement from carers, family members or friends. The person's doctor may also be able to help.

Giving up driving will seem especially hard if physical problems make it difficult to use public transport. And, in some areas, cuts in public transport mean that it is very difficult to get about without a car. If the person with dementia has been the driver, the decision will also have serious implications for their partner. It is not easy.

If a person has to give up driving they will probably feel unhappy about losing some of their independence. Encouraging them to take charge of their new transport arrangements – perhaps by opening and managing their own taxi account – may be helpful.

When persuasion fails

For some people with dementia, no amount of persuasion can convince them that it is no longer safe for them to drive. Eventually, as their disease progresses, they will probably forget all about driving. However, until they do, driving can become an extremely trying issue for all concerned.

If it becomes necessary to prevent someone from driving, it may be worth considering the following strategies, which have worked for others in this situation:

- Suggest that public transport or a taxi may be more convenient.
- Keep the car in a different place so that it is no longer visible:
 - Parking it somewhere else.
 - Gifting it to a relative.
 - Selling it.
- Suggest that you drive when you go out together because you need the practice.

EATING AND DRINKING

WEIGHT LOSS AND DEMENTIA

- 20 It used to be thought that weight loss was part of the illness, however research evidence shows rather that people with dementia are at risk of malnutrition because their illness can make it difficult for them to eat or drink enough. Less commonly, overeating and excessive weight gain may be a problem.

EATING / DRINKING DIFFICULTIES IN DEMENTIA

Early Difficulties

- If the person is living on their own they may increasingly have difficulties with both shopping and cooking, or they may simply forget to eat. Consider ready made meals services, meals on wheels, luncheon clubs or day centres, or home care services to provide additional help with shopping and meal preparation.

Loss of appetite

- Some people lose interest in food because they are depressed. There are effective drug treatments for depression, so if you suspect that this is the problem, consult your G.P.
- May be due to badly fitting dentures or sore gums making eating uncomfortable. Ask your dentist to check.
- If the person is not very active during the day they may not feel hungry. Physical activity and exercise should be encouraged if possible.

Transferring food from plate to mouth

- Difficulties due to the physical process of transferring food into the mouth can be assisted by practical measures such as the use of plate guards, non-slip mats, using a spoon rather than a knife and fork or introducing specially adapted cutlery. Ask your GP to refer you to an occupational therapist (OT) who can advise you on eating aids.
- Common sense measures such as using plastic tablecloths and aprons can make it easier to relax and focus on the person's needs rather than worrying about the mess.
- It is important to try to enable the person to be independent for as long as possible – if using a knife and fork becomes difficult consider giving foods that can be picked up and eaten (finger foods).

Visual difficulties

- Visual difficulties (e.g. in being unable to see the food on the plate / only seeing one half of the plate etc) can make it difficult to eat / drink.

- In addition being able to interpret or make sense of what is seen (to recognize food for what it is) can also be a problem for some people.
- It is important to make sure that the dining area is well lit, that the food contrasts clearly with the plate and that the plate stands out against the tablecloth.
- It is better to use a plain rather than a patterned tablecloth, and to keep the table setting simple and uncluttered.

Restlessness

- Sometimes people are simply too restless to be able to sit through a meal.
- Try to ensure a calm peaceful atmosphere around mealtimes e.g. you could try playing calm soothing background music.
- Don't assume that the person has finished if they get up and leave the table. Find ways to keep the meal warm e.g. by using insulated plates, and try to encourage them to either return to the table, or take the meal to where they have settled.
- Alternatively provide finger foods that they can eat while on the move. More frequent snacks may be more successful than one large meal a day.

Overeating

- In some rarer forms of dementia the person may want to eat more food than they require.
- It is usually best to keep food out of sight, or if the person constantly seeks out food, to provide non-fattening snacks such as fruit or raw vegetables.
- Also be aware that they may try to consume non-food items so it is important to keep hazardous non-food items out of reach e.g. cleaning chemicals, poisonous plants, drawing pins etc.

Later stages

- In the later stages of dementia some people may no longer understand what to do with their food, or they may become less aware of the food in their mouths.
- You may need to keep reminding them to chew or to swallow, or to guide the hand holding the spoon to their mouth in order to start / restart eating.
- Food tastes appears to change in dementia. In the later stages people often develop a liking for stronger flavours that they may not have enjoyed in the past so it is worth experimenting with different tastes that might increase awareness of food. Alternating warm and very cold foods may also have this effect.

Swallowing problems

- Swallowing problems may develop in dementia. If the person starts to experience repeated chest infections, if they cough during or shortly after eating or drinking, if their cough is weak or their voice sounds wet or gurgly these could be signs of a swallowing problem. Ask you G.P. to refer

you to a speech and language therapist for assessment and advice on management.

A Healthy Diet

- It is important to encourage the person you care for to eat a healthy balanced diet, providing all the nutrients the body needs in the right amounts to stay healthy.
- Dieticians can provide advice on issues such as poor appetite, weight loss and weight gain, food enrichment and vitamin and food supplements.

FRONTO-TEMPORAL DEMENTIA

WHAT IS FRONTO-TEMPORAL DEMENTIA?

The term 'fronto-temporal dementia' covers a range of conditions including Pick's disease, frontal lobe degeneration and dementia associated with motor neurone disease. You may perhaps have heard the terms 'semantic dementia' or 'progressive aphasia'. These are also sub-types of fronto-temporal dementia.

All are the result of loss of nerve cells causing shrinkage within the frontal lobe and / or the temporal lobes of the brain. These areas of the brain are involved particularly with behaviour, emotional response and language, so it is these functions rather than memory and orientation which are most affected initially.

WHO IS AFFECTED?

- Fronto-temporal dementia is a less common form of dementia occurring far less frequently than for example Alzheimer's disease.
- Younger people, specifically those under the age of 65, are more likely to be affected.
- Generally men and women are equally likely to develop the condition.

WHAT ARE THE SYMPTOMS?

Typically in fronto temporal dementia, nerve cell damage occurs predominantly in the frontal lobe of the brain in the early stages, with the temporal lobes being affected to a lesser extent resulting in:

Personality changes – for example uncharacteristic insensitivity, apparent selfishness, loss of ability to understand how others feel, lack of awareness that anything is wrong, and possibly anxiety and depression but more typically apathy and remoteness.

Changes in behaviour – for example episodes of tactlessness (saying or doing the wrong thing at the wrong time), possibly uncharacteristic swearing, neglect of personal hygiene, loss of drive or the emergence of obsessional routines.

Language changes – often featuring a reduction of speech - sufferers rarely initiating conversation and giving only brief and minimal responses to questioning, and with increasing reliance on particular 'pet' expressions or phrases.

Changes in eating habits –those affected may overeat and / or develop a liking for sweet food.

Memory is usually relatively well preserved in fronto-temporal dementia.

Primary Language Involvement

Sometimes nerve cell damage may be localized more particularly in the temporal lobes of the brain, with initially less involvement of the frontal lobe, giving rise to specific patterns of speech and language impairment whilst leaving personality and behaviour relatively unaffected.

In **Progressive (non-fluent) aphasia** (sometimes called primary progressive aphasia), increasingly speech becomes an effort and has a stuttering quality.

In contrast people with **semantic dementia** speak fluently and at a normal rate and give no indication of effortful word search. However they experience a profound loss of word meaning (sometimes described as word blindness).

LATER STAGES

The rate of progression of fronto-temporal dementia varies enormously, ranging from less than two years to over ten years. Language usually continues to contract over time with sufferers speaking rarely, if at all, in the later stages of the disease.

In the later stages nerve cell damage in the brain tends to become more generalized, and symptoms are less distinguishable from those of Alzheimer's disease.

HOW IS THE DIAGNOSIS MADE?

Fronto-temporal dementia is commonly misdiagnosed as Alzheimer's disease. A specialist may be able to make a diagnosis of fronto-temporal dementia by questioning the person affected and those close to them and by taking a detailed history of their symptoms. Psychological testing and a speech and language assessment can also provide valuable diagnostic information, and a CT and MRI scans may also be used to determine the extent of damage to the brain. Because personality and behaviour change may be an early feature of fronto-temporal dementia, early diagnosis, information and support are particularly important in helping family and friends to understand that these changes have a physical cause.

WHY DOES IT DEVELOP?

There is a family history in about half of all cases of fronto-temporal dementia. In these families the course of the disease usually has a specific pattern across the generations. Some of these inherited forms have been linked to abnormalities on chromosomes 3 and 17.

The causes of non-inherited fronto-temporal dementia are various and in many cases unknown.

WHAT TREATMENT CAN HELP?

As yet there is no proven drug treatment for fronto-temporal dementia.

Knowing more about the disease and why the person is behaving as they are can go some way to making it easier to live with the disease. Carers may be able to develop coping strategies, such as avoiding confrontation and working round obsessions, rather than trying to change the behaviour of those affected.

It may also be helpful to seek the advice of a speech and language therapist if language difficulties are a prominent early symptom.

LEGAL MATTERS

As a carer of a person suffering from dementia, you will probably need to gradually take over the financial affairs of the sufferer as he or she becomes less able to manage them alone.

Carers often drift into taking over routine jobs such as payment of bills or collecting a pension, but it will become necessary eventually to establish this responsibility on a more formal, legal basis. This is especially important if the sufferer's affairs are at all complicated, and you will probably need a solicitor to give you expert legal advice. The cost involved will be similar to that of making a will, and the procedure is known as Enduring Power of Attorney.

ENDURING POWER OF ATTORNEY

An Enduring Power of Attorney may be drawn up by oneself, although it is usually wise to request a solicitor to do so. It should be regarded as a sensible precaution for the future in the same way as we would consider making a will (and it may be appropriate to ask your solicitor to arrange the two matters at the same time if you do not already have a will).

By making an Enduring Power of Attorney, an individual appoints an 'attorney' (usually a relative) who will have the power to act on his/her behalf if he/she becomes unable to do so (through mental frailty in the case of dementia). The power given under an Enduring Power of Attorney does not come into effect until the donor (person giving the power of attorney) is unable to manage his/her own affairs.

If there is doubt about a person capacity to consent to the Power of Attorney a specialist doctors assessment can be asked for through the GP.

When should it be arranged?

It is important to arrange the Enduring Power of Attorney as early as possible once a progressive illness such as dementia has been diagnosed, as the sufferer needs to be capable of understanding the implications of what he/she is arranging. There is a reasonable argument for everyone making an Enduring Power of Attorney as one would make a will, regardless of age or circumstances.

A common procedure for a married couple is for the partner with dementia to appoint their spouse or children as attorney and for the spouse to appoint one or more of their children as his/her own attorney at the same time. This would ensure that matters would still be managed by another person, if the spouse became ill or died.

The Court of Protection

To enforce the Enduring Power of Attorney when the sufferer has reached the stage of being unable to manage his/her own affairs, it is necessary to register with the Court of Protection. This can be done either with your solicitor's help or directly to the Court. It is only at this point that the 'attorney' can legally manage the financial affairs of the sufferer (donor).

The Court of Protection also deals with the affairs of dementia sufferers who have not made out an Enduring Power of Attorney and who cannot manage their own affairs. However, rather than just endorsing an attorney's power to act on the sufferer's behalf, the Court of Protection then has to take on the management of the sufferer's affairs itself.

Thus, if no Enduring Power of Attorney has been made, an application of the Court of Protection has to be made in order for any financial/legal management to take place. In these circumstances, the Court can appoint a 'receiver' to take over the person's affairs and will supervise the receiver, charging a fee for this service. Carers can find the Court of Protection quite costly, and clearly to avoid this more complicated procedure it is advisable to have arranged an Enduring Power of Attorney whenever possible.

FINANCIAL MATTERS

On a day-to-day basis you may need to make some practical rearrangements to routine tasks. For example:

- If you are not living with the sufferer, arranging with the Electricity Board, Water Authority, Local Council etc to have bills sent to you may minimise confusion. Arranging payment by direct debit may also help to avoid problems.
- You can get a form from the Department of Social Security, which allows you to collect the sufferer's pension or benefits as a nominee.
- It may be worth contacting the bank manager to discuss how best to manage bank accounts. A joint bank account would be advisable if appropriate to your circumstances.
- The local Citizen's Advice Bureau is always very willing to help with practical advice if you have any problems.

Where financial circumstances are very complicated, you may wish to seek a solicitor's advice about managing a dementia sufferer's finances. This can be done at the same time as making out an Enduring Power of Attorney.

LEWY BODY DISEASE

WHAT IS LEWY BODY DEMENTIA?

Lewy body disease is responsible for about a fifth of the total cases of dementia in the UK, making it the cause of dementia for about 130,000 people in the UK.

Lewy body disease is a dementia which is caused by damage to the brain. It is similar to Alzheimer's disease, but symptoms are typically different on close examination, with different signs found in the brain after death. The cause is unknown.

Lewy body disease has only recently been accepted as a separate disease in its own right.

It is increasingly important to diagnose such conditions accurately as new drugs are developed which may be more effective in some types of dementia than in others.

WHAT ARE THE SYMPTOMS?

The dementia associated with Lewy body disease affects:

- Memory
- Language
- The ability to judge distances
- The ability to carry out simple actions
- The ability to reason

People with this form of dementia suffer hallucinations – for example seeing a person or pet on a bed or chair when nothing is there.

They may suffer from falls for no apparent reason because their ability to judge distances and make movements and actions accurately is disrupted.

They may develop some Parkinson type symptoms such as slowness of movement, stiffness and tremor. The abilities of the affected person often fluctuate from hour to hour and over weeks to months. This sometimes causes carers to think that the person is “putting on” their confusion.

HOW IS THE DIAGNOSIS MADE?

The main way to diagnose this form of dementia is by taking a careful history of the pattern of symptoms and by excluding other possible causes such as vascular dementia. A scan may reveal degeneration of the brain, but the Lewy bodies can only be discovered after death.

WHAT TREATMENT CAN HELP?

Although there is no cure, there is some evidence that the drugs developed for use in Alzheimer's disease may help some of the symptoms in Lewy body disease. Other drugs are available to help alleviate symptoms but caution is needed with dosage, as sufferers are often sensitive to side effects.

MILD COGNITIVE IMPAIRMENT

Definition of Mild Cognitive Impairment

The word 'cognitive' is not commonly used in everyday language and needs explaining. It simply refers to all aspects of intellectual functioning (things such as intelligence, memory, concentration, speed of thought, ability to use language, problem-solving ability etc.).

Mild Cognitive Impairment (MCI) can be defined as a deterioration in cognitive functioning which is greater than that expected for the person's age, but not severe enough to be classified as a dementia.

Typically, the major concern is with short-term memory (memory for recent events), although other cognitive functions, such as those mentioned above, may be affected. In MCI, these cognitive difficulties are not just isolated events (such as the occasional memory lapse we all experience), but are persistent and severe enough to interfere with daily living.

Symptoms of Mild Cognitive Impairment

One or more of the following common symptoms could be signs of MCI:

- greater difficulty remembering names of family and close colleagues
- difficulty remembering appointments e.g. with family, friends, doctors
- finding it harder to deal with the more complex tasks of everyday life, such as managing finances etc.
- repeating the same stories or jokes, seemingly having forgotten that they've already been told
- problems with concentrating on and remembering everyday things, such as articles read in the newspaper, things watched on TV or things people may have said to you or asked you to do

Is it 'just old age'?

Key questions to ask about the possibility of having MCI

Frequently people will put cognitive problems, such as memory problems, down to the normal process of ageing – to "just getting older". It is true that certain

cognitive functions in particular, such as short-term memory and concentration, do become a little less effective as one gets older, but for the average older person the loss of ability in such areas is relatively minor and less than most people seem to think.

Given this, if the answer to any of the following questions is “yes”, it does the raise the possibility of you having MCI:

1. Has there been a clearly noticeable worsening of my cognitive functioning (e.g. memory) compared to how it was?
2. Have these problems become persistent (rather than isolated events) and begun to affect my daily functioning (managing tasks, social interactions etc)?
3. Is my cognitive functioning now clearly worse than others my age (whereas before it was comparable)?

Numerous causes of mild cognitive problems

In a fairly high proportion of people, persistent mild cognitive problems reflect the early stages of a dementing process (such as Alzheimer’s Disease). However, there are a number of other factors which may cause problems such as mild forgetfulness e.g.

- anxiety / stress, depression and chronic insomnia
- side effects of various medications
- physical illness and chronic pain
- reversible conditions such as hypothyroidism or Vitamin B12 deficiency

What to do if you suspect you might have MCI

Speak to your GP about your concerns and s/he could then arrange a referral for an assessment at your local Memory Clinic. Here you will undergo an assessment to investigate the severity and nature of your cognitive difficulties and treatment options, if applicable, can be discussed.

MOBILITY PROBLEMS AND FALLS

Keeping active and taking exercise is beneficial for general health.

Physical conditions affecting mobility.

There are many physical conditions associated with ageing that can either restrict mobility or affect balance, e.g. arthritis, strokes, heart conditions, acute infections or the side effects of some drugs.

Consult your G.P. if you are concerned about any of the above.

Mobility and Dementia

In addition to the physical problems associated with ageing, mobility may be affected in dementia as a result of:

- hesitancy, confusion or even fear, due to memory problems and disorientation (where am I going and what am I doing?)
- making mistakes in interpreting the environment, i.e. what the eyes are seeing, what the hand is feeling etc. (is that a step?...where is the chair? etc)
- poor co-ordination of movement (making voluntary actions e.g. dressing, turning around etc. difficult to carry out)
- failing to understand advice or instructions (e.g. about where to go and how to get there)

As a consequence of these difficulties a person might e.g.:

- refuse to get out of their chair
- appear clumsy and un-coordinated
- miss the chair when trying to sit down
- step out oddly e.g. as if there was a step
- bump into objects or doorways
- be fearful of falling when descending the stairs
- 'forget' to use their mobility aid (e.g. walking stick or frame) or use it incorrectly
- not let go of e.g. the arms of a chair when getting up, or of a piece of furniture

21 Falls

Whatever the cause, the effect of a fall can be far reaching. Even if there are no physical injuries, the shock and distress can be great and confidence may be lost. As a result the person may be reluctant to walk. Action at this time is very important and referral to a Physiotherapist and/or an Occupational Therapist may be beneficial. They will be able to assess the physical and environmental problems and suggest appropriate strategies and approaches, to encourage and maintain safe mobility.

How to assist:

When encouraging a person with dementia to keep active:

- Give them as much calm reassurance and clarification as needed (about where they are, what is about to happen etc.)
- Give clear, simple step by step instructions.
- Provide gently physical guidance if needed (e.g. by guiding the person's hand to find the arm of the chair when sitting down)

Some tips to help prevent falls:

- Carpet edges should be tacked down.
- Rugs are dangerous lift all rugs if possible.
- Lighting should be even and high, especially on the stairs and when moving between rooms.
- NOTHING should be stored on the stairs.
- Walkways should be free of furniture. Telephone or electrical cables should be tacked out of the way.
- Avoid furniture with casters. Chairs and beds should not be too low, high, or too soft.
- Avoid long clothing eg a long dressing gown, which could cause the person to trip.
- If possible wear well fitting supportive shoes rather than slippers. Wear low heels and avoid leather soles.
- Regular eye tests are advised. – Make sure the correct glasses are worn as prescribed.
- When getting out of a chair or the bed do not rush the person and give them time to recover their balance before moving further.

22 When just a little help is needed

The following sequences of instructions, given one at a time, can help people to move around with more confidence.

To help someone get up from a chair:

“Lean forwards”

“Hold the arm rests firmly”

“Wriggle forwards to the front of the chair”

“Bring your feet back to the edge of the seat”

“Place your feet slightly apart, with one foot a little in front of the other”

“Lean right forward, nose over toes”

“Use both hands to push yourself up”

To help someone to sit down :

“Stand with your back facing the chair”

“Put one foot a small distance behind the other”

“Feel the edges of the chair with the back of your legs”

“Lean down slightly from your hips, and feel for the arm rests” “(You could help by guiding the person’s hand to the arm rests)

“Lower yourself right into the back of the chair”

To walk with someone:

Adopt the same walking pattern as the person (this unconsciously helps to maintain the rhythm of walking)

Give light support if needed by offering the hand furthest away from the person (palm upwards) – this leaves your other hand free to provide gently guidance around the waist if necessary. Do not encourage the person to hang on to you – if this level of support is needed ask for them to be assessed for a walking aid.

Sometimes the person you are walking with may try to grab at furniture, doorframes or people. One solution is to occupy the free hand by asking the person to carry a small object in their hand e.g. a newspaper, book or a handkerchief.

MEDICATION AND DEMENTIA

SPECIFIC TREATMENTS FOR ALZHEIMER'S DISEASE

During the last few years the ACE (Acetyl Cholinesterase Inhibitors) drugs have been promoted to help with both memory decline and everyday tasks (activities of daily living). The three drugs currently available are Aricept (Donepezil), Exelon (Rivastigmine) and Reminyl (Galantamine). In the UK they are licensed for mild to moderate Alzheimer's disease, but are also thought to be useful in dementia with Lewy bodies. As yet (2004), they are not licensed for use in vascular dementia.

Currently in Berkshire they can only be prescribed and continued by a specialist in Old Age Psychiatry, who will follow up the patient in the clinic.

ACE drugs can slow the rate improve memory and the performance of various tasks.

Approximately 50% of those people taking the drugs respond positively to them. Good response normally lasts for about one year but sometimes longer. Once the drugs are stopped a decline usually occurs, but only to the point the person would have been at if they had not taken the tablets in the first place.

OTHER MEDICATION USED IN DEMENTIA

People with dementia may develop symptoms such as depression, restlessness, aggression, hallucinations and difficulty sleeping at some point during their illness.

Where possible, behavioural measures should be tried to address some of these problems (see sheet New Behaviours) but there are a number of instances where these symptoms can be relieved by careful use of medication.

USEFUL GUIDELINES

- Do not expect immediate results. Benefit of medication may take several weeks to appear, particularly with antidepressants.
- Side effects may occur early or later in the course of treatment. Seek advice from your doctor if required.
- Medication should be taken regularly to have an effect; i.e. doses must not be missed. There are reminder packs available from pharmacists, often known as 'nomads', 'dosettes' or 'mediboxes'. These are packs with days of the

week and times of the day that medicines have to be taken printed clearly on them.

- Medication should be reviewed regularly by the GP.
- Medicines should be kept in a secure place, particularly where there is a risk that a person may forget how many tablets they have already taken. If there are a number of carers visiting at different times, it is best to agree one place where medicines will be kept.
- Take all unused medicines to the local chemist for safe disposal.
- When attending hospital out patients, respite care or for a stay in hospital remember to take all the medicines with you.

TYPES OF DRUG

Remember all drugs have at least two names – a generic name which identifies the medicine, and a trade name which will vary according to the manufacturer.

Major Tranquillisers

These are often prescribed to people with dementia for symptoms including agitation, delusions (false beliefs), hallucinations (seeing and hearing things which are not there), sleep disturbance and aggression. Drugs from this group include Quetiapine and Amisulpride. Side effects can include sedation, dizziness and unsteadiness and hence risk of falls. The GP will aim to reduce such side effects by using as small a dose as possible. Often the dose can be built up gradually.

These drugs are usually given by mouth but occasionally a long acting injection is given where a patient is reluctant to take tablets or medicine.

Antidepressants

Depressive symptoms are common in dementia. In the early stages these may be linked to awareness of the diagnosis and failing performance. In the later stages of dementia, they may be secondary to altered chemicals in the brain.

There are now a number of different classes of antidepressants. The choice will depend upon side effect profile, medical problems, sedative properties and possible interactions with other medication that may already be prescribed. Commonly prescribed antidepressants for people with dementia include Citalopram, Venlafaxine, Trazodone.

Antidepressants take between three to six weeks to start to improve mood and will need to be taken for at least six months after the depression has resolved. They may also be helpful in relieving agitation and anxiety.

Side effects will vary depending on the type of antidepressant. However sedation, confusion, nausea and agitation are possible. Antidepressants should be withdrawn gradually.

Benzodiazepines

These are occasionally prescribed to relieve anxiety and agitation associated with dementia.

This group includes drugs such as Diazepam and Lorazepam. They can cause withdrawal symptoms when they are stopped. It is recommended that they are used short-term for less than four weeks. With longer periods of prescribing, they would need to be withdrawn slowly.

Sleeping tablets

Sleep disturbance and night time wandering can be very disturbing for carers. Increased daytime stimulation may help to resolve this problem but some people with dementia tend not to require long periods of sleep at night.

Zopiclone, Zolpidem and Temazepam are sometimes used to help promote nighttime sleep. Major tranquillisers are sometimes also prescribed at night.

As with all medications, benefits need to be balanced against side effects. For instance it should be remembered that increased sedation at night can result in increased incontinence.

Possible side effects are morning 'hangover', unsteadiness on the feet, dizziness and confusion.

MEMORY PROBLEMS

Memory is important because it helps us to organize our daily activities. When memory deteriorates it is typically new information that is forgotten (referring to information from the previous weeks / days or even minutes). Such memory difficulties can make even simple tasks difficult to plan and to carry out.

If you are close to someone who is experiencing memory problems you will want to find ways to help them to cope so that they can retain their confidence and independence as much as possible. The following are some suggestions that might help:

²³

24 Avoiding extra stress

- If the person is tired, unwell, anxious or depressed, they will find it more difficult to remember things. If you think that they may be ill or depressed consult your GP.
- It is generally the case that emerging memory difficulties are largely outside the person's control. Being encouraged or pressed to try to remember will probably have little effect and it is usually less frustrating for everyone if you supply the forgotten information.
- Provide cues rather than 'testing' or asking questions, e.g. say "Here is David, your nephew, come to see you".....rather than "Do you remember who this is?"
- If possible encourage continued independence by sensitively providing just as much practical assistance as is needed. Try to resist taking over.
- Confrontation, accusations and blame can easily occur e.g. when something has been mislaid. Trying not to take this personally, taking a sympathetic view and e.g. joining in the search can defuse anger. Simple distraction may also help. "We'll search after we've had a cup of tea". The mislaid object may be forgotten after 10 minutes and then turn up later.

²⁵

26 New Information

People with memory problems tend to find it very hard to take in new information. It helps to:

- Keep information simple and repeat it frequently.
- Break down new activities into simple step-by-step stages.
- Avoid if possible introducing new gadgets or equipment e.g. a new microwave oven may seem to provide an obvious solution to the problem of safety in the kitchen, but be prepared for the fact that the person might have great difficulty in learning how to use it. Likewise a new lock on the front door may mean that the person can no longer let themselves in or out, or that they are unable to lock the house up when they leave it.

Regular routine

You may have noticed that the person you care for has become increasingly unsettled by any change in their normal routine. This is not usually because they have suddenly become awkward or inflexible, rather it is likely to be because routine acts as an important back-up to memory and contributes towards helping someone with memory problems feel safe and secure.

Memory Aids

We all use memory aids such as diaries, calendars, notebooks, written lists etc to jog our memories. Some people worry that by relying on memory aids they will make their mind lazy and actually make their memory worse, but there is evidence that the opposite is in fact the case. Using simple ways to get around memory problems will help to reduce the amount that the person has on their mind and thereby allow the memory to work as efficiently as possible.

Day / Date / Appointments / Timekeeping / Keeping busy:

- Have a large clock with clear numbers, the day and the date. Hang it close to a large one- week- to- a- page calendar, preferably with each day divided a.m./ p.m. in which can be written things to do at specific times. Before going to bed mark off the day. Both should be where they are readily seen.
- Another idea is to put up a notice board or wipe clean white board in a prominent place for written reminders, important information, things to do today etc.
- Think about using a timer or an alarm clock alongside written reminders to ensure the person's attention will be drawn to a written note at the relevant time.
- If visual problems make reading difficult it may help to use a tape recorder or Dictaphone to record reminders.

Losing things:

- Try to encourage the person always to keep things in the same place. The old sayings: 'Method is the mother of memory' and 'A place for everything, and everything in its place' become especially important if memory for the recent past is unreliable.
- Keys could be attached to a handbag or a belt by a cord and spectacles could be hung around the neck.
- Mark possessions that are risk of getting lost e.g. umbrellas, handbags, walking- sticks etc. with the person's name, phone number or address enabling others to return them.
- Put labels on room doors, cupboards, drawers etc. to remind the person of their contents.

The Phone:

- Keep a list of important numbers, a large pad and a pen for messages near to the phone.
- Many telephones can now store numbers that can then be dialled by pressing a single button.

- To avoid the confusion that may arise from direct marketing phone calls you can register with the Telephone Preference Service by calling 0845 07 007 07 or online www.tpsonline.org.uk

Appliances:

- Use tape or brightly coloured labels to identify switches.
- Remove or cover switches that are never used or that have settings that should not be changed.
- Write simple step- by- step instructions for operating equipment and attach them onto or beside the relevant appliances.

Tablets:

- There are various pill organizers on the market, alternatively your pharmacist may be able to put the person's medication into a bubble pack.
- Ask your doctor if the number or timing of the person's tablets can be simplified.

General Points:

- When choosing a memory aid try to base it on something that the person is already familiar with for example if they already place written notes in one particular place e.g. on the hall table, make this the place to add additional aids such as calendars a clock etc. and remember that as a rule the most successful memory aids are the least complicated.
- Any 'new' memory aid is likely to take some time to become established into the person's routine e.g. reminding the person to consult a new notice-board for details of the day / date /or of what is due to take place. The repeated and consistent prompting necessary at this stage is not easy and demands considerable energy and patience.
- There are various electronic organizers and sonic / infra red devices available that might be of help to some individuals.

MOBILITY PROBLEMS AND FALLS

Keeping active and taking exercise is beneficial for general health.

Physical conditions affecting mobility.

There are many physical conditions associated with ageing that can either restrict mobility or affect balance, e.g. arthritis, strokes, heart conditions, acute infections or the side effects of some drugs.

Consult your G.P. if you are concerned about any of the above.

Mobility and Dementia

In addition to the physical problems associated with ageing, mobility may be affected in dementia as a result of:

- hesitancy, confusion or even fear, due to memory problems and disorientation (where am I going and what am I doing?)
- making mistakes in interpreting the environment, i.e. what the eyes are seeing, what the hand is feeling etc. (is that a step?...where is the chair? etc)
- poor co-ordination of movement (making voluntary actions e.g. dressing, turning around etc. difficult to carry out)
- failing to understand advice or instructions (e.g. about where to go and how to get there)

As a consequence of these difficulties a person might e.g.:

- refuse to get out of their chair
- appear clumsy and un-coordinated
- miss the chair when trying to sit down
- step out oddly e.g. as if there was a step
- bump into objects or doorways
- be fearful of falling when descending the stairs
- 'forget' to use their mobility aid (e.g. walking stick or frame) or use it incorrectly
- not let go of e.g. the arms of a chair when getting up, or of a piece of furniture

27 Falls

Whatever the cause, the effect of a fall can be far reaching. Even if there are no physical injuries, the shock and distress can be great and confidence may be lost. As a result the person may be reluctant to walk. Action at this time is very important and referral to a Physiotherapist and/or an Occupational Therapist may be beneficial. They will be able to assess the physical and environmental problems and suggest appropriate strategies and approaches, to encourage and maintain safe mobility.

How to assist:

When encouraging a person with dementia to keep active:

- Give them as much calm reassurance and clarification as needed (about where they are, what is about to happen etc.)
- Give clear, simple step by step instructions.
- Provide gently physical guidance if needed (e.g. by guiding the person's hand to find the arm of the chair when sitting down)

Some tips to help prevent falls:

- Carpet edges should be tacked down.
- Rugs are dangerous lift all rugs if possible.
- Lighting should be even and high, especially on the stairs and when moving between rooms.
- NOTHING should be stored on the stairs.
- Walkways should be free of furniture. Telephone or electrical cables should be tacked out of the way.
- Avoid furniture with casters. Chairs and beds should not be too low, high, or too soft.
- Avoid long clothing eg a long dressing gown, which could cause the person to trip.
- If possible wear well fitting supportive shoes rather than slippers. Wear low heels and avoid leather soles.
- Regular eye tests are advised. – Make sure the correct glasses are worn as prescribed.
- When getting out of a chair or the bed do not rush the person and give them time to recover their balance before moving further.

28 When just a little help is needed

The following sequences of instructions, given one at a time, can help people to move around with more confidence.

To help someone get up from a chair:

“Lean forwards”

“Hold the arm rests firmly”

“Wriggle forwards to the front of the chair”

“Bring your feet back to the edge of the seat”

“Place your feet slightly apart, with one foot a little in front of the other”

“Lean right forward, nose over toes”

“Use both hands to push yourself up”

To help someone to sit down :

“Stand with your back facing the chair”

“Put one foot a small distance behind the other”

“Feel the edges of the chair with the back of your legs”

“Lean down slightly from your hips, and feel for the arm rests” “(You could help by guiding the person’s hand to the arm rests)

“Lower yourself right into the back of the chair”

To walk with someone:

Adopt the same walking pattern as the person (this unconsciously helps to maintain the rhythm of walking)

Give light support if needed by offering the hand furthest away from the person (palm upwards) – this leaves your other hand free to provide gently guidance around the waist if necessary. Do not encourage the person to hang on to you – if this level of support is needed ask for them to be assessed for a walking aid.

Sometimes the person you are walking with may try to grab at furniture, doorframes or people. One solution is to occupy the free hand by asking the person to carry a small object in their hand e.g. a newspaper, book or a handkerchief.

UNDERSTANDING NEW BEHAVIOURS

Dementia is a broad term for a variety of specific brain diseases that occur more often in older people, but can affect younger age groups too. All of these diseases involve a progressive decline in memory, thinking, reasoning and co-ordination. This decline affects a person's ability to complete tasks that they used to manage independently. (see Activities and Physical Aspects sheets) It can also result in 'new behaviours' i.e. the person saying or doing things that they would not have done before the onset of Dementia.

Unexpected Reactions

It is probable that uncharacteristic behaviours are linked to the emotions the person is experiencing as a result of the losses associated with their condition. They may be unable to explain why they have done something or reacted in a certain way, and could feel very threatened if asked directly 'Why?' Understanding the feelings behind new behaviours can help you to know how best to respond.

A Step by Step Approach to New Behaviour

Define the problem	Exactly what happened? When? For how long? Is there a pattern?
Consider the cause: emotionally	How is the person feeling physically / 29 Have they misunderstood what was said or done? (Body language and facial expressions provide important clues)
Your response:	How did you react? How did your reaction affect the person
New ways to respond:	Think about your answers to the above Could you try something different next time? Discuss different approaches with someone

Your needs:

Talk to someone about your feelings

It is important to find an outlet for your emotions

Lack of interest / response

Sometimes people with Dementia can appear withdrawn or disinterested in people and events around them. This behaviour could be as a result of their reduced ability to recognise people or places, or to plan and initiate tasks or conversation independently. (see Activities sheet for advice)

Low mood can also cause a person to become less responsive. If you think that the person you care for might be depressed, it is important to seek advice from your GP or CPN

You know more than you think

Your intimate knowledge of the person, their lifestyle, likes and dislikes, will help you to establish what they might be feeling. It is not always possible to get it right first time. It may be necessary to work through a process of trial and error several times. Also, as the person's condition progresses, they may experience different emotions, and you may need to adapt your response to meet their changing needs

Further Tips

- Keep calm, don't rush things, count to ten
- Acknowledge the person's feelings e.g. 'You seem worried'
- Give reassurance in a low gentle voice
- Does it help to use touch? e.g. holding their hand / stroking their arm
- Explain what is happening in short simple phrases
- Gesture / physical demonstration can reinforce what you say
- Avoid conflict – leaving the room or distracting the person by doing something different may defuse the situation so you can try again

If you are troubled by a specific new behaviour you may find it helpful to discuss coping strategies with your CPN or GP.

Quality of Life

Persevering with this approach to new behaviour can reduce some of the stress involved and improve the quality of the relationship you have with the person.

NIGHT DISTURBANCE

Some people with dementia may experience difficulties in sleeping through the night. This may be due to physical problems such as:

- Discomfort
- Pain
- Hunger/thirst
- Needing the toilet
- Infections
- Reduced need for sleep due to ageing

It should also be considered that Depression might be the cause of sleep disturbance. If you think this applies please speak to your GP.

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31 EVERYDAY TIPS TO PROMOTE SLEEP

- Encourage a reasonably active lifestyle, ideally with some time outdoors each day.
- Try to avoid long periods of sleep during the day as this may reduce the need for sleep at night
- As much as possible stick to the persons preferred bed-time.
- Offer a warm, caffeine free drink before bed
- Ensure a last visit to the toilet before sleep
- Leave a nightlight on to help the person to feel more secure on waking.
- If getting to the toilet is difficult, consider the use of a commode nearer the bed.

NIGHT DISTURBANCE AND DEMENTIA

Some difficulties with sleeping may be more specifically due to changes in the brain as part of the illness resulting in:

- Getting day and night mixed up,
- Believing they have already had a full nights sleep and that it is time to get up
- Not recognising their home or the people around them as familiar and 'safe'. This often results in fear and anxiety making people restless and wanting to leave the house.
- Mixing up the real and the imaginary.
- Being unable to communicate e.g. physical discomfort or pain.

HOW TO RESPOND

Night disturbance can be difficult and upsetting you as a carer – particularly when your own sleep is being disturbed. There is no single 'correct' approach but some of the following ideas may be helpful:

- Try to avoid **over stimulation prior to bed-time** e.g. violent films or disturbing news items on the TV prior to sleep. Instead try to wind down by creating a calm atmosphere
- Try and **tell the person the correct time** (and e.g. that it is too early to get up) but avoid getting involved in an argument over the facts.
- **Reassure** the person as to where they are and who you are. It may be helpful here to **reminisce** a little about your life together and to use familiar objects and photographs to reinforce your words.
- If this doesn't work you could try **distraction** (as opposed to trying to 'correct' the facts) e.g. "Shall I make us a cup of tea" or "Let's listen to some music"
- In addition it often helps to **focus on the feelings behind the person's words** (rather than responding directly to what they are saying). This may be enough to reassure them by making them feel that they are being heard and taken seriously. e.g. "I can hear that you are worried / upset " etc.

If the person you live with is having disturbed nights then **it is very likely that you are not getting enough sleep either.**

In order to preserve your own health and well being you may need to consider the following sources of help:

- Engaging a night sitter (contact Social Services).
- Asking other relatives to take a turn in looking after the person at night.
- Trying to make a point of sleeping yourself whenever the person is sleeping (night or day).
- Making use of technological aids for increased peace of mind e.g. an alarm that sounds when the front door is opened. (Contact your local Social Service Department for information.)
- Enquiring about respite through Social Services (see Initial Contact Sheet)
- Asking the District Nurse about Incontinence aids
- Contacting your GP for further advice

VASCULAR (MULTI INFARCT)

WHAT IS DEMENTIA?

Dementia is a term used to describe a gradual loss of mental abilities. The most usual change is in a person's memory but other changes may also be noticed, for example being unable to hold a conversation or carry out every day tasks such as driving, cooking or managing money. Personality may also change and behaviour become unfamiliar.

Approximately 600,000 people in the UK have dementia and vascular dementia occurs in about a third of these cases.

WHAT IS VASCULAR DEMENTIA?

Vascular or multi infarct dementia is usually caused by several small "strokes". When a person has a stroke the blood supply to an area of the brain is blocked, This causes the brain cells in that area to die (the medical term for this is infarction). When an area of the brain is infarcted there is a loss of brain function. After a major stroke the result may be obvious, the person being unable to move a limb or speak. Smaller strokes in smaller blood vessels cause less obvious loss of function. Each small stroke may be so slight that no one is aware that anything has happened. However, the effects of several strokes eventually accumulate so that mental function is affected mainly in the area of memory and thinking.

It is common for symptoms to fluctuate from day to day and this can be perplexing and sometimes lead to the false belief that the sufferer is aware of what they are doing.

HOW IS THE DIAGNOSIS MADE?

A doctor may suspect a diagnosis of vascular dementia if there is a history of high blood pressure, stroke, heart disease, diabetes or poor circulation. The diagnosis can be difficult to make in the absence of a clear history. A CT brain scan can be helpful. This will show if there are areas of the brain affected by poor blood supply or previous strokes. When someone develops problems with their memory it is important to have an accurate diagnosis so that the illness can be managed properly.

WHAT MEDICAL TREATMENT CAN HELP?

The brain, unlike other organs, cannot re-grow once damaged. However, the treatment of factors, which increase the risk of vascular or stroke disease, can prevent further damage. This includes:

- Treatment of high blood pressure.
- Stopping smoking.
- Treatment of associated heart disease.
- Treatment of diabetes.

A small daily dose of aspirin has been shown to increase blood flow to the brain. This should only be given on your doctor's advice.

WASHING AND DRESSING

Some difficulties in washing and dressing may be due to **Physical Problems** (unrelated to dementia) including:

- Conditions that restrict mobility, cause muscular weakness or difficulty in coordinating movements e.g. arthritis or stroke.
- Reduced eyesight.
- Poor balance.

Sometimes, increasing physical frailty can lead to a person becoming depressed. Untreated **depression** often results in a lack of motivation and a lowering of interest in the usual standards of hygiene and personal care.

In both the above cases please contact your GP who may suggest treatment or referral to specialist services for advice and support in helping with practical aspects of coping at home.

Washing and Dressing and Dementia

Washing and dressing involves skills which people with dementia sometimes find difficult. The level of difficulty will vary from one individual to another. If you detect a decline in standards of appearance and personal hygiene this may be due to the person:

- **Forgetting** to wash, shave, launder clothes etc or believing that it has already been done.
- Struggling to cope with **all the steps involved** in completing the task.
- Having difficulty in **recognising** items such as flannel, soap or specific items of clothing.
- Having difficulty in **getting started** on a task or in **remaining focussed** throughout.
- Having difficulty in **coordinating the actions** necessary.
-

How you can help

Tackling these difficulties requires patience, tact, understanding and a positive approach. You should try to maintain the highest possible degree of independence, while being aware of the need to consider safety. Try to work out how much help is required at any one time. For a person with dementia this will change as the illness progresses. Consider ways in which you can encourage or help the person to carry out the tasks. It is helpful if the person's own routine can be maintained as much as possible.

Some ways of coping at home

- Support a routine as much as possible by leaving notes or giving telephone reminders.
- Consider involving home care services (see contacts sheet).
- Try and maintain previous standards, e.g. frequency of baths but be realistic about what is possible now.
- Think about whether a strip wash would do, rather than a bath.
- Prompt washing but try not to let it become cause for an argument.

- Remove dirty clothing at bedtimes and replace with clean.
- Sometimes, for a variety of reasons, a person with dementia remains resistive to the need to change clothes. If you are able to provide a second set of identical clothes this could help to overcome this problem.
- In some cases, clothes with simple patterns or contrasting colours are easier to differentiate and can help the person to make a choice.

- Try to use clothes which are easier for the person to put on such as jogging suits and slip-on shoes. You may find Velcro fastener easier than Zips or buttons

- Try and break up washing or dressing tasks into steps e.g. by laying out clothes in sequence and give verbal prompts

- Help the person to get started but then let take over for themselves as soon as they are able.

- To help with safety in the bathroom there are a variety of aids available e.g. grab rails, bath stool, non-slip mats. You can ask for an Occupational Therapy assessment for advice on the type required.

- Try and create a relaxed atmosphere, allow plenty of time for the washing and dressing, make sure the room is warm, try and minimise distractions to make it a pleasant experience.

- Consider switching to an electric razor rather than wet shaving.

OTHER CONSIDERATIONS

- Before the advent of automatic washing machine, people did not necessarily change their clothes as often as they do now. Try not to impose your own values.
- Being reminded to change your clothes or wash could be a very embarrassing and humiliating experience. It is important to remember

these feelings if there is some resistance to this. Any extra time taken to maintain a feeling of independence is well worthwhile.

- Sometimes a person with dementia starts to undress inappropriately. This can be embarrassing, but try to hold on to the fact that they are unlikely to realise what they are doing, or to be deliberately trying to be provocative.

Behaviour is another way of communicating (see Communication sheet). E.g. in the case of undressing you may need to consider:

- Is the person too hot?
- Is their clothing too tight or otherwise uncomfortable?
- Does the person want to go to the toilet?
- Are they bored or restless?
- Are they tired and trying to go to bed?

Recognising what lies behind the behaviour provides the key as to how to respond.

WEBSITES

The following websites are provided as a useful starting point for sources of help and information.

INFORMATION ON DEMENTIA

32 <http://www.alzheimers.org.uk>

33 The Alzheimer's Society UK website. A very large site with information and help on all aspects of dementia, and links to other sites.

34

35 <http://www.alz.co.uk>

36 Alzheimer's Disease International website.

37 <http://www.candid.ion.ucl.ac.uk>

Click on the link marked candid for some useful information sheets.

38 <http://www.lewybodydementia.org>

An American based site with information and carer support for this particular form of dementia.

<http://www.pdsg.org.uk>

Picks Disease Support Group site

<http://www.kingshill-research.org>

Kingshill are a Memory Service and Research Centre based in Swindon. The website gives details of their latest research which you can volunteer to take part in.

<http://mentalhealth.org>

Information and support on dementia as well as general advice on all aspects of mental health.

GENERAL ISSUES FOR OLDER PEOPLE

<http://www.ace.co.uk>

Age Concern, England providing information about a wide range of issues affecting older people. Contact details and helpline information.

<http://www.helptheaged.org.uk>

Help the Aged UK providing information about improving the quality of life for older people.

<http://www.retirenet.co.uk>

Information about issues of interest to older people. Ideas and information about leisure and pleasure items.

GENERAL INFORMATION FOR CARERS

<http://www.carer.org>

The Princess Royal Carer's Trust

<http://carers.gov.uk>

The Dept. of Health website giving information and advice to all carers.

<http://www.alzwell.com>

An American site providing information and support to carer's of people with dementia.

<http://www.ec-online.net>

A linked site to alzwell providing general as well as dementia related information for carer's.

<http://www.caregiver.org>

A general website for carer's

LOOKING FOR CARE

<http://www.caringmatters.dial.pipex.com>

Information on care issues, including respite care and assisting in making decisions about care and care choices.

<http://www.carehomesuk.net>

This site allows you to search for a care home in the UK according to needs, location etc.

<http://nhfa.co.uk>

Information about funding and choosing care.

HOLIDAYS FOR PEOPLE WITH DEMENTIA

<http://www.holidaycare.org.uk>

<http://www.wft.org.uk>

These sites provide information about holidays for people with special needs such as dementia and their families.

DEMENTIA IN YOUNGER PEOPLE

Dementia is a term used to describe a progressive, gradual loss of mental abilities. The most unusual change is in the person's memory but other changes may also be noticed, for example, difficulty in carrying out everyday tasks such as driving, cooking or managing money. Personality may also change and behaviour becomes unfamiliar.

Most people assume that it affects only older people, however, 17,000 young people in the UK between the ages of 40 and 64 have dementia.

The most usual form of the condition is Alzheimer's disease, but others have Vascular disease, Lewy Body disease, Pick's disease or Huntingdon's disease.

When dementia affects someone under the age of 65, the medical profession refers to it as 'early onset dementia' or presenile dementia.

Why does it develop?

The disease causes a gradual death of individual nerve cells resulting in the brain shrinking or atrophy. In the case of Alzheimer's disease, it is also known that there are deficiencies of certain vital chemicals in the brain. The underlying cause of this is unknown. In a small number of families, the disease has a genetic link. In such cases, relatives may wish to consider referral to a genetic counsellor.

How is the diagnosis made?

There is no simple test which can make the diagnosis of Alzheimer's disease with certainty. A post mortem after death can confirm the diagnosis by examining brain tissue under the microscope.

During life, the diagnosis is based on carefully noting of the way symptoms develop and change over time, the results of psychological testing, blood tests and sometimes a CT brain scan. Relatives' observations and report of changes are also crucial, as it is often those close to the patient who notice the very early change in behaviour.

The uncertainty prior to receiving a diagnosis can be a very worrying time for relatives. It is common for symptoms to fluctuate from day to day and this can be very perplexing and lead to the belief that the sufferer is 'trying it on'. Practical advice and support can help carers to cope better with unexpected behaviour.

Confirmation of the diagnosis has significant practical implications for the future. Immediate concerns often involve issues such as driving, handling finances and employment.

Specific problems of dementia in younger people

When a younger person suffers from dementia, there may be many more adjustments that need to be made for both the sufferer and their family. For instance, the sufferer may still be supporting a family, carving out a career or have significant financial commitments such as a mortgage. Since dementia results in a progressive loss of skills, starting with those of greater complexity it becomes increasingly impossible for the sufferer to actively take part in the decisions and management of every day life.

Whilst the symptoms of dementia in the young are the same as in older people, the emotional and physical responses may vary considerably. A younger person may feel more anger and frustration or may find it harder to come to terms with their reduced ability to cope with daily living, and yet they are by no means physically frail.

Children

Children of any age need to understand the disease, how it affects their parent's behaviour and what other behaviour changes to expect.

If you have children be aware that their ages may affect how they react to your relative's illness. Your children may become angry, withdraw from your family, or, because of embarrassment, withdraw from their friends. They may believe that they have caused the illness or provoked their relative's behaviour. They may be afraid that they will get the disease and younger children may fear that you will become ill.

If it is your husband or wife who has the disease, in addition to losing a parent your children have lost an adult role model. They may also be undertaking responsibilities that previously were undertaken by your spouse, such as looking after a young child or doing household chores. Make time to talk to your children to explain the disease and to listen to their feelings. Each of your children will have different needs – find out what they are and how you can meet them.

What can be done?

Referral may have already been made to a neurologist, psychiatrist or physician. Your doctor will want to exclude other conditions such as infection, medication reaction, depression or stress. Although there is no cure, a lot can be done to manage the condition.

Currently there is a lack of coordinated specialist provision for younger people with dementia; you can still get access to monitoring and support services such as a community psychiatric nurse, care manager, psychologist and voluntary organisations.

What of the future?

Research has led to some recent advances in drug treatment in the UK and there are now medications available, such as Donepezil (Aricept), Rivastigmine (Exelon) and Galantamine (Reminyl) in the UK, for which clinical trials suggest a moderate benefit in cognition and abilities for some patients for a limited time. In Berkshire treatment can only be initiated by a specialist in Old Age Psychiatry and there will be regular monitoring of response.