



Social care (Adults, England)

KNOWLEDGE SET FOR DEMENTIA

CONTINUOUS TRAINING PROGRAMME

Candidate Name.....



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1. SUPPORT OF INDIVIDUALS WITH DEMENTIA

1.1 Understand the need for a person-centred and strengths- based approach to the support and well-being of individuals with dementia:

Value and accept the individual by seeing the person first and the dementia second

Sufferers Views

- As a person with dementia, I am accepted and understood as an individual
- I am treated as a person not a disease, and am acknowledged as “present”
- I am cared for by people who understand me, and about my dementia
- I have regular opportunities to access and share my rich & meaningful past
- I practice rituals that comfort or calm me
- I continue my own cultural lifestyle
- My orientation to time and reality is respected and supported
- I continue my familiar routines
- My environment is anchored in things I value that are familiar to me
- I have continuity in relationships with caregivers
- I have physical privacy
- My sexual identity is treated with respect
- I am free from all forms of abuse

Communicate effectively so that the individual has the opportunity to make decisions

We all need to communicate with other people. Communicating our needs, wishes and feelings is vital – not only to improve our quality of life, but also to preserve our sense of identity. As a carer, it's important to encourage the person with dementia to communicate in whichever way works best for them.

We tend to think of communication as talking, but in fact it consists of much more than that. As much as 90 per cent of our communication takes place through nonverbal communication such as gestures, facial expressions and touch.

- Non-verbal communication is particularly important for a person with dementia who is losing their language skills
- When a person with dementia behaves in ways that cause problems for their carer, they may be trying to communicate something.

Dementia and language

An early sign that someone's language is being affected by dementia is that they can't find the right words - particularly the names of objects. They may substitute an incorrect word, or they may not find any word at all.

There may come a time when the person can hardly communicate in language at all. Not only will they be unable to find the words of objects, they may even forget your name. People with dementia often confuse the generations – mistaking their wife for their mother, for example. This may be very distressing for you as the carer, but it's a natural aspect of their memory loss.

The person you are caring for may be trying to interpret a world that no longer makes sense to them because their brain is interpreting information incorrectly. Sometimes you and the person with dementia will misinterpret each other's attempts at communication. These misunderstandings can be distressing, and you may need some support.

Difficulties with communication can be distressing and frustrating for the person with dementia and for you as a carer. But there are lots of ways to help make sure that you understand each other.

- Try to listen carefully to what the person is saying and give them plenty of encouragement.
- If they have difficulty finding the right word or finishing a sentence, ask them to explain in a different way. Listen out for clues.
- If their speech is hard to understand, use what you know about them to interpret what they might be trying to say. But always check back with them to see if you are right – it's infuriating to have your sentence finished incorrectly by someone else!
- If the other person is feeling sad, let them express their feelings without trying to 'jolly them along'. Sometimes the best thing to do is to just listen, and show them that you care.

Listening skills

Getting their attention

- Try to catch and hold the attention of the person before you start to communicate.
- Make sure they can see you clearly.
- Make eye contact. This will help them focus on you.
- Try to minimise competing noises, such as the radio, TV, or other people's conversation.

Using body language

A person with dementia will read your body language. Agitated movements or a tense facial expression may upset them and can make communication more difficult.

- Be calm and still while you communicate. This shows the person that you are giving them your full attention, and that you have time for them.
- Try to find ways to relax so that your body language communicates confidence and reassurance.
- If words fail the person, pick up cues from their body language. The expression on their face and the way they hold themselves and move about can give you clear signals about how they are feeling.
- Speaking clearly

- As the dementia progresses, the person will become less able to start a conversation, so you may have to start taking the initiative.
- Speak clearly and calmly. Avoid speaking sharply or raising your voice as this may distress the person, even if they can't follow the sense of your words.
- Use simple, short sentences.
- Processing information will take the person longer than it used to – so allow them enough time. If you try to hurry them, they may feel pressured.
- Avoid asking direct questions. People with dementia can become frustrated if they can't find the answer, and they may respond with irritation or even aggression. If you have to, ask questions one at a time and phrase them in a way that allows for a 'yes' or 'no' answer.
- Try not to ask the person to make complicated decisions. Too many choices can be confusing and frustrating.
- If the person doesn't understand what you are saying, try getting the message across in a different way rather than simply repeating the same thing.
- Humour can help to bring you closer together and is a great pressure valve. Try to laugh together about misunderstandings and mistakes – it can help.
- Where an individual cannot make a decision about their own care or welfare, the worker should act in their best interests and in the least restrictive manner
- Develop a person-to-person relationship with the individual
- Involve the individual with dementia in their own care planning
- Take account of history (personal, family, medical, etc.) and work towards meeting the needs of the whole person
- Adhere to the value base of care (identity, dignity, respect, choice, independence, privacy, rights, culture)
- Take account of the individual's personal beliefs including spiritual beliefs, emotional needs and preferences
- Maintain a responsive and flexible approach to the individual, taking account of changing needs
- Take account of some of the feelings and issues that are commonly experienced by people with dementia, for example, around loss (of control, community, etc)

1.2 *Understand the need to support and work with family and friends of the individual:*

Develop their understanding of a person-centred approach to support and care of individuals with dementia

What is Person Centred Care (PCC)?

The foundations of "Person Centred Care" (PCC) in dementia care are based on the work of the late Professor Tom Kitwood who was head of the Bradford Dementia Group from 1992 to 1998 in the UK.

Professor Kitwood was a leading researcher in the development of the way we think about people who have dementia. Historically dementia has sat within the fields of medicine and psychiatry which led to an over-emphasis on the "treatment" of people with dementia. This included focusing on the physical changes that are happening in the brain and how best to "manage" the symptoms related to these cognitive changes.

However, what was missing from this approach is the recognition of the person with the illness, who they are, their life before the illness and how they currently feel. The approach also overlooked the influence of social and physical environments of a person with dementia.

PCC, on the other hand, seeks to view the person with dementia as a whole and how the person is influenced by factors beyond the physical changes in the brain.

Principles of PCC

A person centred approach subscribes to the following principles:

Uniqueness

Regardless of illness, all people are unique and this must be acknowledged for people with dementia.

Complexity

Humans are complex beings and a myriad of factors influence the way we see and respond to the world around us.

Professor Kitwood summed up the influences on a person with dementia as:

$$D = P + B + H + NI + SP$$

Where:

D = the person with dementia's presentation

P = Personality

B = Biography (or a person's life history)

H = Physical Health status

NI = Neurological Impairment

SP = Social psychology (or the social and physical world around us)

(Kitwood, 1993)

Enabling

It is all too easy to focus on the disability and loss associated with cognitive impairment. We need to recognise the strengths and abilities of people with dementia and ensure opportunities exist for them to be utilised.

Personhood

This refers to the recognition of a sense of self, who we are and what place we hold in the world around us. Personhood is an intrinsic part of PCC and places an emphasis on the positive effects of daily interaction with other people. PCC teaches the recognition of well-being and ill-being of personhood.

Value of Others

PCC is not just about the way we interact with a person with dementia but also recognises the personhood of all people. This includes organisations valuing the important roles of direct care staff, the formulation of policies and procedures and the way staff are supported by each other and by the organisation.

Provide information about services and support networks available (e.g. support groups, specialist organisations like Alzheimer's Society, etc)

ALZHEIMER'S SOCIETY

For nearly three decades the Alzheimer's Society has given hope and support to hundreds of thousands of people affected by dementia. Our staff and volunteers are united by an absolute commitment to the goal of building a better world for people with dementia (and those of the people who care for them), combat stigma and ignorance, and ensure that everybody affected by dementia can find the help they need.

About the Society

The Society has over 25,000 members and operates through a partnership between over 250 branches and support groups and the national organisation in England, Wales and Northern Ireland. It was founded in 1979 as the Alzheimer's Disease Society.

What the Society does

The Society has expertise in information and education for carers and professionals. It provides helplines and support for carers, runs quality day and home care, funds medical and scientific research and gives financial help to families in need. It campaigns for improved health and social services and greater public understanding of all aspects of dementia

Working for the Society

The Society has over 1,000 staff based in its national, regional and branch centres in England, Wales and Northern Ireland.

Each year, the Society holds an annual conference for people with dementia, carers and professionals. This event includes its annual general meeting.

The Society tries to ensure that it provides a high quality service in all areas of its work. However, sometimes things go wrong.

Finances

For every £1 given to us, we have 87p to spend on our charitable activities.

Relationship with pharmaceutical companies

The Alzheimer's Society has strict guidelines on working with pharmaceutical companies and donations make up less than 1 per cent of our total income.

OUR VISION

Our vision is of a radically improved world for people with dementia.

A world where they have their rights recognised, where they can fully contribute to family and community life and where they can live with dignity, free from discrimination.

A world where they, and those who care for them, have their needs fully met.

A world, ultimately, where dementia can be defeated.

OUR MISSION

We exist to champion the rights of everyone with dementia and those who care for them.

Drawing on our unique knowledge:

- We will become a world-class authority on all aspects of living with dementia
- We will guarantee the availability of accurate and authoritative information
- We will strive for universal access to quality services

We will galvanise investment for research into the causes, prevention, treatment and care of people with dementia.

OUR VALUES

Passion

We are driven by a commitment to achieving the best quality of life for people with dementia

Quality

We have an absolute commitment to achieving excellence in everything we do

Integrity

We are honest, transparent and accountable in all our dealings both internally and externally

Inclusion

We work proactively to ensure that we reach out to and involve people from every group and community

Challenge

We strive for innovation based on evidence and are prepared to question the status quo

Mutual Respect

We work together to create an environment in which people treat each other with respect.

OUR OPERATING PRINCIPLES

People with dementia will always be at the centre of everything we do. We will work to ensure that their perspectives inform all our activities.

We can't do it alone

We seek to work collaboratively where there are clear benefits for people with dementia

Being evidence based

Our actions will be based on evidence and we will prioritise our work on the basis of demonstrable need and effectiveness

Involving volunteers as extensively as possible.

The continued development of volunteering is an essential means of achieving

OUR OBJECTIVES

Enabling people to maximise their contribution

We will create an environment that will enable volunteers and staff to carry out their roles effectively

Acting as one society

Operating within one strategic framework, we will respond locally to different cultural, legislative and service needs

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Email enquiries@alzheimers.org.uk

Registered charity no 296645

HELP THE AGED

Help the Aged is an international charity fighting to free disadvantaged older people from poverty, isolation and neglect.

We research the needs of older people in the UK and overseas and campaign for changes in policy. We provide community services and publish information for the elderly on finance, how to stay healthy as well as guidance on choosing a care home

AGE CONCERN

The UK's largest charity working with and for older people

1.3 *Understand the need to protect the individual from abuse, injury and harm:*

Staff awareness and training

What is required:

Greater awareness

Over time we hope to achieve a change in society's attitudes to older people and their treatment.

We want increased awareness of the nature and scale of elder abuse and of what people should do if they suspect that an older person is being abused.

Why this is important: If people can recognise the signs of elder abuse, they can take action to stop it. Help the Aged believes that confusion around how to recognise, respond and take action on abuse means it could remain undetected and unreported by many people.

More and better training

Raising awareness of elder abuse amongst professionals enables them to take action against it.

We want training in the prevention, recognition and management of elder abuse to be a basic element of all staff training for anyone who has a frontline role working with older people: for example care agency staff, doctors, nurses, council staff and social workers.

Why this is important: This would increase the access to and quality of help for those affected by elder abuse. Awareness-raising with professionals who go into people's homes can help to increase early detection of abuse and ensure older people are protected.

- Involving family and friends

FAMILIARITY

Families and friends are familiar with the individual, therefore any changes in the individuals' attitude, behaviour and cognition would be noticeable, so any fear, anger, aggression or isolation would be identifiable and could be an indicator of abuse on the individual

ASSESSMENTS

Families and friends assess the individual and if any assessments are different from previous meetings then those assessments are reported to workers, health and social workers or police and any other appropriate agency who are involved

MONEY

Financial abuse can be seen as a risk from families and friends as well as workers. Scams like taking small amounts of cash, jewellery etc may be easily seen, as is withdrawals of money from an individuals accounts, but other abuses can be getting a will changed, forging signatures and selling the home to take advantage of the assets of the individual, without others seeing can also occur.

This can mean:

- Taking money or property
- Forging an older person's signature
- Getting an older person to sign a deed, will, or power of attorney through deception, coercion, or undue influence
- Using the older person's property or possessions without permission
- Promising lifelong care in exchange for money or property and not following through on the promise
- Confidence crimes ("cons") are the use of deception to gain victims' confidence
- Scams are fraudulent or deceptive acts
- Fraud is the use of deception, trickery, false pretence, or dishonest acts or statements for financial gain
- Telemarketing scams. Perpetrators call victims and use deception, scare tactics, or exaggerated claims to get them to send money. They may also make charges against victims' credit cards without authorization

ISOLATION

Families and friends can cause isolation and also be able to spot it with the individual and take action

The abuser will control whom the victim sees, where s/he goes, whom s/he speaks to and what s/he does. This can take the form of simply not allowing her /him using the phone, have her/his friends round or visit her family, or ensuring it simply isn't worth it by being in a bad mood because s/he left some housework undone, making her feel guilty that s/he was out enjoying herself while s/he worked, or even encouraging her/him - theoretically - to make friends, and then discounting them or complaining that s/he cares more for her/his friends/family/hobby than s/he does him or is neglecting her/him. Some abusers may move home frequently to prevent their victim from building a social support network.

Many abusers justify their control over their victim by stating that it is proof of their love, or that they worry about their safety when out, etc. In reality however, the abuser needs to isolate his victim to feel secure themselves, they feel as though any relationship, be it family, friend or colleague, will undermine their authority over and take their partner away from them, i.e. poses a threat. The effect of this isolation is that the victim feels very alone in her struggle, doesn't have anyone with whom to do a 'reality check', and is ultimately more dependant on the abuser for all her social needs.

Forms of Isolation include:

- checking up on you
- accusing you of unfaithfulness
- moving to an isolated area
- ensuring you lack transport or a telephone
- making your friends or family feel uncomfortable when visiting so that they cease
- punishing you for being 10 minutes late home from work by complaining, bad moods, criticism or physical abuse

- not allowing you to leave the house on your own or taking away your passport
- demanding a report on your actions and conversations
- preventing you from working
- not allowing any activity which excludes him
- finding fault with your friends/family
- insisting on taking you to and collecting you from work

In extreme cases the victim may be reduced to episodes of literally becoming a prisoner, being locked in a room and denied basic necessities, such as warmth, food, toilet or washing facilities. Other family members or the perpetrators friends can also be used to 'keep an eye on' the victim, acting effectively as prison guards.

LEGAL PROTECTION

Families and Friends can Report abuse to the police

Some types of abuse - including assault (sexual or physical) and theft and fraud – are criminal offences and should be reported to the police, which may lead to prosecution following a criminal investigation.

Families and friends may feel too afraid to report abuse, especially if the carer is the abuser. But individuals are entitled the protection of the law and to dignity and respect. Anyone concerned about a friend, relative or carer who is being abused needs to take action to prevent further abuse and protect others.

Families and Friends can make a complaint

They can also make a complaint. The Commission for Social Care Inspection (CSCI) regulates care homes and inspects every care home registered by them. Any registered care provider must, by law, have a complaints procedure. Services have rules about the staff they employ and the standards of care they provide.

Most local authorities have procedures for investigating cases of abuse, and you can complain to the council about any services they provide.

If you or a relative is in hospital and not being cared for properly you can make a complaint to the NHS.

YELL

Sometimes families and friends have to make a noise in order to get things dealt with, this may mean discussing issues with staff with concerned voice and manner, writing letters to the home, police and the local M.P., it may be an act of whistle-blowing where relevant.

The families and friends may also see a fearful individual who shouts and gets angry when approached, this may be because they have been harmed and abused, and need protection, safety and security

Independent advocacy

1. PURPOSE OF ADVOCACY

Advocacy is speaking up for, or acting on behalf of, yourself or another person. The other person is often receiving a service from a statutory or voluntary organisation and is referred to throughout this handbook as the individual.

Advocacy can help individuals to:

- make clear their own views and wishes;
- express and present their views effectively and faithfully;
- obtaining independent advice and accurate information;
- negotiate and resolve of conflict.
- Some people aren't clear about of their rights as citizens, or have difficulty in fully
- understanding these rights. Others may find it hard to speak up for themselves.
-

Advocacy can enable people to take more responsibility and control for the decisions which affect their lives.

KEY PRINCIPLES

- What the person says and wants is the most important thing.
- Advocacy enables individuals to do more for themselves and lessens their
- dependency on other people.
- Advocacy should help people to make informed choices. An advocate must ensure the individual is making real choices based on good quality information.
- Advocates should not have a conflict of interest. So that they can speak up for someone effectively, there must be no other pressures on the advocate. This is why the advocate needs to be independent of the service provider.
- People must have choice about the type of Advocacy they use. Individuals
- should be able to choose the type of Advocacy that suits them best).
- Some individuals feel that they need one person who is willing to act on their behalf whereas others will prefer the support of a group.

Others will want to advocate for themselves, as far as is possible, with only the minimum of support.

ADVOCACY MODELS

SELF ADVOCACY

This is where an individual, or group of people, speaks or acts on their own behalf in pursuit of their own needs and interests - speaking up for yourself. Speaking up may be difficult because of a disability or illness or simply because people don't take individuals seriously or think they are incapable of making decisions.

CITIZEN ADVOCACY

This is where someone else speaks up on behalf of the individual or helps them to speak up for themselves. It is based on the idea of a 'valued citizen' (i.e. someone who does not have a problem getting heard), working with a person who is discriminated against. The relationship may develop into friendship or just working together to develop the individual's skills or confidence to manage their own situation. Citizen Advocates usually come from a recognised and coordinated scheme.

CRISIS ADVOCACY

This is where an advocate is found to help with a one-off difficult situation or crisis. The advocate may be someone who is already a Citizen's Advocate.

PEER ADVOCACY

This is where individuals who have experienced similar problems of not being listened to, may help others to speak up for themselves. A peer advocate is likely to have a very good understanding of what other service users are going through.

PROFESSIONAL ADVOCACY

This can mean experts in a professional field, such as lawyers, being commissioned to speak up on behalf of an individual individual or group. They may or may not receive payment for acting as an advocate.

COLLECTIVE ADVOCACY

This is where a group of people, sometimes from very different backgrounds, campaign on behalf of themselves or others to try and change things. This could be a national organisation or a local one focusing on either national or local issues

Assistive technologies (pressure mats, door alarms linked to staff pagers, personal pendant alarms, colour-coded handrails, pictures/images on doors)

Dementia can make day-to-day life more difficult. Little things like forgetting to turn the gas off or letting the bath overflow can cause great damage and may put the person with dementia and others in danger. This information sheet looks at technological developments that can help make life easier for people with dementia and their carers. It also suggests the steps to take if you think that you, or someone you are caring for, could benefit from some of these devices.

What is assistive technology?

The term 'assistive technology' refers to any product or service designed to enable disabled and older people to be independent. This includes equipment and devices to help people who have problems with:

- speaking
- hearing
- eyesight

- moving about
- memory
- cognition (thought processes and understanding).

Assistive technology ranges from very simple tools, such as walking sticks, to high-tech solutions such as satellite-based navigation systems to help find someone who has got lost.

What are the benefits?

Assistive technology can help by:

- Enabling people with dementia to retain their self-reliance and confidence
- Helping carers monitor the person they are caring for 'remotely' – from another room or another location – without having to watch the person all the time, so they can offer their help when they are needed
- Allowing people to choose whether to stay at home for longer or move to a residential home or hospital.

Finding the right solution

Selecting the right device is not an easy task. Different people react differently to different products. One person might find a sophisticated monitoring system helpful, while another might prefer a simple tape-recorded message that plays when they open the front door, reminding them to take their keys. Seek as much advice as possible. Whenever you can, involve social services and your occupational therapist or GP in your decision, to ensure a tailored solution.

Keep it simple: tips

- Solutions don't need to be high-tech. Simple ideas such as a diary, notebook or notice-board can provide a reminder of appointments, important phone numbers and things to do.
- Decide on a permanent place to keep important items such as keys.
- Label cupboards or rooms to help you remember where things are.

What technology is available?

There are many different technologies that can be adapted to the needs of someone with dementia. You can buy many of these devices independently, but before you do, contact your local authority social services or Supporting People departments (see Useful contacts), or your occupational therapist or GP. Even if they can't offer you the products, you may be eligible for a proper assessment, help in finding the best product, or financial assistance.

- Assistive technologies (pressure mats, door alarms linked to staff pagers, personal pendant alarms, colour-coded handrails, pictures/images on doors)

Sensors

Unobtrusive wireless sensors can be placed around the home to raise the alarm if there is a potential problem inside the home of the person with dementia. If the sensors detect possible smoke, gas, flood or fire, they sound an audible alarm as well as alerting a carer, keyholder or a 24-hour monitoring service.

Sensors can be used to detect:

- Floods – These detectors can be fitted on skirting boards or floors in the kitchen and bathroom. If the taps have been left running they shut off the water and raise the alarm.
- Extreme temperatures – This device will send a warning signal if the temperature is very low, very high, or if there is a rapid rise in temperature. This can be useful in the kitchen to detect a pan that has boiled dry, for example.
- Scalding baths – A temperature-regulated plug replaces the standard bath plug and changes colour from blue to bright pink at high temperatures.
- Carbon monoxide – This alerts carers to high levels of carbon monoxide, due to a faulty boiler or gas fire.
- Gas – If someone forgets to turn the gas off, this device will automatically shut off the gas and raise the alarm.
- Falls – Sensors worn on the wrist can detect the impact of a person falling.
- Absence from a bed or chair – If a person gets up from their bed or chair and doesn't return for an unusual period of time, or if they don't get up in the morning, this device raises an alarm.
- Getting up in the night – A pressure mat sensor is placed by the bed and a sensor activates an alarm when the person gets up in the night, so that their carer can help them get to the toilet.

More complex sensor technology can be used for a range of other situations:

- Nightlights – Sensors can be set to automatically switch lights on as a person enters or leaves a room. This is useful if someone gets up in the night but doesn't need to be helped by a carer.
- 'Wandering' sensors – If someone likes to come and go inside and outside the house, these sensors, based on passive infra-red technology used in burglar alarms, can help retain their independence. If they don't return to bed safely because they might have fallen, if they don't return home within a pre-determined period of time, or if they are moving around the house outside their normal patterns (such as at night), the sensor will be activated and help sought.
- Tracking and tagging devices – Tracking devices use satellite technology to help trace someone who has got lost. They have their limitations; they are accurate to within 400m or 9km, depending on the geographical area. Tagging devices trigger an alarm if the wearer strays outside a defined area. This is controversial as some people consider tagging to be an infringement of a person's civil liberties.

Memory aids

Reminder messages

When a person enters or leaves their home, these gadgets activate a voice telling them to pick up their keys or lock the front door etc. The messages can be recorded so that the voice is of someone they know, such as a family member. Messages can also be recorded to remind the person of their daily appointments, to tell them not to go out at night, or to provide reassurance, such as 'Go back to bed, Mum – it's night time.' Door reminders can remind people not to trust bogus callers. This can be useful as people with dementia are often vulnerable to burglary.

Clocks and calendars

Automatic calendar clocks can be helpful for people who forget which day it is. Try to find one that shows the date and day of the week too. Clocks that show whether it is evening or morning can help prevent disorientation, particularly in the dark winter months.

Medication aids

Dosset boxes are simple boxes for pills, with compartments for particular days of the week and times of day. They help people remember to take their medication at the right time. Simple versions are available from the local chemist. Automatic pill dispensers are also available. When the medication needs to be taken, the dispenser beeps and a small opening allows access to the particular pill at the right time.

Locator devices

These devices can be attached with a keyring or Velcro to items that are often mislaid. If a person wants to find a particular item, they press a colour-coded button on a radio transmitter and the device with the corresponding colour will beep until the item is picked up.

Mobility aids

Other problems associated with dementia include mobility problems, incontinence and difficulties with sight or hearing. For information about mobility aids, continence devices and pressure relief mattresses and cushions, see the Society's information sheets *Equipment to help with disability* and *Adaptations, improvements and repairs to the home*.

Things to think about

Is assistive technology for you

Assistive technology can make a huge difference to the lives of people with dementia and their carers. But it is not always the answer. Some people might find that the very presence of the equipment reminds them about their memory problems, which can cause distress. Some technological solutions may be unnecessarily complex or expensive, and small changes in daily activities may be enough to overcome a problem. Finally, it goes without saying that assistive technology can only be effective when combined with good care.

Fit for the job

Dementia can sometimes make people wary of trying new things, adapting to changing situations or learning new skills, so it's important to find a product that really suits their situation, and their likes and dislikes. To overcome this difficulty, aim to find solutions that can be integrated into the person's normal routine without being noticed, or with the minimum disruption. Involve the person in decisions about which product or solution to use, and take their opinions on board. There is a higher chance of success if you can introduce assistive technology when the dementia is still at an early stage, so that the person can gradually get used to the new way of doing things.

Technology for tomorrow

There is extensive research into new advances in this area. Projects underway include:

- Devices for helping people who have difficulty communicating, including touch-screen computer programmes
- Multimedia software to evoke memories and stimulate positive conversation, by incorporating photographs of film stars and songs familiar to older people, and videos about how life used to be
- Lifestyle monitoring packages – complex systems that help a carer to check a sudden change from the person's normal routine. The system might include movement detectors, door usage detectors (on fridges, and food and tableware cupboards), and monitoring of electrical usage (on the kettle, toaster and television).

The effect an environment can have that includes space choice and access to gardens. An enabling and safe environment (circular paths, floor coverings/soft furnishings that are not heavily patterned, distinct difference between walls and ceilings through use of colours and textures, etc)

One specific area of mental health in which therapeutic horticulture has found a place is the care and treatment of patients suffering from Alzheimer's disease and other forms of dementia.

Gardens must be designed that provide a safe and stimulating environment for patients and sensory stimuli associated with gardens and gardening have been used to provoke memories in reminiscence therapy. The actual design of the garden is of great importance and there has been a lot of interest and research in this aspect.

It is suggested that a garden has four key elements - *enclosing wall, water, canopy, and hill*. The enclosing wall is of particular significance because it creates the space of the garden and it is a feature of many gardens designed specifically for patients with dementia.

These enclosing walls associated with a residence, originally constructed of mud or stone, provided a degree of privacy essential to family life. The walls sheltered plants from the searing wind which swept the desert; they protected against undesirable entry of thief and wild beast; and they secured the space for pleasure of shade, fruit and flower...

Circular Paths with interesting features along them to stimulate interest and aid Orientation.

It is essential to ensure that there are soft furnishings in rooms. They absorb sound and stop it echoing around

Floor fittings should be plain (heavy patterns cause confusion) and non-slip. Textile and colour should be consistent as possible throughout scheme with flatted areas and communal areas distinguished by different colour flooring

Wall surfaces should have enough texture to enable clients to support themselves but not be so abrasive as to cause injury. Wallpapers with a vinyl finish are easy to clean and a wide range of

attractive patterns are available. For painted walls, emulsion paint is practical and convenient. Gloss paint is very suitable for doors and woodwork but care should be taken to avoid shiny paints on walls as even the satin finishes, which are very easy to clean, can catch the light, causing high spots of glare and an institutional appearance in rooms which should be restful and domestic in character.

Fairly soft colours should generally be used for walls and ceilings in order to create a light and tranquil environment. Most elderly people have failing or defective eyesight and it may therefore be useful to have a difference in tone and colour

Floor coverings must be the same colour to assist residents, and particularly those with dementia who like to wander, by creating a flowing space where it is appropriate to walk. In areas such as cleaning rooms, offices and the main kitchen a different coloured floor is used which creates a visual step, indicating an area where residents are not encouraged to walk. Bedrooms are also decorated in a way which ensures rooms next to each other are not the same colour, to assist residents in finding their own room.

For the individual with Alzheimer's disease, the walled or fenced space serves as a refuge.



1.4 Understand the importance of maintaining the general good health and well-being of the individual with dementia:

Food, nutrition, eating and drinking at regular intervals

People with dementia and older people often require special consideration when food is prepared for them. Nutritional deficiencies are a common problem among people in residential or nursing homes and long-stay hospital wards.

General

Individuals may begin to decrease variety in diet, i.e., eat mostly cereal, soup, sweets, drink only soda – resulting in vitamin deficiency, especially B complex vitamins (needed for good cognition).

They may occasionally forget to eat, or forget that they already have eaten, and eat again, and may forget to drink, or deliberately restrict fluids (for less frequent urination), resulting in dehydration and complication of concurrent health problems and/or reduced cognition

Caffeine consumption may add to incontinence and/or agitation problems

Alcohol consumption patterns may change – 5 pm cocktail may turn into 2-3, drinking more because s/he's forgotten she already had one

Judgement

1. They may be unaware of spoiled food in the refrigerator
2. They may eat from dirty dishes or saved containers that have not been properly cleaned
3. They may forget that food is cooking on stove - resulting in burning or fire, or lose track of cooking times and serve food that is not cooked sufficiently

General Guidance

- Make available a variety of high quality and nutritious foods, choose foods with longer shelf life and easy access (e.g., nutritional soups with pull-top can openings, pre-sliced cheese, fresh fruit, etc.)
- Keep non-perishable snacks, juice and water in sight (e.g., on counter, table) to encourage consumption, also give prompts
- Encourage doctor approved vitamin B complex and other supplements needed (e.g., multivitamin, vitamin E, C, etc.), combined with foods high in B vitamins that the person likes, e.g., whole and enriched grain products, bananas, dairy products and leafy greens (research shows B vitamins essential to good cognition, and consumption of a combination of foods and supplements yield best results)
- Have doctor monitor blood nutrient levels periodically if a deficiency
- Eliminate items with high caffeine, substitute where possible or mix half and half
- Provide variety of fluids to encourage fluid intake as much as possible (soup, fruit juice, popcicles, nutritious shakes, decaffeinated coffees or teas, etc.)
- Monitor alcohol consumption, remove bottles from sight, add water to drinks
 - Watch for consumption of “copycat” drinks that may have alcohol in them unknowingly (e.g., hard lemonade or iced tea, wine coolers, etc.)

Interventions

- Check refrigerator and cabinets for spoiled foods, discard discreetly if person objects
- Check cabinets and rooms for saved containers and soiled dishes
- Consider dishwashing assistance, disposable dishes
- Look for burned pots and pans, encourage use of microwave instead and supply microwave-safe cooking items (remove/store metal cookware)
- Consider disconnecting or modifying stove

Expected Outcome

The Individual maintains good hydration and nutritional status while having maximum independence

- Person may have trouble with complex meal preparation (e.g., leave out some ingredients in recipes, forget to prepare parts of the meal, etc.)
- May begin to have problems with grocery shopping
- May skip meals, not eat on days when home delivered meals are not to liking or not sent

Communication

- Person's testimony about food eaten and when, may be unreliable

Practical Inputs

- Simplify menus
- Provide assistance with grocery shopping
- Consider home delivered meals, and/or providing assistance with meal preparation
- Have frozen or pre-made and ready to heat alternatives available for gaps in delivered meals – weekends, holidays, or when person doesn't like delivered meal and won't eat it

Observations

- Set up ways to monitor if food is eaten (e.g., if not in a care home, neighbour or family dropping over at mealtime, monitoring cabinets, refrigerator and garbage, etc.)
- Monitor weight, how clothing fits

Appropriate exercise and activities specific to the needs of the individual

Physical activity and the brain

Physical activity helps the body to remain healthy and mobile by keeping joints and muscles in good condition and keeping the heart and blood circulation pumping. It is also good for the brain. Although it is still not clear why this is the case, it is likely to do with improving blood flow to the brain, enabling it to carry out its function.

If images of gyms and aerobic studios fill you with dread there is no need to panic. The recommended minimum level of physical activity for adults is 30 minutes of moderate activity most

days and could include cycling, jogging, brisk walks, an afternoon gardening or simply using the stairs instead of catching the lift - anything that increases your heart rate and makes you breathe more deeply. An American study of 3,375 men and women over the age of 65 found that those who took part in four or more different kinds of physical activity had about half the risk of developing dementia of those who did just one or none of these activities. Activities included walking, housework, gardening, golfing and swimming.

Social activity and the brain

It is only recently that scientists have begun looking at the effects of social interaction and how it might affect human health, in particular the risk of developing dementia. However the evidence so far suggests that maintaining and developing social activities could be good for your brain.

It is thought that as with mental stimulation, social interaction may help to build cognitive reserves. A lot of the evidence showing the benefits of social interaction comes from Sweden and one study in particular showed that having a poor or limited social network increased the risk of dementia by up to 60 per cent. Later studies from the same large scale project found that activities involving mental, physical and social stimulation individually offered some protection against dementia but that combining two or three of these offered the most benefit.

With our increasingly hectic lifestyles we tend to make ourselves our last priority. It is therefore important to make sure you do something sociable and enjoyable every day. Activities that combine mental, physical and social stimulation may be even better for protecting against dementia. Keep in touch with friends and family by phone, email or a letter, go out with friends of colleagues, volunteer for something that interests you or join a club. If you are coming up to retirement, plan how you will remain socially involved – you could start a completely new and different hobby!

Personal care (including measures to reduce risk of infection)

Introduction

Personal care is important to all of us. It affects how we feel about ourselves and how other people react to us. Good personal hygiene is important for health. The impact of dementia on a person's ability to look after themselves will vary from one individual to another. Washing, dressing and attention to personal care all need to be approached in a fairly ordered way. They involve skills which people with dementia sometimes find difficult. Lack of motivation, forgetfulness and inappropriate behaviour all have a serious effect on a person's ability to attend to their personal appearance and care.

Difficulties

Difficulties which may be encountered include:

- A loss in personal appearance. This may take the form of inattention to cleanliness, grooming or to the appropriateness and state of dress. Even a previously tidy person may neglect appearances and look unkempt.
- Wearing the same clothes day after day. The person with dementia may refuse to change clothing and if challenged about this become irritable and unco-operative.

- Forgetting to wash, shave, comb hair, brush teeth and so on, or performing certain activities repeatedly but neglecting others.
- Forgetting how to carry out personal care activities or when they were last undertaken.
- A lack of awareness of personal safety when using hot water, electrical appliances, razors, wet floors and so on.
- Confusion over the order in which clothes should be put on.
- Being unable to cope with fastenings such as zips and buttons.
- Dressing or undressing at odd times or in inappropriate places.

How you can help

The very personal nature of these activities can make it hard both to offer and to accept assistance. People with dementia often experience considerable frustration and anxiety when they try to carry out personal care tasks. They may react badly to being reminded or hurried. 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. Think about how much help is required. Consider ways in which you could encourage or help the person to carry out tasks. We all have our own way of going about things and it is helpful if the person's own routine can be kept to as closely as possible.

The following suggestions may help:

- Allow time for activities such as washing and dressing. Make sure the room is warm and comfortable. Try to make things as relaxed as possible.
- Provide the maximum degree of privacy which safety will allow.
- Try giving prompts before assisting more actively, and provide the necessary prompt one step at a time. If assistance is required, give it tactfully and explain what you are doing.
- Avoid discussions and arguments and approach tasks positively.
- Limit choice of clothing but continue to offer a choice if possible.
- Lay items of clothing out in the order to be worn (preferably the same way the person would usually do it.) Lay toiletries out in order of use.
- When the person is trying to do things, give encouragement. Give compliments and generally take an interest in the person's appearance.
- The person's general level of co-operation with you regarding personal care tasks may fluctuate considerably. Remember it is pointless to argue. It is likely that in a short time the person with dementia will forget the dispute but you may be left tense, angry and exhausted! If certain areas prove difficult, try again later, try different approaches or choose a time of day when the person is usually most co-operative.

Some hints on care

Hands and feet

Trim nails when softened, either following a bath or after soaking feet or hands in a basin. Use round tipped scissors and cut toe nails fairly straight. Providing a manicure can be a relaxing experience. Nails generally become harder with age and you should not trim them if they do not cut fairly easily.

People with circulatory problems, especially diabetics, have to take special care of their feet and regular chiropody may be essential. Comfortable, well-fitting shoes are important and preferable to slippers indoors.

Hair

It is best to keep to a routine familiar to the person, while providing as much assistance as necessary. If the person has been a regular visitor to the hairdressers, try to maintain this. Simple, easily cared for styles are best. Perhaps you could arrange for a visitor to call at the person's home. (Choose a comb or brush which is easy for the person to grasp).

Mouth

Mouth care is important to everyone's general health. A person with dementia may neglect teeth cleaning, and dentures can become ill fitting due to weight loss. Other problems include oral infections, inflammation and difficulties with chewing food.

You can help by giving prompts, one step at a time throughout the process of cleaning teeth or dentures, to maintain independence as much as possible. If you have to provide care yourself, clean teeth or dentures thoroughly at least once a day. Regular check-ups are important and a home service is available.

Dressing

Choose clothing which is easy to wear and care for. Clothing can be made more manageable by replacing hooks, buttons and zips with Velcro fastenings. Dressing aids, such as long handled shoe horns, elastic shoelaces, sock or stocking holders, may help to maintain independence and make it easier to help.

Take away clothes which need washing to avoid them being worn again. If the person requires complete assistance with dressing, dress him or her in stages, dressing just the top or bottom half of the body at one time. If a person has a weakness on one side, it is easiest to put clothing on this side first and remove it last.

Washing and bathing

When you help someone to bathe, check the water temperature and depth. Less water in the bath is not only safer but may help to reduce fears about getting into a bath. A shower unit is easier to use but some people may be unused to showers or afraid of them. In a shower use a stable seat in the cabinet. A number of aids to safety are available, including non-slip mats, support rails and bath seats. Ask the Occupational Therapist (OT) at your local hospital or social work department about these aids.

Having a fairly regular routine in relation to bathing can be helpful. Although bath oils and foams can make bathing more enjoyable, they must be used with extreme care as they can make the bath or shower tray very slippery. It may be best to use a favourite body oil or lotion after the bath.

When you supervise, prompt or assist someone with washing, be aware of the importance of carefully washing and drying skin folds. These areas are particularly vulnerable to soreness. Check for areas of redness, dryness, rashes or sores. If you use talcum powder at all, apply it very sparingly as it can be an irritant and cause inflammation, especially on moist skin.

Shaving

Changing over from the use of a blade razor to an electric shaver will be safer and can enable someone to shave himself for longer. It is probably best to encourage this change at an early stage, before it becomes essential.

Living in a clean and enabling environment

Living in a clean and enabling environment can ensure

- The maintenance of facilities and prevention of deterioration of standards to ensure a hygienic safe environment
- Physical needs are met, such as prevention of infection,
- Personal safety, such as non slip environment that enables client's to move around safely and securely
- Keeping hygiene as a high priority, enabling clients to be safe and secure
- A clean and enabling environment supports social contact, with clients able to move from one area to another, at meal times establishing an environment for communication and social discussion
- Control over daily routine, risk assessing, ensuring work routines are carried out, monitored and evaluated for improvements

Providing a safe and enabling environment

The living environment for older people becomes tremendously important as they age, and families and older persons are often confronted with painful or expensive choices. Homes that were wonderful for a young family can prove to be an obstacle course for an older person.

Adequate housing and a *safe and enabling environment* is a basic need when it comes to older people. It can make all the difference in quality of life. T

As people age from young older to older old and oldest, disabilities become much more common, and mobility, and consequently access, become more and more limited. At the same time, it is important to remember - and very easy to forget - that, as people age, they also become more diverse in terms of abilities, health, participation, and other types of activity.

Many older persons living in inappropriate housing usually are unhappy with their homes. They may complain about the inadequate size, poor construction and unhealthy surroundings in which they lived.

A common issue is personal safety. Older people want protection - from crime, from social

discrimination, from traffic - and from many other hazards. They also wanted basic things, such as an adequate water supply; solid waste and sewage disposal; access to their homes by road or path; and electricity, telephones and fuels at affordable costs. They wanted air and water pollution and hazardous wastes reduced or eliminated. Finally, they wanted safer housing units, that are not located on steep slopes or in wet areas.

A common desire is for more social contacts within the community, community centres or elder centres for social contacts, recreation, counselling and minor health care, and opportunities to participate in community affairs, employment, education and training services for those able to work, and more opportunities for inter-generational contacts.

Active ageing and ageing in place

Active ageing means what it says: remaining active as one grows older. People who continue to be productive members of society and contribute to the economy have better health, live longer and have a higher quality of life.

This can be demonstrated by

- Provide opportunities for and encourage lifelong learning, particularly to keep older persons abreast of technological changes and changes in work and skills;
- Create conditions that allow older persons to remain involved in mainstream activities of society, such as transportation to shopping, voting, or public entertainment;
- Make affordable and effective medical interventions, such as hip replacements and cataract surgery, more readily available.
- Make public transportation accessible to older people who may have some disabilities.

Just as more active older people have a higher quality of life, they are also more independent and better able to finance their own needs.

Ageing in place is more specific to adequate housing and a safe and enabling environment. Older people who wish to do so should be enabled to remain in their own homes and environments as long as possible. Institutional arrangements, such as long-term care, should be avoided or delayed as long as possible. Appropriate improvements to housing, such as changes in design and easier access to services, can do a lot to sustain the activity level of older people, and thereby reduce their dependency.

But the physical environment is not all that is important. Ageing-in-place policies should also include social integration as a fundamental and necessary element. It is crucial that older people be supported and encouraged to continue their participation in the social and economic life of their communities. For active ageing and its healthful consequences to be achieved, social integration should be given equal importance as surroundings that are safe and easy to navigate. At the same time, it is also important that the implementation of ageing-in-place policies does not limit the options available to older people or their families. Sometimes the best option may mean moving - to a more convenient dwelling and/or renting, sharing, or selling homes that may have become impractical or burdensome.

1.5 *Understand the need to protect the individual from abuse, injury and harm:*

Awareness of the possibility of an increased risk of falls

Safety and degree of acceptable risk needs to be assessed for each individual, and changes with time. Some exercise is important for general health, prevention of pressure sores and aid to sleeping.

Advice must be given to carers on the risks of small items of furniture, loose rugs, trailing wires etc. It may be possible to make a garden area safe for the patient to wander in. If s/he is able to open the front door and leave the home, Alternative locks or an alarm such as a shop type bell will reduce the need for continual observation.

Falls can occur while wandering or be caused by postural hypotension or ill-fitting shoes. Painful feet lead to unsteadiness and a visit from the community chiropodist can be rewarding. Topographical disorientation, or "getting lost", both in the home or in the surrounding once familiar area is a sign of parietal lobe involvement in the dementia and points to the diagnosis of dementia.

Causes of fall risk are:

Aggression.

Aggressive outburst can cause flailing of arms, fists legs and feet which may cause the individual to jerk and lose balance and topple over

Sleep disturbance.

Waking up in the dark or low light can cause the individual to get out of bed and wander, in the dark and low light, the individual may stumble over furnishings, fittings, or fall down stairs.

Urinary Incontinence.

May cause wetness and puddles which the individual may walk into, and slip, especially on smooth surfaces

Faecal incontinence.

Faecal incontinence may cause a slippery surface that may cause an individual when standing in it to slip and fall. Faeces may be runny, textured or solid

Constipation.

Constipation can cause confusion, and increase the likelihood of falls and slips

Communication difficulties.

Frustration due to communication difficulties may lead to anger and agitation which will make the tendency to fall increasing

Depression

Depression can cause absent mindedness or indifference which may make the individual susceptible to falls

Psychotic features.

Psychotic features can cause absence of mindedness or indifference which may make the individual susceptible to falls

Malnutrition.

Poor diet can make the individual subject to falls due to hydration, vitamin and mineral imbalance

Illnesses.

Illnesses make feature in any liability to fall

Medication.

Sedatives and tranquilizers may make the individual susceptible to falls due to tiredness and sudden relaxation

Types of abuse include: physical, sexual, racist, emotional, financial, institutional, neglect.

Some adults with dementia might be more at risk of abuse than others - this may be because

- They have physical disabilities
- They have learning disabilities
- They have sight or hearing loss
- They have mental health problems
- They have are very ill
- They might be confused or forgetful
- They are elderly or frail
- They are not able to stop someone else from hurting them or taking advantage of them
- They depend on someone else to look after them

Different types of abuse

Physical Abuse

Where someone physically hurts you. This can be:

- Hitting
- Kicking
- Pulling hair
- Pinching, scratching, shaking
- Giving someone too much or not enough medicine

Sexual Abuse

Someone making you do sexual things that might make you sad, angry or frightened.

This can be:

- Being touched where you do not want to be touched, in your private parts
- Being made to touch other people in their private parts
- Undressing or having sex when you don't want to

Emotional Abuse

When someone says things to you that hurt your feelings or scare you.

This can be:

- Calling you names
- Threatening you
- Laughing at you
- Treating you like a child
- Not letting you spend time with other people, or go out
- Ignoring you

Financial Abuse

When someone takes your money or things.

This can be:

- Stealing your money or things
- Making you buy something you don't want to buy
- Using your money to pay for their things
- When you don't have a choice in how your money is spent
- When someone tells you that you have to give them your money or your home

Neglect

Not giving you things that you need.

This can be:

- Not having your prescribed medicine when you need it
- Not being taken to the doctor if you are ill
- Being cold a lot of the time

- Being hungry a lot
- Only having dirty clothes to wear
- Not having your equipment when you need it (like hearing aids, walking frames, wheel-chairs)

Discrimination

When people are treating you unfairly because you are different.

This could be:

- Because of the colour of your skin
- Because of your religion
- Because of your sex
- Because of your age
- Because of your disability
- Because of your language
- Because you are lesbian or gay

Institutional Abuse

This is the mistreatment or abuse of a vulnerable person by a regime or an individual within an institution. It can be repeated acts of poor or inadequate care and / or poor or inadequate professional practice.

It can occur when the needs of the individual are overridden by the needs of the institution. Vulnerable adults are particularly at risk when placed in residential, nursing home or other institutional settings especially if the placement is not rigorously monitored.

Who could abuse you?

Anyone.

Most people will not abuse you.

Where could someone abuse you?

Abuse could happen anywhere.

- In your home
- At a day centre or college
- At work
- In a hospital
- In a care home
- At a club
- Outside

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Dressing

Choose clothing which is easy to wear and care for. Clothing can be made more manageable by replacing hooks, buttons and zips with Velcro fastenings. Dressing aids, such as long handled shoe horns, elastic shoelaces, sock or stocking holders, may help to maintain independence and make it easier to help.

Take away clothes which need washing to avoid them being worn again. If the person requires complete assistance with dressing, dress him or her in stages, dressing just the top or bottom half of the body at one time. If a person has a weakness on one side, it is easiest to put clothing on this side first and remove it last.

Washing and bathing

When you help someone to bathe, check the water temperature and depth. Less water in the bath is not only safer but may help to reduce fears about getting into a bath. A shower unit is easier to use but some people may be unused to showers or afraid of them. In a shower use a stable seat in the cabinet. A number of aids to safety are available, including non-slip mats, support rails and bath seats. Ask the Occupational Therapist (OT) at your local hospital or social work department about these aids.

Having a fairly regular routine in relation to bathing can be helpful. Although bath oils and foams can make bathing more enjoyable, they must be used with extreme care as they can make the bath or shower tray very slippery. It may be best to use a favourite body oil or lotion after the bath.

When you supervise, prompt or assist someone with washing, be aware of the importance of carefully washing and drying skin folds. These areas are particularly vulnerable to soreness. Check for areas of redness, dryness, rashes or sores. If you use talcum powder at all, apply it very sparingly as it can be an irritant and cause inflammation, especially on moist skin.

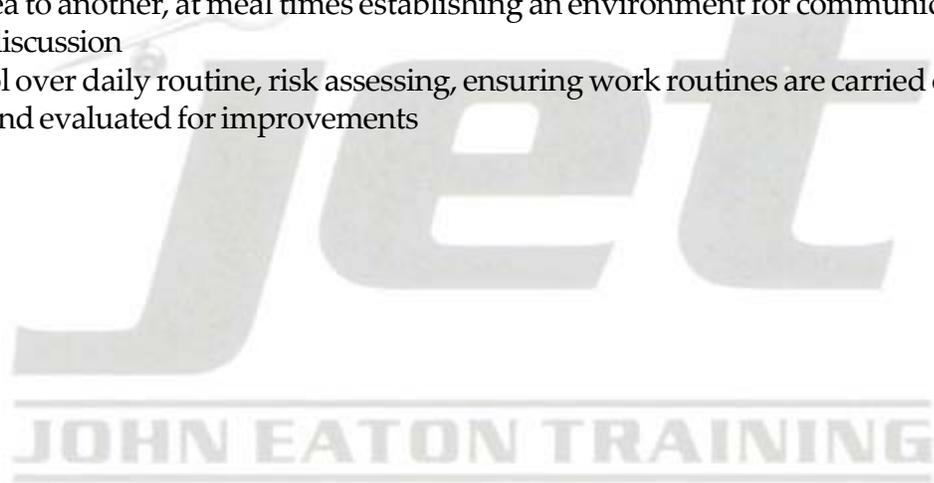
Shaving

Changing over from the use of a blade razor to an electric shaver will be safer and can enable someone to shave himself for longer. It is probably best to encourage this change at an early stage, before it becomes essential.

Living in a clean and enabling environment

Living in a clean and enabling environment can ensure

- The maintenance of facilities and prevention of deterioration of standards to ensure a hygienic safe environment
- Physical needs are met, such as prevention of infection,
- Personal safety, such as non slip environment that enables client's to move around safely and securely
- Keeping hygiene as a high priority, enabling clients to be safe and secure
- A clean and enabling environment supports social contact, with clients able to move from one area to another, at meal times establishing an environment for communication and social discussion
- Control over daily routine, risk assessing, ensuring work routines are carried out, monitored and evaluated for improvements



1.7 *Understand the need for a positive and effective communication with the individual with dementia:*

Recognise that the individual's behaviour will often be directly related to their need to communicate about their feelings and needs

COMMUNICATING

We all need to communicate with other people. Communicating our needs, wishes and feelings is vital – not only to improve our quality of life, but also to preserve our sense of identity. As a carer, it's important to encourage the person with dementia to communicate in whichever way works best for them.

We tend to think of communication as talking, but in fact it consists of much more than that. As much as 90 per cent of our communication takes place through non-verbal communication such as gestures, facial expressions and touch.

- Non-verbal communication is particularly important for a person with dementia who is losing their language skills
- When a person with dementia behaves in ways that cause problems for their carer, they may be trying to communicate something.

Dementia and language

An early sign that someone's language is being affected by dementia is that they can't find the right words - particularly the names of objects. They may substitute an incorrect word, or they may not find any word at all.

There may come a time when the person can hardly communicate in language at all. Not only will they be unable to find the words of objects, they may even forget your name. People with dementia often confuse the generations – mistaking their wife for their mother, for example. This may be very distressing for the carer, but it's a natural aspect of their memory loss.

The person being cared for may be trying to interpret a world that no longer makes sense to them because their brain is interpreting information incorrectly. Sometimes the carer and the person with dementia will misinterpret each other's attempts at communication. These misunderstandings can be distressing, and the carer and the individual may need some support.

Difficulties with communication can be distressing and frustrating for the person with dementia and for carer's. But there are lots of ways to help make sure that the carer and the individual understand each other.

DEALING WITH AGGRESSIVE BEHAVIOUR

If the carer is caring for someone with dementia, they may find that at times they behave aggressively. This can be very distressing. By understanding what causes this type of behaviour and learning some ways to deal with it, they can make sure it happens less often, and feel better able to manage when it does.

What is meant by 'aggressive behaviour' in people with dementia

People with dementia can behave aggressively in one or more of the following ways:

- Being verbally abusive or threatening
- Being physically threatening, such as kicking or pinching
- Lashing out violently at people or property.

This may take the form of overreacting to a situation or becoming very agitated as a result of what seems to be a very minor setback or criticism.

What causes aggressive behaviour?

There are many reasons why a person with dementia may act aggressively, including:

- If they feel frightened or humiliated
- If they feel frustrated because they are unable to understand others or make themselves understood
- If the dementia has eroded their judgment and self-control

If they are no longer restrained by inhibitions learned in early childhood, and have forgotten how to behave appropriately.

Dealing with aggressive behaviour is not easy, and there are no simple answers.

Carers can help to make it less of a problem through a gradual process of identifying what triggers the aggression and finding some effective ways to deal with it.

Look and listen carefully and take account of what an individual is communicating

When a person with dementia finds that their mental abilities are declining, they often feel vulnerable and in need of reassurance and support. The people closest to them – including their carers, friends and family – need to do everything they can to help the person to retain their sense of identity and feelings of self-worth.

Feeling valued

The person with dementia needs to feel respected and valued for who they are now, as well as for who they were in the past. As a carer, there are many things you can do to help:

- Try to be flexible and tolerant.
- Make time to listen, have regular chats, and enjoy being with the person
- Show affection in a way you both feel comfortable with.

If you can understand what the person is going through, it might be easier for you to realise why they behave in certain ways. It is important to remember that a person with dementia is still a unique and valuable human being, despite their illness.

Things to remember

- Each person with dementia is a unique individual, with their own very different experiences of life, their own needs and feelings, and their own likes and dislikes.
- Although some symptoms of dementia are common to everyone, dementia affects each person in different ways.
- Everyone – including friends, family members, carers, and the person with dementia – reacts to the experience of dementia in their own way.

Listening skills

Try to listen carefully to what the person is saying and give them plenty of encouragement.

- If they have difficulty finding the right word or finishing a sentence, ask them to explain in a different way. Listen out for clues.
- If their speech is hard to understand, use what you know about them to interpret what they might be trying to say. But always check back with them to see if you are right – it's infuriating to have your sentence finished incorrectly by someone else!
- If the other person is feeling sad, let them express their feelings without trying to 'jolly them along'. Sometimes the best thing to do is to just listen, and show them that you care.

Getting their attention

- Try to catch and hold the attention of the person before you start to communicate.
- Make sure they can see you clearly.
- Make eye contact. This will help them focus on you.
- Try to minimise competing noises, such as the radio, TV, or other people's conversation.

Dementia means different things to different people.

Look for the meaning behind their words, even if they don't seem to be making much sense. Whatever the person is saying, they are usually trying to communicate with you about how they feel.

- Try to imagine how you would like to be spoken to if you were in their position.

Avoid situations in which the person is bound to fail, as this can be humiliating.

Look for tasks they can still manage and activities they enjoy.

- Give them plenty of encouragement. Let them do things at their own pace and in their own way.
- Do things with them, rather than for them, to help them retain their independence.
- Break activities down into small steps so that they feel a sense of achievement, even if they can only manage part of a task.
- Our self-respect is often bound up with the way we look.
- Encourage the person to take a pride in their appearance, and compliment them on how they look

Respond appropriately and positively to an individual's various forms of communication (using non-threatening body language and tone of voice, use of simple sentences, being calm and unrushed)

Non-threatening body language

- Stay calm — be aware of your ability to affect the individual. Assess what is needed in the situation and feel free to ask others for help.
- If you're with others, stay together. Discuss possible responses ahead of time so you can respond quickly.
- If the individual is being loud or confrontational, attempt to talk with them.
- If the individual is aggressive, create a clear separation to protect yourself. Where appropriate, ask others to join you. Show that you don't support the violence.
- Remember that it's okay to say how you feel about what's happening, for example, "Peter, you know when you do that it hurts me"
- Other techniques to maintain non-threatening body language: Talking, singing, chanting in a calm voice; eye contact; listening; not getting in heated arguments; linking hands; sitting down; using non-threatening body language, humour and common sense.

Tone Of Voice

It's not so much what you say,
as the manner in which you say it;
It's not so much the language you use,
as the tone in which you convey it.

"Come here", I sharply said,
And the individual cowered and wept.
"Come here", I said he looked and smiled,
And straight to my lap he crept.

Words may be mild and fair,
But the tone may pierce like a dart;
Words may be soft as the summer air,
But the tone may break my heart;

For words come from the mind
Grow by study and art,
But tone leaps from the inner self,
Revealing the state of heart.

Whether you know it or not,
Whether you mean or care,
Gentleness, kindness, love and hate,
Envy, anger are there.

Then, would you quarrels avoid
and peace and love rejoice?
Keep anger not only out of your words,
Keep it out of your voice.

Use of simple sentences

COMMUNICATION TIPS FOR PERSON WITH DEMENTIA

- Speak slowly and clearly using short simple. Do not expect a quick response. Give the person time to process the information.
- If it is necessary to repeat statements, use the same words. At first, do not rephrase sentences or use different words.
- The tone of your voice and facial expressions is as important as what you say. Use a normal tone of voice and a calm manner. Persons with dementia can be sensitive to body language as well as tone of voice even if they can't understand what is being said.
- Stand in front or in the direct line of vision of the person. Touch an arm or shoulder gently to get or keep attention. Sustain eye contact.
- Present only one idea at a time. Do not try to give too much information in one sentence.
- Use gestures and visual clues or aids to get across you messages. Try using more than one of these senses to communicate, such as touching as well as talking. Do not use gestures to threaten the person.
- Avoid questions whenever possible, such as quizzing the person on names of family members. Not knowing the answers embarrasses the person. It may be helpful to cue the person with the necessary information, such as supplying the names.
- Only offer simple choices.
- Discuss only concrete actions and objects.
- Use direct statements to initiate action, such as "It's time to take a bath", or "Let's get dressed now".
- Understand that the person with Alzheimer's may say one word and mean another. You may have to guess at the correct meaning. Try to clarify your guess with the person. You could be wrong.
- Do not assume that the person with dementia can always understand and act on messages, either written or verbal.
- Communicate with the person as much as possible, although a constant stream of conversation is neither helpful nor necessary.

1.8 *Understand that activities, therapies and medication may be used to help individuals with dementia:*

Conventional medicines

There may be a link between physical illness and confusion in some individuals. Some medication may add to confusion and/or agitation

People with dementia may at some point in their illness develop symptoms such as depression, restlessness, aggressive behaviour and psychosis (delusions and hallucinations). While it is important to try to understand and address the underlying reasons for these problems, it may be necessary at times to prescribe medication if the symptoms are distressing, persistent and have not responded to psychological treatments.

Before any of the medicines mentioned in this statement are prescribed it is essential to ensure that the person with dementia is physically healthy, comfortable and well cared for.

Whenever possible, the person should be helped to lead an active life, with interesting and stimulating daily activities. By minimising distress and agitation it is usually possible to avoid the use of sedative medicines altogether.

If, after trying non-drug treatments, medicines are considered to be necessary remember:

- All medicines have side-effects that may worsen symptoms.
- Always ask the prescribing doctor (usually the GP) why the drug is being prescribed, what the side-effects may be and what you should do if they occur.
- Don't assume that a drug that has proved to be useful at one time will continue to be effective. Dementia is a degenerative condition. The chemistry and structure of the brain will change during the course of the illness.
- Bear in mind that certain combinations of medicines may counteract each other. Remind your doctor if other medications are being taken.
- If a drug is prescribed, check with your doctor that there is a clear plan to review the medication and to stop it as soon as possible. Usually a trial of stopping medicines is recommended after three months.
- Taking medicines

Medicines will be more effective if they are taken exactly as prescribed by the doctor, in the correct dose and monitored regularly for side-effects.

If symptoms are difficult to control, the GP may refer to a specialist for further advice.

- Some medicines need to be taken regularly to have an effect – for example, antidepressants and major tranquillisers (often called antipsychotics or neuroleptics). These medicines are not helpful when given on an 'as needed basis'. Other medicines, such as hypnotics or anxiety-relieving medicines, may be more effective when taken on an as needed basis. This should only be done after discussion with the doctor.
- Do not expect immediate results. Benefits may take several weeks to appear, particularly with antidepressants and major tranquillisers.
- Side-effects may occur early or late in the course of treatment – it is important that you ask the doctor what to expect.

- Side-effects are usually related to the dose. The doctor will usually 'start low and go slow', gradually increasing the dose until the desired effects are achieved.
- Once treatment has been established it is important that it is reviewed regularly. Take all medications to clinic and hospital appointments.
- Remember that some of the medicines taken to control behavioural symptoms can be dangerous if accidentally taken in large quantities. Make sure medicines are kept safe and secure.

Names of medicines

All medicines have at least two names – a generic name, which identifies the substance, and a proprietary (trade) name, which may vary depending upon the company that manufactured it. Generic names are used in this information sheet – at the end you will find a list of medicines in common use, giving both the generic and proprietary names.

Medicines for treating agitation, aggression and psychotic symptoms

Major tranquillisers (also known as neuroleptics or antipsychotics) are medicines that were originally developed to treat people with schizophrenia.

The use of major tranquillisers in people with dementia remains controversial and clinical trials are in progress to better determine their effectiveness. At the moment, none of these treatments are specifically licensed to treat people with dementia, although they are frequently prescribed to treat symptoms including agitation, delusions (disturbed thoughts and false beliefs), hallucinations (seeing and hearing things that are not there), sleep disturbance and aggression.

Side-effects

- Side-effects include excessive sedation, dizziness, unsteadiness and symptoms that resemble those of Parkinson's disease (shakiness, slowness and stiffness of the limbs).
- Major tranquillisers may be particularly dangerous for people with dementia with Lewy bodies, possibly causing sudden death. If a person with dementia with Lewy bodies must be prescribed a major tranquilliser, it should be done with the utmost care, under constant supervision, and should be monitored regularly.
- A new generation of major tranquillisers may be less prone to produce troublesome side-effects, although some of these medicines (risperidone and olanzapine) have been determined to be unsuitable for use in people with dementia because of the high risk of stroke. So far, there is very little information about the possible risk of stroke with other medicines in this class, such as quetiapine; therefore, their use is not recommended at the moment.
- Whichever drug is used, treatment with major tranquillisers should be regularly reviewed and the dose reduced or the drug withdrawn if side-effects become unacceptable.
- Excessive sedation with major tranquillisers may reduce symptoms such as restlessness and aggression at the expense of reducing mobility and worsening confusion.
- Evidence is also beginning to accumulate to suggest that major tranquillisers may accelerate the rate of decline and disease progression in people with dementia, so there are particular concerns about the long term use of these medicines.

Anticonvulsant medicines, such as sodium valproate and carbamazepine, are sometimes also used to reduce aggression and agitation, as is the antidepressant drug trazodone.

Medicines for treating depression

Symptoms of depression are extremely common in dementia. In the early stages they are usually a reaction to the person's awareness of their diagnosis. In the later stages of the illness, depression may also be the result of reduced chemical transmitter function in the brain. Simple non-drug interventions, such as an activity or exercise programme, can be very helpful. In addition, both types of depression can be effectively treated with antidepressants, but care must be taken to ensure that this is done with the minimum of side-effects.

Antidepressants may be helpful not only in improving persistently low mood but also in controlling the irritability and rapid mood swings that often occur in dementia and following a stroke.

Once started, the doctor will usually recommend prescribing antidepressant medicines for a period of at least six months. In order for them to be effective, it is important that they are taken regularly without missing any doses.

Improvement in mood typically takes two to three weeks or more to occur, whereas side-effects may appear within a few days of starting treatment.

Side-effects

- Tricyclic antidepressants, such as amitriptyline, imipramine or dothiepin, which are commonly used to treat depression in younger people, are likely to increase confusion in someone with dementia. They might also cause a dry mouth, blurred vision, constipation, difficulty in urination (especially in men) and dizziness on standing, which may lead to falls and injuries.
- Newer antidepressants are preferable as first line treatments for depression in dementia.
- Medicines such as fluoxetine, paroxetine, fluvoxamine, sertraline and citalopram (known as the selective serotonin re-uptake inhibitors) do not have the side-effects of tricyclics and are well-tolerated by older people. They can produce headaches and nausea, especially in the first week or two of treatment. There is very limited information about the use of other newer antidepressants in people with dementia, although one large treatment study (M Roth, CQ Mountjoy and R Amrein, 1996) suggests that moclobemide is an effective treatment. Venlafaxine has many of the side-effects of tricyclic antidepressants, but can be very helpful in people who have not responded to other treatments.

Medicines for treating anxiety

Anxiety states, accompanied by panic attacks and fearfulness, may lead to demands for constant company and reassurance.

Short-lived periods of anxiety, for example in response to a stressful event, may be helped by a group of medicines known as benzodiazepines. Continuous treatment in excess of two to four weeks is not advisable because dependency can occur, making it difficult to stop the medication without withdrawal symptoms.

Side-effects

- There are many different benzodiazepines, some with a short duration of action, such as lorazepam and oxazepam, and some with longer action, such as chlordiazepoxide and diazepam. All of these medicines may cause excessive sedation, unsteadiness and a

tendency to fall, and they may accentuate any confusion and memory deficits that are already present.

- Major tranquillisers (see above) are often used for severe or persistent anxiety. If taken for long periods these medicines can produce a side-effect called tardive dyskinesia, which is recognised by persistent involuntary chewing movements and facial grimacing. This may be irreversible, but is more likely to disappear if it is recognised early and the medication causing the problem stopped.

Medicines for treating sleep disturbance

Sleep disturbance, and in particular persistent wakefulness and night-time restlessness, can be distressing for the person with dementia and disturbing for carers. Many of the medicines commonly prescribed for people with dementia can cause excessive sedation during the day, leading to an inability to sleep at night.

Increased stimulation during the day can reduce the need for sleep-inducing medications (hypnotics) at night.

Hypnotics are generally more helpful in getting people off to sleep at bedtime than they are at keeping people asleep throughout the whole of the night. They are usually taken 30 minutes to one hour before going to bed.

Chlormethiazole is generally well tolerated by elderly people, although some cannot take it because it produces an unpleasant itching sensation in the nose. Benzodiazepines (see section on medicines for treating anxiety) such as temazepam are frequently prescribed.

Side-effects

- If excessive sedation is given at bedtime, the person may be unable to wake to go to the toilet and incontinence may occur, sometimes for the first time. If the person does wake up during the night despite sedation, increased confusion and unsteadiness may occur.
- Hypnotics are often best used intermittently, rather than regularly, when the carer and person with dementia feel that a good night's sleep is necessary for either or both of them. The use of such medicines should be regularly reviewed by the doctor.

Anti-dementia medicines

The new generation of anticholinesterase medicines was originally developed to improve memory and the ability to carry out day-to-day living activities in people with Alzheimer's disease. Evidence suggests that these medicines also have beneficial effects on behavioural symptoms, particularly apathy (lack of drive), mood and confidence, delusions and hallucinations. Taking anti-dementia medicines may therefore reduce the need for other forms of medication. However, in higher doses these anti-dementia medicines may occasionally increase agitation and produce insomnia with nightmares.

Memantine is the most recent anti-dementia drug to be developed. It works in a different way to the anticholinesterase medicines and is the first drug suitable for those in the middle to later stages of Alzheimer's disease. It is thought to slow the rate of disease progression rather than to have immediate effects on behavioural symptoms.

Commonly prescribed medicines

This list includes the names of many (but not all) of the different medications available. New medicines are appearing all the time and you may need to ask your doctor what type of medication is being prescribed. The generic name is given first, followed by some of the common proprietary (trade) names.

- **Major Tranquillisers**

- Amisulpride (Solian)
- Chlorpromazine (Largactil)
- Fluphenazine (Modecate)
- Haloperidol (Haldol, Serenace)
- Olanzapine (Zyprexa)
- Promazine (Promazine)
- Quetiapine (Seroquel)
- Risperidone (Risperdal)
- Sulpiride (Dolmatil, Sulparex, Sulpitol)
- Trifluoperazine (Stelazine)
- Zotepine (Zoleptil)
- Zuclopenthixol (Clopixol)

- **Antidepressants**

- Amitriptyline (Lentizol)
- Amoxapine (Asendis)
- Citalopram (Cipramil)
- Dothiepin (Prothiaden)
- Doxepin (Sinequan)
- Fluoxetine (Prozac)
- Fluvoxamine (Faverin)
- Imipramine (Tofranil)
- Lofepramine (Gamanil)
- Mirtazipine (Zispin)
- Nefazodone (Dutonin)
- Nortriptyline (Allegron)
- Paroxetine (Seroxat)
- Reboxetine (Edronax)
- Sertraline (Lustral)
- Trazodone (Molipaxin)
- Venlafaxine (Efexor)

- **Other mood stabilisers**

- Lithium carbonate (Camcolit, Priadel, Liskonum)

- **Anxiety-relieving medicines**

- Alprazolam (Xanax)
- Bupirone (Buspar)
- Chlordiazepoxide (Librium)
- Diazepam (Valium)

Lorazepam (Ativan)
Oxazepam (Oxazepam)

- **Hypnotics**

Chloral hydrate (Welldorm)
Clomethiazole (Heminevrin)
Flurazepam (Dalmane)
Nitrazepam (Mogadon)
Temazepam (Temazepam)
Zopiclone (Zimovane)
Zolpidem (Stilnoct)

- **Antidementia medicines**

Donepezil (Aricept)
Rivastigmine (Exelon)
Galantamine (Reminyl)
Memantine (Ebixa)

- **Anticonvulsant medicines**

Sodium valproate (Epilim)
Carbamazepine (Tegretol)

Complementary therapies and activities (herbal medicine, acupuncture, aromatherapy and massage, sensory therapy, music therapy, etc)

Public interest in complementary therapies is growing at a significant rate, easily outpacing the research conducted into their safety and effectiveness. People are often attracted to the 'natural' and safe image of these therapies, particularly in treating chronic medical conditions, for which conventional treatments are often less than completely effective. This sheet addresses some of the issues surrounding the use of complementary and alternative treatments and outlines the current evidence for their effectiveness.

What is complementary and alternative medicine?

The term complementary and alternative medicine (CAM) covers many therapies. There is no aAphasiarent connection between many of these therapies, which often have diverse origins, theories and appearances.

There is no precise definition of what exactly constitutes CAM. A good practical definition is 'interventions neither taught widely in medical schools, nor generally available in hospitals'. What may be 'complementary' medicine in one country may be 'conventional' in another. Vitamin supplementation may or may not be considered CAM depending on whether the dose is the recommended daily amount or not. Furthermore, many health care professionals now offer CAM treatments within the bounds of the NHS.

Common therapies that are covered in this leaflet include herbal medicine, aromatherapy and massage, music therapy, acupuncture, dietary supplements and melatonin and bright light therapy.

Complementary versus alternative medicine

CAM should only be used in addition to, not instead of, conventional medicine. If you decide to use CAM, it is important that you continue to see your doctor and keep him or her informed of the treatments you are undergoing and any medication you are taking.

Although most CAM therapies have a good safety profile, it is not true to say that they are 100 per cent safe just because they are 'natural'. There are serious safety concerns about some forms of complementary and alternative medicine. For example, herbal preparations may interact harmfully with conventional medicines. It is, therefore, very important for your doctor to know what you are taking.

Don't worry about telling your doctor what you are using. Awareness of complementary and alternative medicine is increasing amongst the medical profession and most doctors are sympathetic to its use.

Is CAM widely used?

Surveys conducted in the UK suggest that as many as one-third of the population have used some form of CAM at some point in their lives.

This interest helps to encourage research in the area. A report by the House of Lords called for more regulation and more research to investigate effectiveness and safety. This could lead to the provision of better services and sounder evidence to guide this use.

What is the potential for CAM to treat dementia?

Although the symptoms of dementia are numerous and change over time, most types of dementia have symptoms in common. It is useful to consider which symptoms are prominent in an individual when assessing which CAM intervention may be most suitable.

The aims of treatment range from improving memory with herbal preparations such as ginkgo biloba to providing relaxation with therapies such as massage and aromatherapy. This sheet focuses only on those therapies for which there is evidence of effectiveness.

Preventing the progression of dementia is currently the subject of trials of ginkgo biloba and of vitamin E. One review concludes from a number of studies that good nutrition, in the form of vitamins, minerals and other micronutrients, may prevent cognitive decline.

2. ROLES, RESPONSIBILITIES AND BOUNDARIES

2.1 Understand the roles, responsibilities and boundaries of individuals and how team work and support can lead to better support of individuals with dementia:

Individual

Role, Responsibilities and boundaries

The individual with dementia is central to the activities of all others and their role is essentially to manage their signs and symptoms with the aid of other, activities, prompts and medications to minimise the spread of the illness and maximise the individuals abilities to manage their daily lives.

Some of the first signs of Alzheimer's disease include lapses in memory and problems with finding the right words.

Other symptoms that may develop include:

Memory problems

For example, forgetting the way home from the shops, or being unable to remember names and places.

Mood changes

Particularly as the parts of the brain that control emotion become affected by disease. People with dementia may also feel sad, frightened or angry about what is happening to them.

Communication problems

For example, a decline in the ability to talk, read and write.

Family and friends of individual

Role, Responsibilities and boundaries

When a family and friend carer/s is caring for someone with dementia, it can be all too easy to ignore their own needs and to forget that they matter too. But it's much easier to cope if they look after their own health and wellbeing, and there is lots of support available.

If they care for someone with dementia they may sometimes feel guilty, even if others are reassuring them that they are doing the best they can. There are many issues that can cause family and friend carer/s to feel guilty. It is important to deal with these feelings.

People who care for someone with dementia often carry on without realising how tired or tense they have become. A break or holiday can help them relax and recharge their batteries.

Maintaining skills

Each person experiences dementia in their own individual way. However, they can help the person to continue to make the best use of their particular skills and abilities as their condition changes by using encouragement, a reassuring routine and common-sense measures.

Hobbies, pastimes and everyday activities

We all need to do things that keep us occupied and stimulated. If they can help the person they are caring for to find activities that they enjoy, from taking a walk to looking at photos, they can improve their quality of life. This will make them feel better, too.

Communicating

We all need to communicate with other people. Communicating our needs, wishes and feelings is vital – not only to improve our quality of life, but also to preserve our sense of identity. As a family and friend carer/s, it's important to encourage the person with dementia to communicate in whichever way works best for them.

Memory loss

They will also want to find ways to help the person they are caring for cope with memory problems, so that they can retain their confidence and independence for as long as possible

Holiday periods

Christmas and other holidays can be particularly stressful times both for family and friend carer/s and for people with dementia. Many family and friend carer/s choose to spend Christmas with the person they care for, whether they live with them year round or invite them to stay over the Christmas period. Others have a loved one living in a care home.

Independent advocate

Role, Responsibilities and boundaries

Taking responsibility, intended to help those who have to meet care management objectives to understand the local context and ensure co-ordinated policies and responses;

Working with multi-agency working, helping practitioners and their managers build links and work effectively across professional and organisational boundaries;

Involvement in assessment, with front-line staff who need to ensure that dementia is identified early, that presenting problems are handled appropriately and that referrals are made to relevant specialist services where necessary;

Involvement in care planning, to assist practitioners consider appropriate planning, provision and review from the individuals' perspective

Care worker

Role, Responsibilities and boundaries

“Confusion is not a barrier to participation”, is one of the key messages care workers can implement working with confused clients. They can put an emphasis on developing stimulating and meaningful activities for clients with dementia that can range from helping with routine, everyday tasks to specific activities either individually or in a group. Professionals acknowledge the expertise of the care worker in recognising the individuality of the client and adapting tasks accordingly according to the clients needs and abilities. Their overall aim within the care plans to increase the individuals awareness and skills, thus improving the quality of life for the client.

Care workers can use a common-sense approach. There is nothing we, as carers, do not already know. That is not to say that it states the obvious, but the care worker’s role is recognised as being challenging and stressful and with the introduction of small daily changes, the benefits can be appreciated by both client and care worker. The client can be involved in routine tasks normally carried out solely by the care worker, such as making the bed or a cup of tea.

The advantage for the client is that they feel useful and valued, and this raises confidence and self-esteem, especially if they receive praise for their achievements.

For the care worker based in a care home, there are many suggestions for activities that may make a client’s day more interesting and stimulating. Many of these activities may be done in the comfort of an armchair but still encourage participation. The ideas presented include music, exercise and arts and crafts. As reminiscence is found to be particularly effective with confused clients compiling a collage or scrapbook can help them retain their identity, and this can help the care worker to understand the client’s needs, preferences, values and beliefs and adapt the care given accordingly.

The activities devised, thought through and presented by the care worker should give them an ample portfolio of ideas to inform their practice and help them to recognise each client’s individuality. The care worker based in a busy or understaffed environment may have limited time to spend on the individual and group activities, but introducing even small changes may be enough to have a positive effect on both the client and care worker’s day.

Manager

Role, Responsibilities and boundaries

For individuals who are self-funding and without a Care Management assessment/Care Plan, the registered person carries out a needs assessment covering:

- personal care and physical well-being;
- diet and weight, including dietary preferences;
- sight, hearing and communication;
- oral health;
- foot care;
- mobility and dexterity;

- history of falls;
- continence;
- medication usage;
- mental state and cognition;
- social interests, hobbies, religious and cultural needs;
- personal safety and risk;
- carer and family involvement and other social contacts/relationship

The manager ensures that proper care planning is in place:

The individual plan of care generated from a comprehensive assessment is drawn up with each individual and provides the basis for the care to be delivered.

The individual's plan sets out in detail the action which needs to be taken by care staff to ensure that all aspects of the health, personal and social care needs of the individual (see Standard 3) are met.

The individual's plan meets relevant clinical guidelines produced by the relevant professional bodies concerned with the care of older people, and includes a risk assessment, with particular attention to prevention of falls.

The individual's plan is reviewed by care staff in the home at least once a month, updated to reflect changing needs and current objectives for health and personal care, and actioned.

Where the individual is on the Care Programme Approach or subject to requirements under the Mental Health Act 1983, the individual's plan takes this fully into account.

The plan is drawn up with the involvement of the individual, recorded in a style accessible to the individual; agreed and signed by the individual whenever capable and/or representative (if any).

The manager promotes and maintains individuals' health and ensures access to health care services to meet assessed needs.

The manager ensures that there is a policy and staff adhere to procedures, for the receipt, recording, storage, handling, administration and disposal of medicines, and individuals are able to take responsibility for their own medication if they wish, within a risk management framework.

The manager ensures that individuals have the opportunity to exercise their choice in relation to:

- leisure and social activities and cultural interests;
- food, meals and mealtimes;
- routines of daily living;
- personal and social relationships;
- religious observance;

The manager conducts the home so as to maximise individuals' capacity to exercise personal autonomy and choice.

The manager ensures that individuals receive a varied, appealing, wholesome and nutritious diet, which is suited to individual assessed and recorded requirements, and that meals are taken in a congenial setting and at flexible times.

The manager ensures that there is a simple, clear and accessible complaints procedure which includes the stages and timescales for the process, and that complaints are dealt with promptly and effectively.

The manager ensures that individuals are safeguarded from physical, financial or material, psychological or sexual abuse, neglect, discriminatory abuse or self-harm, inhuman or degrading treatment, through deliberate intent, negligence or ignorance, in accordance with written policies.

The manager demonstrates that an assessment of the premises and facilities has been made by suitably qualified persons, including a qualified occupational therapist, with specialist knowledge of the client groups catered for, and provides evidence that the recommended disability equipment has been secured or provided and environmental adaptations made to meet the needs of individuals.

Social worker

Role, Responsibilities and boundaries

Social workers often work with people experiencing crisis or people who are socially excluded. Their aim is to provide support to enable individuals to help themselves. They maintain professional relationships with individuals, acting as a guide, advocate or as a critical friend.

Social workers work in a variety of settings within a framework of relevant legislation and procedures, supporting individuals, families and groups within the community. Settings include individuals' homes, schools, hospitals and other public sector and voluntary organisations.

Qualified social work professionals are often supported by social work assistants. They also work closely with other health and social care staff.

Government legislation focusing on the integration of health and social work services means that social workers often work in multidisciplinary teams.

Tasks typically involve:

- undertaking and writing up assessments (often with medical staff), which meet specified standards and timescales;
- conducting interviews with individuals and their families to assess and review their situation;
- offering information and counselling support to individuals and their families;
- organising and managing packages of support to enable individuals to lead the fullest lives possible;

- recommending and sometimes making decisions about the best course of action for a particular individual;
- liaising with, and making referrals to, other agencies;
- participating in multidisciplinary teams and meetings, for example child protection, mental health;
- maintaining accurate records and preparing reports for legal action;
- giving evidence in court;
- participating in training, supervision and team meetings.

General Practitioner

Role, Responsibilities and boundaries

Dementia is sometimes a 'heartsink' diagnosis, but the GP can take positive steps to:

Exclude treatable causes such as hypothyroidism and B12 deficiency

- Take a full blood count for macrocytosis suggesting B12/folate deficiency (or high alcohol consumption)
- Thyroid function tests to exclude hypothyroidism
- Random blood sugar
- Serum calcium.

Exclude overlapping conditions - for example, depression, acute confusional state and psychotic symptoms, and concurrent physical illnesses

Minimise associated disabilities.

Refer to consultant colleagues if the diagnosis is in doubt or to access additional resources.

Act as the gateway to other resources.

Help carers to care. Provide information and advice, especially about the emotional and behavioural changes which have already or will take place as the illness progresses.

Direct people to voluntary organisations for additional help

Specialist personnel (psychiatrist, therapists, community psychiatric nurse)

Role, Responsibilities and boundaries of the Psychiatrist

A variety of skills are required for consultants in general adult psychiatry to fulfill their roles. The key skills are listed below.

Specialist psychiatric assessment; based on history, clinical examination and all relevant information, taking into account biological, psychological and social and personality factors, including diagnostic assessment and risk assessment.

Care plan and treatment plan formulation; within in-patient and community settings and in emergency and non-emergency situations.

This includes discharge planning and community care plans. These plans are drawn up in close collaboration with the multidisciplinary team and other agencies.

Management of complex cases; including multidimensional problems, comorbidity, chronicity, significant risk, serious functional and **role** impairment and treatment resistance.

Mental Health Act implementation; in accordance with the Code of Practice.

Develop and sustain ethical practice; employ ethical reasoning in psychiatric practice, recognise sources of disadvantage, discrimination and oppression in mental health services, promote and value individual differences and cultural, ethnic and religious diversity.

Pharmacological treatment; detailed knowledge and understanding of risks and benefits, wide experience of application of such treatments.

Recognition of the importance of a collaborative approach and of establishing a concordance with the individual.

Physical treatment; detailed understanding of risks and benefits of electroconvulsive therapy (ECT) and awareness of controversies.

Trained in the safe application of ECT. Awareness of other modes of physical treatment and seeks appropriate advice in regard to these.

Psychological treatment approaches; considerable training and experience in communication skills and psychiatric interviewing skills. Theoretical and supervised clinical experience of long-term and short-term therapies. Ability to take an overview and make referrals for appropriate assessments. Some consultants will be accredited in specific psychological therapies.

Physical medicine skills; possess and maintain the clinical skills appropriate to a general doctor and the ability to apply these in the context of their area of specialist practice.

Role, Responsibilities and boundaries of the Occupational Therapist

The Occupational Therapist is involved with the treatment of, people with dementia and complex needs which cannot be met in community residential and nursing home facilities.

Occupational Therapy interventions include:

- Assessment of skills and difficulties
- Obtaining personal history information
- Facilitation of activities which are meaningful to the individual and which use their skills and/or meet their needs
- Activities designed to maintain skills and promote well-being
- Support of client and carers
- Participation in discharge planning

Role, Responsibilities and boundaries of the Primary Care Nurse

Positive steps which the primary care nurse can take to support people with dementia and their families before and after diagnosis are:

- To report any signs of increased confusion or disorientation, changes in mood or behaviour in elderly people in their care to GP in charge of that person's medical care, and to maintain regular contact with them until a cause has been identified
- To observe closely, during surgery or home visits, for changes in mental as well as physical state. Assess using a recognised screening tool if necessary, such as CAPE or AMTS
- To assist in the exclusion of possible causes of increased confusion or increased behavioural disturbance in a person with dementia, such as infection or increased level of pain
- To maintain open channels of communication between all disciplines involved in the person's care
- To maintain close contact with carers as much as possible to gain a full picture of the person's health care needs and social circumstances
- To act as an information source for people with dementia and their carers on the progression of the illness and to assist them to make plans to deal with possible issues or difficulties which may occur as the illness progresses
- To act as a referral link between carers and care services including voluntary organisations (see help and support)
- To provide support and practical assistance to carers to help them cope with changes in their relative's functional capabilities or in their behaviour eg provision of continence aids or orientation aids
- To maintain close contact with people with dementia with no carer, looking out especially for signs of falls or confusion with medication.

2.2 *Understand the importance of communicating, reporting and recording effectively in the care environment:*

Distinguish between subjective and objective language, fact and opinion

When communicating, reporting and recording issues and evidence, it is important to understand the various ways that language can be construed or misconstrued

SUBJECTIVE LANGUAGE

Subjectivity in natural language refers to aspects of language used to express opinions, evaluations, and speculations. There are numerous natural language processing applications for which subjectivity analysis is relevant, including information extraction and text categorisation.

OBJECTIVE LANGUAGE

Objectivity Principle

Standing back decreases emotion and increases logic.

How it works

Have you ever been in a conversation where the other person said something like 'Let's look at this in another way. If you stand back and look at the problem objectively, it seems less important.'? Taking an objective stance has a calming effect, helping people to see things as they really are or from a different viewpoint.

Objectivity works in two ways. First, it helps to remove emotion, allowing people to think more rationally. The other use of objectivity is that it provides neutral territory that allows an equitable discussion to take place.

When we say 'be objective' we typically mean a number of things:

- Be unemotional, not getting agitated or distressed in any way.
- See things as they really are, not from a personally biased viewpoint.
- Be neutral, understanding both points of view.

An objective viewpoint is thus more realistic, fairer and far more likely to result in an agreeable resolution to human differences.

Subjectivity

Objectivity is the opposite of subjectivity. A person who has a subjective viewpoint sees things only from their own position, complete with all biases, internal mental models and so on.

The problem with a subjective point of view is that it is invariably different from everyone else's subjective viewpoint.

Removal of emotion

Think of a time when you were upset or angry. Relive the experience, seeing things through your own eyes again. Notice how you start to re-experience the emotions. Now imagine floating out of your body and looking down on the scene. Notice now how the emotions are less.

Standing back and literally seeing the situation from an external viewpoint has the very useful property of removing emotion. This is a very helpful tool for calming people down and assisting them to think more rationally.

Neutral territory

A big attraction of an objective viewpoint is that it is neutral territory on which both people can meet. In particular, it plays to our need for .

The neutrality of an objective view lets us both look from the same position, and if we cannot do this then at least we can get someone else to do it. This is the role played by mediators, judges and other intermediaries who stand in the third place.

The third position

In a conversation or relationship there are three positions. The *first position* is me, my subjective self. The *second position* is you, the other person, and your subjective viewpoint. In argument and discussion we tend to see only these two positions. But there is a third.

The *third position* is the objective viewpoint, as a neutral observer watching the discussion from outside. Anyone watching the conversation is, of course, in the third position. Either or both of the participants can also find this third position.

FACT

Generally, a fact is something that is the case, something that actually exists, or something that can be verified according to an established standard of evaluation. There is a range of other uses, depending on the context. People are interested in facts because of their relation to truth.

OPINION

An opinion is a person's ideas and thoughts towards something. It is an assessment, judgment or evaluation of something. An opinion is not a fact, because opinions are either not falsifiable, or the opinion has not been proven or verified. If it later *becomes* proven or verified, it is no longer an opinion, but a fact.

**Use clear, objective statements in care plans, reports, daily logs,
handover reports, etc**

Policy and Procedure

1. Introduction

- The communication process is important in several ways. It is: a therapeutic tool, a means of improving outcomes and engaging with the individual, their relatives and others in the planning, setting and meeting goals in care.
- a key component in ensuring continuity, consistency of care and communication between those providing care to individual service users and their families.
- an important part of the legal record of an individual's care

2. General

An initial general assessment and risk assessment will be completed at the point of admission by the admitting doctor and a qualified person (except in exceptional circumstances). A Risk Assessment will always be completed.

Good practice, such as attempting to access relevant notes prior to the assessment, should be followed.

Where circumstances do not allow a complete assessment and/or risk assessment to be fully completed immediately, e.g. if the individual is unable to discuss their situation, an initial plan of care will be made based on the limited information available. Gaps in information will be filled in as soon as is practicable.

The initial multi-disciplinary team plan will be recorded at the admission assessment by the admitting doctor. The plan should always be discussed with the individual as far as that is possible.

The initial multi-disciplinary team plan will be reviewed at the next multi-disciplinary team review, or at an earlier time where clinically indicated. The new plan, or any changes, will be clearly documented

3. Care plans, reports, daily logs, handover reports, etc,

The person in charge of the shift when a individual is admitted is responsible for the allocation of a qualified admitting person.

The admitting person is responsible for recording the Initial care plans and associated reports. This will be based on the initial multi-disciplinary team plan including the Risk Assessment. It will detail the interventions to be made by the team for the first 48 hours following admission. The care plans and associated reports should always be discussed with the individual, as far as that is possible. The individual should be encouraged to sign the care plans and associated reports and given a copy unless they do not wish this. In the event that a form is not signed or a copy not given, then the reasons why must be recorded in the multi-disciplinary record.

A detailed care plans and associated reports will be written by the allocated named person, or his/her deputy, within 48 hours of admission. Up to this point activity will be directly guided by the Initial care plans and associated reports, as devised at admission. The care plans and associated reports should always be discussed with the individual, as far as that is possible. The view's of the individual, or where appropriate, carer, should be recorded.

The individual should be encouraged to sign the care plans and associated reports and given a copy unless they do not wish this or in exceptional circumstances. In the event that a form is not signed or a copy not given, then the reasons why must be recorded in the multi-disciplinary record.

- **Care plans reports, daily logs, handover reports, etc,** will be written in a way that allows any member of staff to be able to provide the planned care and assess whether objectives have been met. All notes should be written in a manner comprehensible to individuals

Identified problem/need will summarise key problems/needs,.

Aims for caret relate to the identified problems/needs, and be:

- individualised
- specific
- measurable
- achievable
- realistic
- timed

- numbered

Individual/Carer's View will report views as to the contents of the care plans and associated reports

Action will describe those activities carried out by staff to try and meet the individual's defined problems/needs

For both the Initial and subsequent care plans and associated reports etc, entries evaluating whether objectives have been met will be made each shift (or at other time periods if this is explicitly stated) in the multi-disciplinary progress notes.

Aims should be referred to by number.

The care plans and associated reports will be reviewed in the light of any changes made in the multi-disciplinary team care plans and associated reports, or due to significant clinical changes. The named person or qualified person acting for the named person is responsible for making these changes. Any changes should always be discussed with the individual.

If any problem, action or aim is no longer applicable, then an entry will be made explaining this in the notes and that item will be lined through on the care plans and associated reports, initialled, dated and filed within the current set of notes.

The use of appropriate language and to avoid the use of negative statements and language when describing a person with dementia

2.3 Understand the roles and responsibilities of services and organisations in relation to dementia care:

- **Care homes with personal care or nursing care**

Policy and trends :

- major shift of responsibility from NHS (e.g. the old "long-stay" geriatric hospitals) to provision by Local Authorities, and the private/voluntary sector. Onus of cost now on Local Authorities (LAs) and on patients (fees), although NHS compensated the LAs for transfers.
- major shift from residential care towards care at home. Aim: that 30% of all older people receiving long term care should receive intensive home care. This policy is driven by 2 very different forces: a) relative cost (though the most intensive home care may in some circumstances be as costly as residential care), and b) people's preference for staying in their own homes. This preference in turn is partly driven by an increase in owner occupation.
- consequent shift away from low level home care packages (small numbers of hours in day-time) to intensive home care (more hours, and at unsocial times), and from domestic care (home helps) to personal care (care assistants, with SVQ training). It raises the dilemma of whether focussing resources on keeping highly dependent patients at home means leaving more people

with lower dependency needs unsupported and assigned unnecessarily to residential care.

- All this, together with the effects (both direct and indirect) of Free Personal Care, the Supporting People scheme (going beyond straight housing benefit to services allied to personal care), and a drive to reduce delayed discharges (bed blocking), led to an increase of 51.7% in social care spending on older people between 2000/01 and 2003/04. This growth rate (17.2% pa) was “unsustainable” relative to a 2.5% annual growth in the Scottish economy.
- Regulation of care: following the Care Standards Act 2000 the Care Commission (CSCI) strictly regulates all care services according to person-centred National Care Standards. The latter set down what patients/clients can expect to receive, and the Care Commission (not the LAs) then determines at initial registration how each individual project should be built, equipped and staffed to meet the Standards for its stated objectives. This is a major (and necessary) hurdle when starting up any new care project.

Options among types of provision

RANGE OF OPTIONS :

- **Care homes with personal care or nursing care**

Choice of Home

Each home must produce a statement of purpose and other information materials (client’s guide) setting out its aims and objectives, the range of facilities and services it offers to clients and the terms and conditions on which it does so in its contract of occupancy with clients.

In this way prospective clients can make a fully informed choice about whether or not the home is suitable and able to meet the individual’s particular needs. Copies of the most recent inspection reports should also be made available. The statement of purpose will enable inspectors to assess how far the home’s claims to be able to meet client’s requirements and expectations are being fulfilled. While it would be unreasonable and unnecessary to expect every home to offer the same range of facilities and lifestyle, older people do want a range of choice when they decide to move into a care home. By requiring proprietors to ‘set out their stall’, the problem of leaving choice to chance is overcome. There can be no room for doubt either on the part of the prospective client, the inspector or the proprietor. In this way diversity and range of choice across the care home sector can be maintained.

For example:

- if the home says it provides for the needs of people with dementia, it will have to make clear in the prospectus how this is done – for example, small group living and structured activities, with décor and signage helpful to people with dementia;
- if a home says it can cater for the needs of Muslim elders whose first language is not English, it must show that it can do so by, amongst other things, showing that it can prepare and provide halal food, offer links with the local mosque and provide appropriate washing facilities and demonstrate that it employs staff who speak appropriate languages;

- a home will make clear in its information materials whether it aims to offer clients a family-like environment at one end of the spectrum, or whether it offers hotel-style accommodation where clients live more independently from one another at the other.

The key must be the choice and the opportunity to exercise choice. This can only be achieved if full information is provided.

In recognition of the needs of people with dementia, many homes have created Memory Lane Communities to set the highest standards in specialist care for those with dementia and support for their families.

Memory Lane Communities are based on the following values:

- creating a home-like feel
- providing specialised care
- promoting self-esteem
- encouraging independence
- supporting life-skills and individuality
- enabling freedom of choice
- providing a comfortable and safe environment where someone can live with their dementia and not just exist

No two people are the same

Recognising, supporting and celebrating each person's individuality is fundamental to the Memory Lane philosophy.

Specialist Training

Each member of the care team recognises, supports and celebrates each person's individuality. They receive training through our bespoke dementia care programmes and have regular refresher courses thereafter.

Regular meetings and social gatherings are organised for families and friends and form an essential support network.

Home like feel

Many of our Memory Lane communities use various features to ensure the best environment for residents:

- Memory boxes
- Adapted crockery and tableware
- Enclosed sensory gardens and low risk walkways
- Rummage boxes and other features to engage residents
- Lifeskills areas including specially adapted kitchens

'Activity in Mind' Programme

Dementia Homes have skilled activity co-ordinators work alongside care teams to create lively and involving programmes for everyone's enjoyment including:

- Gardening
- Baking
- Outings
- Pet care
- Gentle exercise
- Life skills

Other specialist activities such as reminiscence therapy, music therapy and various complimentary therapies may also be provided.

Standard care home*

Provided by: Social Services, or private /voluntary sector. May be developed to form part of a complex managed jointly with the health service.

Access: By assessment, if provision is provided by social services, or the individual is subsidised by a Direct Payment. He/she is assigned a key worker and a personal plan.

Staff: Manager has to be a registered social service worker who has undergone a prescribed post registration training. Support workers also have to be registered with the SSSC and to have or to be working towards a qualification (at least SVQ level 2).

Level of provision: New care homes must meet standards including single rooms with ensuite facilities and space to install hoist tracking and other equipment and technology. Mainly provision of long-term residential care, but also often including some beds for convalescence and respite.

Critical limits: Brochures for residents in care homes in the Western Isles make clear that they would only have to move on "in the event that (their) medical and nursing needs were so high that (they) would be at risk without 24-hour medical or nursing care."

Hospital

Dementia care

Provided by: NHS,

Access: Assessments.

Staff: There is an obvious overlap with psycho-geriatric medicine, and staff, including support care workers, need relevant qualifications in dementia care. But the major burden of the 24-hour care required by this condition is born, at least until the late stages, by informal carers (ie. relatives)

Level of provision : There are dementia units attached to some care homes and nursing homes, and also in some NHS community and psychiatric hospitals. I think these units mostly offer 24-hour respite and/or short-term medical care, rather than long term residential care. Specialist

residential care is also provided in the private and voluntary sector by eg the Alzheimer's Society. Otherwise the focus seems to be on home care teams, and PAMS, aiming to offer support to informal carers at home.

Critical limits : lack or disability of an informal carer. Need for 24-hour nursing and medical care.

Palliative care/Hospices

Provided by : a) *Palliative care* : is provided jointly by social services, NHS and the private/voluntary sector.

b) *Hospices* are provided in the voluntary sector, and supported mainly by charitable funds. Additional NHS funding is widely variable but averages at 32%.. Also, some NHS hospitals have specialist palliative care units.

Access: Assessment by the most appropriate member of the multi-professional team.

Hospice provision is free to patients.

Staff: a) *Palliative care*: General palliative care is given by home care teams and care homes (both with or without nursing), supported by GPs, community nurses, MacMillan nurses, and PAMS etc . Staff should have basic training in the "palliative care approach" (working towards SVQ3), and nurses should have completed modules on palliative care during training for their degree. Specialist care and support is given by NHS palliative care teams, and the voluntary sector eg Marie Curie Foundation.

b) *Hospices*: "Hospice care is provided by a multi-professional team who have undergone specialist palliative care training. Hospices which have a full team of appropriately qualified doctors, nurses and other healthcare professionals are recognised as providing specialist palliative care for those patients and families with complex needs" (Ref: National Care Standards). Small hospices must have support from an specialist NHS consultant. Voluntary workers also play an important role

Level of provision :

a) *Palliative care*: As implied by level of staffing , see above.

b) *Hospices* Ditto. But essentially *short term* residential care, with a mix in some cases of day care and home care. There may be a series of respites up to and including the final days of life. Average length of stay is 13 days.

Critical limits: self explanatory.

- **Domiciliary, respite and day services**

Intermediate/respite care

Provided by: Joint Partnerships, care services, NHS etcetc

Access: Shared assessments (presumably)

Staff: Depends on which aspect of provision:

a) tackling delayed discharge from hospital : supported discharge, rapid response or mobile support teams (integrated care service + health service personnel); step up/down beds both in care homes and in community hospitals, etc

b) respite for informal carers : some care homes and dementia units have respite beds (Otherwise, mainly day centre respite).

Level of provision: Essentially short term:

a) on discharge: short term intensive home care or short term residential care, on or pending discharge from hospital, further assessment and some degree of rehab pending or shortly after discharge.

b) convalescence/respite : short term residential care in care home or dementia unit, or daycare in a day centre.

Critical limits : a) depends on patient's clinical condition ... research has found it successful for stroke, some lung conditions, and hip and knee operations.

b) dementia care needs appropriate training, and is often short term only.

- **Sheltered accommodation and supported housing**

Care and support enables people with dementia to live independently and assists them to secure and maintain their tenancies. Services can be provided either on-site in a particular supported housing scheme or as an outreach / floating support service to people wherever they live.

Care and support includes advice, guidance and encouragement to, or assistance with:

- secure and set up a home;
- develop/maintain home management skills such as cooking and cleaning;
- access benefits, health and community care services;
- establish and maintain social support;
- personal care;
- medication;

Care and support can be provided from either a few hours per week to 24 hour on-site support, depending on the type of service and the needs of the people using it.

These services can be provided either by the landlord, or by a support provider agency working together with the landlord, and is usually funded by charges to the tenant and/or funding from the County Council.

Traditional sheltered housing.

Provided by: LA housing department, Housing Associations, private/voluntary sector. In some cases (eg in Western Isles) the warden's post is funded by social services. But there the LA is now planning conversion to 'very sheltered' housing.

Access: assessment principally by Housing Department and Housing Association, support as for housing benefit (now 'Supporting People'). With move towards Shared Assessment other agencies are involved where need for them is perceived. .

Staff: Traditionally a single resident warden, often without formal qualifications. Now, due to changing nature of need for this housing, such a person often requires more training, and also, due to EU working time directive etc, cannot provide 24 hour cover. In some instances there is a move towards non-resident duty managers, with alarm system plus NHS 24 out of hours.

Levels of provision: The house or flat, designed and equipped for disabled use etc, and meeting appropriate standards (older schemes apparently lack many features now recommended). Care, if needed, by home care teams, as for Home Care (above), but with increasing move towards joint working between housing and care providers.

Critical limits: Demand for such housing is now falling, especially with the rise of owner occupancy and the increase in levels of home care offered. Need for ordinary sheltered housing now arises mainly for people in privately rented or other accommodation that cannot be converted to meet their needs. Also it may arise when people live in isolated situations which cannot easily be served by the home care services. *End limit* of provision is the same as for Home Care.

4. Very sheltered /Extra care housing

Provided by:

LA Social services and housing departments jointly (there being now considerable overlap between housing support and personal care), together in partnership with community health services.

Housing Associations and private/voluntary sector with support from Communities United Kingdom (successor of "Scottish Homes").

NB: "Very sheltered" residents have tenancies with the housing providers, whereas "extra care" residents have "**occupancy agreements**" with the joint providers of housing and care. **Could this be an important distinction for us (in Colonsay)?**

Access : Shared assessment, if provision itself and/or individual fees are supported from the public purse.

Staff: for larger schemes one dedicated team, often based on-site, which provides better co-ordination than piecemeal home care services. Sometimes also complex electronic monitoring and telecare linked to a small dedicated call centre, eg West Lothian "Careline". Efficient estate management is also important.

Level of provision: main difference between this and traditional sheltered housing is the provision of additional support services including 24-hour cover (or 24-hour telecare), personal care, and meals. The average level of care has been variously estimated at around 10 hours a week, but particularly intensive support can rise to 20 hours. However, above average intensive care can prove as or more expensive than residential care.

Critical Limits: *Very sheltered/extra-care housing has been considered a realistic alternative to residential care homes, but some researchers suggest that it may not be appropriate for the most highly dependent elderly people .* Intuitively it seems unlikely that, in the absence of an informal carer, an elderly person who is demented or who requires constant 24-hour attendance could be cared for indefinitely in this way. And as always a limit is set by the need for a level of medical

of keeping a unit for temporary occupancy (convalescence and respite).

Voluntary and charitable organisations (e.g. Alzheimer's Society, Mental Health Foundation, Age Concern, Anchor Trust, MIND)

Mental Health Foundation

Founded in 1949, the Mental Health Foundation is a leading UK charity that provides information, carries out research, campaigns and works to improve services for anyone affected by mental health problems, whatever their age and wherever they live.

We aim to help people survive, recover from and prevent mental health problems. They do this by:

- learning what makes and keeps people mentally well
- communicating our findings to a wide range of people
- turning our research into practical solutions that make a difference to people's lives

Anchor Trust

Anchor Trust is a not-for-profit organisation dedicated to helping older people live safely, securely and independently-with a choice of services to suit all needs.

Getting older means different things for different people. You may want help to manage your home, or a place that is more affordable. You might be looking for more security or companionship.

MIND

Mind is a leading mental health charity in England and Wales. They work to create a better life for everyone with experience of mental distress by:

- advancing the views, needs and ambitions of people with mental health problems
- challenging discrimination and promoting inclusion
- influencing policy through campaigning and education
- inspiring the development of quality services which reflect expressed need and diversity
- achieving equal rights through campaigning and education.

In all their work they promote their values: informed, determined, diversity, integrity and partnership.

3. DEFINING DEMENTIA

3.1 *Understand the definition of dementia and the difference between dementia, depression and confusional states. Understand the importance of diagnosis and the implications for support and care of the individual.*

Dementia is a term used to describe various different brain disorders that have in common a loss of brain function that is usually progressive and eventually severe. There are over 100 different types of dementia. The most common are Alzheimer's disease, vascular dementia and dementia with Lewy bodies.

Symptoms of dementia include loss of memory, confusion and problems with speech and understanding.

Source: Alzheimers Society

Dementia

- Onset- insidious
- Duration- months/years
- Course- stable and progressive vascular dementia: usually stepwise
- Alertness- usually normal
- Orientation- may be normal: usually impaired for time/place
- Memory- impaired recent, and sometimes, remote memory
- Thoughts- slow
- ed reduced interests perseverate
- Perception- ? normal hallucinations in 30-40% (often visual)
- Emotions - shallow, apathetic, labile ? irritable, careless irritable,
- Sleep- often disturbed nocturnal wandering common nocturnal confusion

Depression

- Onset- gradual
- Duration- hours/days/??weeks
- Course- improves as day goes on
- Alertness- normal
- Orientation- usually normal
- Memory- recent memory may be impaired remote memory intact
- Thoughts- usually slowed preoccupied by sad and hopeless thoughts
- Perception- mood congruent auditory hallucinations in 20%
- Emotions - flat, unresponsive or sad and fearful may be imitable
- Sleep- early morning wakening
- Other features- ? past history of mood disorder

Confusional state

- Onset- acute
- Duration- weeks/months
- Course- worse at night fluctuates: lucid periods usually worse in mornings
- Alertness- fluctuates
- Orientation- always impaired: time/place/person
Memory- recent memory impaired
- Thoughts- often paranoid and grandiose ? bizarre ideas and topics
- Perception- visual and auditory hallucinations common
- Emotions – irritable, aggressive, fearful
- Sleep- nocturnal confusion
- Other features- other physical disease may not be obvious

3.2 *Understand the most common types and causes of dementia, for example:*

Alzheimer's Disease

Alzheimer's disease is the most common form of dementia, affecting around 450,000 people in the UK. This information sheet outlines the symptoms and causes of Alzheimer's disease, and describes what treatments are currently available.

Alzheimer's disease, first described by the German neurologist Alois Alzheimer, is a physical disease affecting the brain. During the course of the disease 'plaques' and 'tangles' develop in the structure of the brain, leading to the death of brain cells.

We also know that people with Alzheimer's have a shortage of some important chemicals in their brain. These chemicals are involved with the transmission of messages within the brain.

Alzheimer's is a progressive disease, which means that gradually, over time, more parts of the brain are damaged. As this happens, the symptoms become more severe.

Symptoms

People in the early stages of Alzheimer's disease may experience lapses of memory and have problems finding the right words. As the disease progresses they may:

- Become confused, and frequently forget the names of people, places, appointments and recent events.
- Experience mood swings. They may feel sad or angry. They may feel scared and frustrated by their increasing memory loss.
- Become more withdrawn due either to a loss of confidence or to communication problems.

As the disease progresses, people with Alzheimer's will need more support from those who care for them. Eventually they will need help with all their daily activities.

While there are some common symptoms of Alzheimer's disease, it is important to remember that everyone is unique. No two cases of Alzheimer's are likely to be the same. People always experience illness in their own individual way.

What causes Alzheimer's disease?

So far, no one single factor has been identified as a cause for Alzheimer's disease. It is likely that a combination of factors, including age, genetic inheritance, environmental factors, diet and overall general health, are responsible.

Age

Age is the greatest risk factor for dementia. Dementia affects one in 14 people over 65 and one in 6 over the age of 80. However, Alzheimer's is not restricted to elderly people: there are over 15,000 people under the age of 65 with dementia in the UK.

Genetic inheritance

Many people fear that they may inherit Alzheimer's disease. Scientists are currently investigating the genetic background to Alzheimer's.

We do know that there are a few families where there is a very clear inheritance of the disease from one generation to the next. This is often in families where the disease appears relatively early in life.

In the vast majority of cases, however, the effect of inheritance seems to be small. If a parent or other relative has Alzheimer's disease, your own chances of developing the disease are only a little higher than if there were no cases of Alzheimer's in the immediate family.

Environmental factors

The environmental factors that may contribute to the onset of Alzheimer's disease have yet to be identified. A few years ago, there were concerns that exposure to aluminium might cause Alzheimer's disease. However, these fears have largely been discounted.

Other factors

Because of the difference in their chromosomal make-up, people with Down's syndrome who live into their 50s and 60s may develop Alzheimer's disease.

People who have had severe head or whiplash injuries appear to be at increased risk of developing dementia. Boxers who receive continual blows to the head are also at risk.

Research has also shown that people who smoke and those who have high blood pressure or high cholesterol levels increase their risk of developing Alzheimer's.

Vascular dementia

Vascular dementia is the second most common form of dementia after Alzheimer's disease. This information sheet will help you to understand vascular dementia by explaining the causes, symptoms and treatments available.

What is vascular dementia?

The term 'dementia' is used to describe the symptoms that occur when the brain is damaged by specific diseases. These diseases include Alzheimer's disease and vascular dementia. Someone with dementia may have difficulties remembering, solving problems or concentrating. Vascular dementia is a type of dementia caused by problems in the supply of blood in the brain.

How does vascular dementia develop

To be healthy and function properly, the brain cells need a good supply of blood. The blood is delivered through a network of blood vessels called the vascular system. If the vascular system within the brain becomes damaged and blood cannot reach the brain cells they will eventually die. This can lead to the onset of vascular dementia.

What causes vascular dementia?

There are a number of conditions that can cause or increase damage to the vascular system. These include high blood pressure, heart problems, high cholesterol and diabetes. It is therefore important that these conditions are identified and treated at the earliest opportunity.

What are the symptoms of vascular dementia?

Vascular dementia affects different people in different ways and the speed of the progression varies from person to person. Some symptoms may be similar to those of other types of dementia. However, people with vascular dementia may particularly experience:

- Problems concentrating and communicating
- Depression accompanying the dementia
- Symptoms of stroke, such as physical weakness or paralysis
- Memory problems (although this may not be the first symptom)
- A 'stepped' progression, with symptoms remaining at a constant level and then suddenly deteriorating
- Epileptic seizures
- Periods of acute confusion.

Other symptoms may include:

- Hallucinations (seeing things that do not exist)
- Delusions (believing things that are not true)
- 'Wandering' and getting lost
- Physical or verbal aggression
- Restlessness
- Incontinence.

Are there different types of vascular dementia?

There are two main types of vascular dementia: one caused by stroke and one caused by small vessel disease. For many people, however, the causes of dementia may be mixed.

Stroke related dementia

A stroke is the term used to describe permanent brain damage caused by an interruption in the supply of blood to specific parts of the brain. The symptoms that a person experiences as a result of a stroke depend on which area of the brain has been damaged. If the damaged area is responsible for movement of a limb, paralysis might occur. If it is responsible for speech, the person might have problems communicating. Equally, damage to particular areas in the brain can cause the symptoms of dementia.

When vascular dementia is caused by a single stroke, it is called single-infarct dementia. Vascular dementia can also be caused by a series of small strokes. These can be so tiny that the person might not notice any symptoms, or the symptoms may be only temporary. This is called multi-

infarct dementia.

Always consult a doctor if you experience any sudden symptoms such as slurred speech, weakness on one side of the body or blurred vision, even if they are only temporary. These episodes may be caused by temporary interruptions in the blood supply within the brain, known as transient ischaemic attacks. They can lead to permanent damage if left untreated.

Small vessel disease related dementia

This type of dementia, also known as sub-cortical vascular dementia or, in a severe form, Binswanger's disease, is caused by damage to tiny blood vessels that lie deep in the brain. The symptoms develop more gradually and are often accompanied by walking problems.

Vascular dementia and Alzheimer's disease (mixed dementia)

A diagnosis of mixed dementia means that Alzheimer's disease, as well as stroke or small vessel disease, may have caused damage to the brain.

Are some people more likely to get vascular dementia?

Certain factors can increase a person's risk of developing dementia. These include:

- A medical history of stroke, high blood pressure, high cholesterol, diabetes (particularly type II), heart problems, or sleep apnea (where breathing stops during sleep)
 - A lack of physical activity, drinking more than recommended levels of alcohol, smoking, eating a fatty diet, or leaving conditions such as high blood pressure or diabetes untreated
 - A family history of stroke or vascular dementia
 - Gender – men are slightly more likely to develop vascular dementia
 - An Indian, Bangladeshi, Pakistani, Sri Lankan or African Caribbean ethnic background.
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- **Pick's Disease (Fronto-Temporal)**

This sheet provides some general information about one of the rarer forms of dementia, fronto-temporal dementia. It outlines who is likely to be affected and what symptoms they may experience.

What is fronto-temporal lobe 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.

All are caused by damage to the frontal lobe and/or the temporal parts of the brain. These areas are responsible for our behaviour, emotional responses and language skills.

Who is affected?

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

What are the symptoms?

Damage to the frontal and temporal lobe areas of the brain causes a variety of different symptoms. Each person will experience the condition in his or her own individual way.

Personality and behaviour change.

Typically, during the initial stages of fronto-temporal dementia, memory is still intact, but the personality and behaviour of the person changes.

People with fronto-temporal dementia may:

- Lack insight and lose the ability to empathise with others – they may appear selfish and unfeeling
- Become extrovert when they were previously introverted, or withdrawn when they were previously outgoing
- Behave inappropriately – for example, making tactless comments, joking at the ‘wrong’ moments, or being rude
- Lose inhibitions – for example, exhibiting sexual behaviour in public
- Become aggressive
- Be easily distracted
- Develop routines – for example, compulsive rituals.

It is important to recognise that these symptoms have a physical cause, and cannot usually be controlled or contained by the person.

Language problems

The person with fronto-temporal dementia may experience language problems, including:

- Difficulties finding the right words
- A lack of spontaneous conversation
- Circumlocution, or using many words with little content
- A reduction in or lack of speech.

Changes in eating habits

The person may overeat and/or develop a liking for sweet foods.

Later stages

The rate of progression of fronto-temporal dementia varies enormously, ranging from less than two years to over ten years.

In the later stages, the damage to the brain is usually more generalised, and symptoms usually appear to be similar to those of Alzheimer’s. People affected may no longer recognise friends and family and may need nursing care.

How is this form of dementia diagnosed?

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 taking a detailed history of their symptoms. They may also ask for information from family, friends and carers, to gain a wider picture of the person’s behaviour.

CT (computerised axial tomography) and MRI (magnetic resonance imaging) scans may also be used to determine the extent of damage to the brain.

A firm diagnosis may only be possible after death, when changes in the structure **of the brain can be directly observed at post mortem.**

Is it a genetic disease?

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 so far unknown.

Is treatment possible?

As yet, there is no cure for fronto-temporal dementia and the progression of the condition cannot be slowed.

Drugs that are designed for the treatment of Alzheimer's disease, such as Aricept, Exelon and Reminyl, may make symptoms worse and increase aggression.

However, much can be done to ease symptoms. Knowing more about the disease and understanding why the person is behaving in certain ways can help the person to cope 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.

Speech therapists may be helpful for language problems.

Dementia with Lewy bodies

Dementia with Lewy bodies (DLB) is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's diseases. It may account for 10 to 15 per cent of all cases of dementia in older people. This information sheet outlines the symptoms of DLB, how it is diagnosed and how it is treated.

What are Lewy bodies?

Lewy bodies (named after the doctor who first identified them in 1912) are tiny, spherical protein deposits found in nerve cells. Their presence in the brain disrupts the brain's normal functioning, interrupting the action of important chemical messengers, including acetylcholine and dopamine.

Lewy bodies are also found in the brains of people with Parkinson's disease (PD), a progressive neurological disease that affects movement. Some people who are initially diagnosed with PD later go on to develop a dementia that closely resembles DLB. Researchers have yet to understand fully why Lewy bodies occur in the brain.

Dementia with Lewy bodies (DLB) is sometimes referred to by other names, including Lewy body dementia, Lewy body variant of Alzheimer's disease, diffuse Lewy body disease, cortical Lewy body disease and senile dementia of Lewy body type. All these terms refer to the same disorder.

Symptoms

DLB is a progressive disease. This means that over time the symptoms will become worse. In general, DLB progresses at about the same rate as Alzheimer's disease, typically over several years.

People with DLB will typically have some of the symptoms of Alzheimer's and Parkinson's diseases.

- People who have DLB often experience the memory loss, spatial disorientation and communication difficulties associated with Alzheimer's disease.
- They may also develop the symptoms of Parkinson's disease, including slowness, muscle stiffness, trembling of the limbs, a tendency to shuffle when walking, loss of facial expression and changes in the strength and tone of the voice.

Symptoms characteristic of DLB

There are also symptoms that are characteristic of DLB. People with DLB may:

- Find that their abilities fluctuate daily, even hourly
- Faint, fall, or have 'funny turns'
- Experience detailed and convincing visual hallucinations, often of people or animals
- Fall asleep very easily by day and have restless, disturbed nights with confusion, nightmares and hallucinations.

Who gets DLB?

DLB appears to affect both men and women equally. As with all forms of dementia, DLB is more prevalent in people over the age of 65. However, in certain rare cases people under 65 may develop DLB.

Diagnosing DLB

DLB can be difficult to diagnose. People are often diagnosed as having Alzheimer's disease or vascular dementia. The diagnosis is made on the basis of the symptoms, particularly visual hallucinations, fluctuation and the presence of the stiffness and trembling of Parkinson's.

While it is always important to get an accurate diagnosis of dementia, a proper diagnosis is particularly important in cases of suspected DLB since people with DLB have been shown to react badly to certain forms of medication (see below).

DLB and neuroleptics

Neuroleptics are strong tranquillisers usually given to people with severe mental health problems. In the past they have been prescribed to people with dementia.

It is always preferable to find ways of dealing with a person's distress and disturbance that do not involve medication. Under no circumstances should neuroleptics be prescribed as a substitute for good quality care.

For people with DLB, neuroleptics may be particularly dangerous. This class of drugs induce Parkinson-like side-effects, including rigidity, immobility, and an inability to perform tasks or to communicate. Studies have shown that when prescribed for people with DLB they may cause sudden death.

If a person with DLB must be prescribed a neuroleptic it should be done with the utmost care, under constant supervision, and it should be monitored regularly.

The following list includes the names of many of the major neuroleptics available. New drugs are appearing from time to time. The generic name is given first, followed by some of the common proprietary (drug company) names for that particular compound.

- Chlorpromazine (Largactil)
- Clopenthixol (Clopixol)
- Haloperidol (Haldol, Serenace)
- Olanzapine (Zyprexa)
- Promazine
- Quetiapine (Seroquel)
- Risperidone (Risperdal)
- Sulpiride (Dolmatil, Sulparex, Sulpitil)
- Trifluoperazine (Stelazine)

Treatment

At the moment there is no cure for DLB. Recent research suggests that the cholinesterase inhibitor drugs used to treat Alzheimer's disease may also be useful in treating DLB, although they are not yet licensed for this use.

Symptoms such as hallucinations may respond to being challenged, but it can sometimes be unhelpful to try to convince the person that there is nothing there. It is sometimes better to try to provide reassurance and alternative distractions.

People who are experiencing rigidity and stiffness owing to parkinsonism may benefit from anti-Parkinson's disease drugs although these can make hallucinations and confusion worse. Physiotherapy and mobility aids may also help.

When caring for someone with DLB, it is important to be as flexible as possible, bearing in mind that the symptoms of DLB will fluctuate.

Creutzfeldt Jakob Disease (CJD)

Prions are infectious agents that attack the central nervous system and then invade the brain, causing dementia. The best-known prion disease is Creutzfeldt-Jakob disease, or CJD. This information sheet provides an overview of the symptoms and different types of CJD.

Prion disease

Prions are abnormal forms of protein that are extremely hardy and cannot be eradicated by normal sterilisation procedures. Their presence in the brain results in spongiform encephalopathy, so-called because areas of the brain where cells have died take on a sponge-like appearance when viewed under the microscope.

There are a number of prion diseases that affect humans. These include Creutzfeldt-Jakob disease, as well as two extremely rare inherited diseases, Gerstmann-Straussler-Scheinker disease (GSS) and fatal familial insomnia (FFI).

Creutzfeldt-Jakob disease (CJD)

Creutzfeldt-Jakob disease was first reported by two German doctors (Creutzfeldt and Jakob) in 1920.

What are the symptoms of CJD?

- Early symptoms include minor lapses of memory, mood changes and loss of interest.
- Within weeks, an infected person may complain of clumsiness and feeling muddled, become unsteady in walking and exhibit slow or slurred speech.
- The disease progresses to jerky movements, shakiness, stiffness of limbs, incontinence and the loss of the ability to move or speak. It is likely that the person is no longer aware of their surroundings or disabilities at this stage. Eventually they will need full nursing care.
- People affected by CJD usually die within six months of early symptoms, often from pneumonia. In a minority of patients, the disease may take two years to run its course. Very rarely, the disease can last for many years.

There is no evidence that someone with CJD is in pain, provided they are well nursed and comfortable. Drugs can alleviate symptoms such as shakiness.

Types of CJD

There are four forms of CJD: sporadic, familial, iatrogenic and variant.

Sporadic CJD

The cause of sporadic CJD (also called classical CJD) remains unknown, but the disease mainly affects those over the age of 50. Sporadic CJD is marked by rapid onset of dementia. The course of the disease is usually measured in months.

Familial CJD

This is an inherited form of CJD. Those affected appear to be genetically predisposed to produce the abnormal form of prion proteins. People usually develop familial CJD at an earlier age than the sporadic form and the course of the illness is usually longer.

Iatrogenic CJD

This form of CJD arises from contamination with tissue from an infected person, usually as a result of a medical procedure such as corneal transplants, grafts or the use of growth hormone. A few people have been infected through the use of neurosurgical instruments.

Today, no transplants are taken from infected people, growth hormone is made artificially and surgical instruments used on people with CJD are never used on other patients.

Variant CJD and the link with BSE

In 1996, a new type of CJD, variant CJD, was reported. Variant CJD appears to affect younger people than the other forms of the disease. The average age of death is 29 years. (However, one case of a 74-year-old man with variant CJD has been reported.)

There is now evidence that variant CJD is caused by bovine spongiform encephalopathy (BSE), a form of prion disease affecting cattle. Prion diseases have been found in several other animal

species, including sheep (scrapie), deer, cats, mink and zoo animals. The consumption of infected beef products appears to have led to the development of BSE in humans.

Since 1989, action has been taken to remove those parts of cattle where the greatest concentrations of infective agent are found, including brains and spinal cords, from the human food chain.

There is some evidence that the number of deaths from variant CJD has reached a peak and is now in decline. However, there is currently no firm scientific basis for predicting future numbers of cases of variant CJD and there could be more than one peak to the epidemic. One problem is that the length of the incubation period for the disease remains uncertain. Prions may exist in the body for many years before symptoms begin.

Huntington's Disease

Huntington's disease is an inherited disorder that affects the brain. It results in a progressive loss of the control of movement, changes in personality and mental ability.

Around 4800 people in the UK are living with Huntington's disease. It is also called Huntington's chorea. Chorea means jerky, involuntary movements - a main symptom of the condition.

How it develops

The symptoms usually start between the ages of 30 and 50. Symptoms can then develop over a period of up to 20 years, but the illness invariably causes premature death. Although there is currently no cure for this disease, there are ways to manage symptoms effectively.

Causes

Huntington's disease is caused by a faulty gene and runs in families.

Most genes in the body are present in two copies, one from the mother and one from the father. The gene (which is called "huntingtin") that causes Huntington's disease is dominant. This means that if a person inherits one copy of this gene from either parent, they will go on to develop the disease at some point in their life.

A person who has one parent with Huntington's disease has a 50% chance of inheriting the faulty gene. This risk is 50% for each child and is not altered by gender or whether brothers and sisters are affected. Only people who have the faulty gene are capable of passing it on to their own children.

Very occasionally some people can develop the condition even though there is no family history of it. This is usually because previous generations were not diagnosed as a result of early death from other causes, or loss of contact through adoption.

Huntington's disease causes damage to brain cells in the areas of the brain involved in the control of movement, planning and motivation.

Symptoms

People usually have symptoms for up to 10 years before they find out they have Huntington's disease. Most people are diagnosed between the ages of 30 and 50, although this can happen much earlier or later. Symptoms are often overlooked, as they are mild and commonly experienced by well people. They include:

- mild tremor
- clumsiness
- lack of concentration
- difficulty remembering things
- mood changes, including depression
- sometimes, aggressive antisocial behaviour

As the disease continues, the symptoms become progressively worse, and lead to incapacitation.

Symptoms fall into three categories:

Physical symptoms include chorea (involuntary movements of the limbs, face and body). Chorea may lead to difficulty walking, speaking and swallowing. Choking is a particular hazard, due to reduced ability to control the muscles of the tongue, neck and diaphragm. People often lose weight because they have difficulty eating and burn more calories due to the continuous movement.

Emotional symptoms include depression, not only because of the burden of having a progressive disorder, but also as a direct result of the damage to certain brain cells. People often become frustrated at being unable to work or carry out previously simple tasks. They also seem to behave stubbornly, probably due to a reduced ability to react flexibly and to understand the needs and emotions of others. People with Huntington's may also become more irritable and antisocial than usual, or make inappropriate sexual advances.

Cognitive symptoms include a loss of drive and initiative. People with Huntington's may appear to be lazy or uninterested in life, spending days doing little or neglecting personal hygiene. They may also lose the ability to organise themselves, as planning skills and ability to carry out more than one task at once deteriorate. In later stages, people may get memory loss and be less able to understand speech.

The behavioural changes that occur in people with Huntington's disease are often the most distressing for them, their family and their carers. People with previously full and active lives gradually lose their independence and mobility. At the same time, their personality may become gradually more self-centred and apathetic, straining personal relationships.

Juvenile Huntington's disease

A juvenile form of Huntington's disease also exists. Symptoms start before the age of 21 and the condition is usually inherited from the father. Symptoms are similar to those of adult Huntington's, but develop more rapidly and include muscular rigidity and fits.

Treatment and support

Unfortunately, there is currently no cure for Huntington's disease. However, drug treatments are available to help people manage some of their symptoms. There are drugs available to treat abnormal movements. Antidepressants such as fluoxetine (eg Prozac) can be helpful with depression, and mood stabilisers and antipsychotic drugs can help with some of the emotional disturbances.

The general health needs of a person with Huntington's are also important. Dieticians can advise on adequate calorie and nutrient intake. Social and psychiatric support can help with family relationships and antisocial behaviour.

Scientists have investigated a number of drug treatments to slow the progress of the disease, but these have not yet shown any major benefit.

Some clinical studies have involved using stem cells (the most basic form of cells from which others develop) to grow cells that can be transplanted into the brain of a person affected by the disease. This approach may eventually improve the outlook for those who possess the faulty huntingtin gene.

3.3 *Understand the common signs and symptoms of dementia, for example:*

Decline in memory

Many people find that they become more forgetful as they become older - this is common and is often not due to dementia. Illnesses such as depression and an underactive thyroid can also cause memory problems. Dementia is the most serious form of memory problem. It causes a loss of mental ability and other related symptoms. Symptoms of dementia develop gradually and typically become worse over a number of years. The most important part of treatment for dementia is good quality support and care for the person with dementia, and for their carers

Memory loss. As a rule, the most recent events are the first forgotten. For example, a person with early stages of dementia might go to the shops and then cannot remember what they wanted. It is common to misplace objects. However, events of the past are often remembered well until the dementia is severe. Many people with dementia can talk about their childhood and early life. As things progress, sometimes memory loss for recent events is severe and the person may appear to be 'living in the past'. They may think of themselves as young and not recognise their true age.

- Decline in reasoning and communication

Every person experiences dementia in their own individual way, but there is usually a decline in memory, reasoning and communication skills and a gradual loss of the skills needed to carry out daily activities.

Aphasia

Aphasia is an element of dementia that can occur in individuals under the age of 65 (and sometimes as early as in the 40's), and involves a decline in one or more language functions. It is due to brain cell degeneration.

"Aphasia" is a general term used to refer to deficits in language functions. Our language functions include speaking, understanding what others are saying, repeating things we have heard, naming common objects, reading and writing.

Aphasia begins very gradually and initially is experienced as difficulty thinking of common words while speaking or writing. APHASIA progressively worsens to the point where verbal communication by any means is very difficult. The ability to understand what others are saying or what is being read also declines. In the early stages, memory, reasoning and visual perception

are not affected by the disease and so individuals with APHASIA are able to function normally in many routine daily living activities despite the aphasia. However, as the illness progresses, other mental abilities also decline.

The time frame within which these changes occur varies greatly between patients. A few cases have been reported in which language deficits were the only symptoms for at least 10 years. On average, impairments are confined exclusively to the area of language for approximately 5 years, but may spread to other areas after 2 years.

Primary Progressive Aphasia

- A form of dementia caused by a disease process in the brain that results in degeneration of nerve cells in the parts of the brain that control our ability to use language
- Begins with the slow decline of the ability to use language in speaking, understanding, reading and writing
- Other types of mental processes are relatively normal initially and may remain normal for years, but begin to decline with time
- This form of dementia is more prevalent in males than in females in comparison to dementia that involves forgetfulness or memory loss, which is more prevalent in females
- This form of dementia is also more common in younger individuals, with symptoms usually starting in the 50's

The types of language difficulties that occur differ among individuals, but generally involve things such as the following:

- Increased difficulty thinking of words that results in:
 - substituting the wrong word (e.g., "school" for "work")
 - mistakes in pronunciation (e.g., "track" for "truck")
 - talking around the word (e.g., "We went to the place where you can get bread" for the words "grocery store")
- Problems reading or writing that result in:
 - inability to write checks, letters
 - difficulty following written directions, reading signs
- Reduced ability to understand speech
 - trouble following conversations, especially in larger groups
 - asking for information to be repeated and misunderstanding things that are said, even though hearing is normal
- Decreased use of language
 - speech may become empty of any real information and difficult to understand early in the course of the illness
 - eventually may be unable to use speech to communicate, becoming mute
- Problems in arithmetic and calculations
 - may lose ability to perform even simple mathematical operations
 - may have problems making change
- Despite the difficulties that occur with APHASIA, many of those who have this disorder are capable of normal, or even superior, achievements in activities that do not rely on language.
- **Changes in behaviour**

Some of the greatest challenges of caring for someone with dementia are the personality and

behaviour changes that often occur. You can best meet these challenges by using creativity, flexibility, patience and compassion. It also helps to not take things personally and maintain your sense of humor.

To start, consider these ground rules:

We cannot change the person. The person being cared for has a brain disorder that shapes who s/he has become. When you try to control or change his behaviour, you'll most likely be unsuccessful or be met with resistance. It's important to:

- *Try to accommodate the behaviour, not control the behaviour.* For example, if the person insists on sleeping on the floor, place a mattress on the floor to make them more comfortable.
- *Remember that we **can** change our behaviour or the physical environment.* Changing our own behaviour will often result in a change in the individual's behaviour.

Check with the doctor first. Behavioural problems may have an underlying medical reason: perhaps the person is in pain or experiencing an adverse side effect from medications. In some cases, like incontinence or hallucinations, there may be some medication or treatment that can assist in managing the problem.

Behaviour has a purpose. People with dementia typically cannot tell us what they want or need. They might do something, like take all the clothes out of the closet on a daily basis, and we wonder why. It is very likely that the person is fulfilling a need to be busy and productive. *Always consider what need the person might be trying to meet with their behaviour—and, when possible, try to accommodate them.*

Behaviour is triggered. It is important to understand that all behaviour is triggered—it doesn't occur out of the blue. It might be something a person did or said that triggered a behaviour or it could be a change in the physical environment. *The root to changing behavior is disrupting the patterns that we create.* Try a different approach, or try a different consequence.

What works today, may not tomorrow. The multiple factors that influence troubling behaviours and the natural progression of the disease process means that solutions that are effective today may need to be modified tomorrow—or may no longer work at all. The key to managing difficult behaviours is being creative and flexible in your strategies to address a given issue.

Get support from others. You are not alone—there are many others caring for someone with dementia.

The following is an overview of the most common dementia-associated behaviours with suggestions that may be useful in handling them.

Wandering

People with dementia walk, seemingly aimlessly, for a variety of reasons, such as boredom, medication side effects or to look for “something” or someone. They also may be trying to fulfill a physical need—thirst, hunger, a need to use the toilet or exercise. Discovering the triggers for wandering are not always easy, but they can provide insights to dealing with the behaviour.

Incontinence

The loss of bladder or bowel control often occurs as dementia progresses. Sometimes accidents result from environmental factors; for example, someone can't remember where the bathroom is located or can't get to it in time. If an accident occurs, your understanding and reassurance will help the person maintain dignity and minimize embarrassment.

Agitation

Agitation refers to a range of behaviours associated with dementia, including irritability, sleeplessness, and verbal or physical aggression. Often these types of behaviour problems progress with the stages of dementia, from mild to more severe. Agitation may be triggered by a variety of things, including environmental factors, fear and fatigue. Most often, agitation is triggered when the person experiences "control" being taken from him.

Repetitive speech or actions (perseveration)

People with dementia will often repeat a word, statement, question or activity over and over. While this type of behaviour is usually harmless for the person with dementia, it can be annoying and stressful to carers. Sometimes the behaviour is triggered by anxiety, boredom, fear or environmental factors.

Paranoia

Seeing a loved one suddenly become suspicious, jealous or accusatory is unsettling. Remember, what the person is experiencing is very real to them. It is best not to argue or disagree. This, too, is part of the dementia — try not to take it personally.

Sleeplessness/Sundowning

Restlessness, agitation, disorientation and other troubling behaviour in people with dementia often get worse at the end of the day and sometimes continue throughout the night. Experts believe this behaviour, commonly called *sundowning*, is caused by a combination of factors, such as exhaustion from the day's events and changes in the person's biological clock that confuse day and night.

Eating/Nutrition

Ensuring that your loved one is eating enough nutritious foods and drinking enough fluids is a challenge. People with dementia literally begin to forget that they need to eat and drink. Complicating the issue may be dental problems or medications that decrease appetite or make food taste "funny." The consequences of poor nutrition are many, including weight loss, irritability, sleeplessness, bladder or bowel problems and disorientation.

Bathing

People with dementia often have difficulty remembering “good” hygiene, such as brushing teeth, toileting, bathing and regularly changing their clothes. From childhood we are taught these are highly private and personal activities; to be undressed and cleaned by another can feel frightening, humiliating and embarrassing. As a result, bathing often causes distress for both carers and their loved ones.

Additional Problem Areas

- Dressing is difficult for most dementia patients. Choose loose-fitting, comfortable clothes with easy zippers or snaps and minimal buttons. Reduce the person’s choices by removing seldom-worn clothes from the closet. To facilitate dressing and support independence, lay out one article of clothing at a time, in the order it is to be worn. Remove soiled clothes from the room. Don’t argue if the person insists on wearing the same thing again.
- Hallucinations (seeing or hearing things that others don’t) and delusions (false beliefs, such as someone is trying to hurt or kill another) may occur as the dementia progresses. State simply and calmly your perception of the situation, but avoid arguing or trying to convince the person their perceptions are wrong. Keep rooms well-lit to decrease shadows, and offer reassurance and a simple explanation if the curtains move from circulating air or a loud noise such as a plane or siren is heard. Distractions may help. Depending on the severity of symptoms, you might consider medication.
- Sexually inappropriate behaviour, such as masturbating or undressing in public, lewd remarks, unreasonable sexual demands, even sexually aggressive or violent behaviour, may occur during the course of the illness. Remember, this behaviour is caused by the disease. Talk to the doctor about possible treatment plans. Develop an action plan to follow before the behaviour occurs, i.e., what you will say and do if the behaviour happens at home, around other adults or children. If you can, identify what triggers the behaviour.
- Verbal outbursts such as cursing, arguing and threatening often are expressions of anger or stress. React by staying calm and reassuring. Validate your loved one’s feelings and then try to distract or redirect his attention to something else.
- “Shadowing” is when a person with dementia imitates and follows the carer, or constantly talks, asks questions and interrupts. Like sundowning, this behaviour often occurs late in the day and can be irritating for carers. Comfort the person with verbal and physical reassurance. Distraction or redirection might also help. Giving your loved one a job such as folding laundry might help to make her feel needed and useful.
- People with dementia may become uncooperative and resistant to daily activities such as bathing, dressing and eating. Often this is a response to feeling out of control, rushed, afraid or confused by what you are asking of them. Break each task into steps and, in a reassuring voice, explain each step before you do it. Allow plenty of time. Find ways to have them assist to their ability in the process, or follow with an activity that they can perform.

Loss of skills to carry out normal daily activities

Dementia usually begins with mild, slowly worsening memory loss. Many older people fear that

they have loss of memory because they can't find their eyeglasses or remember someone's name.

- These very common problems are most often due to slowing of mental processes with age. It is not clear whether this is a normal part of aging.
- While this is a nuisance, it does not significantly impair a person's ability to learn new information, solve problems, or carry out everyday activities, as Alzheimer disease does.
- Mild cognitive impairment (MCI) is the term used by medical professionals when memory loss is greater than what "normally" occurs with aging, but a person is still able to perform normal daily activities

Staff, family members and friends can help someone with dementia cope with mental and physical problems. They can encourage individuals to maintain their daily routines and regular social and physical activities. By talking with them about events and daily experiences, family members can help their loved ones use their mental abilities as much as possible. Some find it helpful to use reminders such as lists, alarm clocks, and calendars to help the individual remember important times and dates.

ACTIVITY PROGRAM FOR PERSONS WITH DEMENTIA

Activities are essential for living. Well-planned daily activities that help to provide structure, meaning and achievement have positive effects for the person with dementia.

Benefits of activities for the person with dementia

1. Enhance physical, mental, social and emotional health;
2. Develop competence, achieve mastery that promote self esteem and self worth;
3. To help the person with dementia to realize his/her fullest potential and to help them to rediscover themselves;
4. Enhance attention and adaptive skills that maximize independence;
5. Provide opportunities for social interaction, emotional release that helps to delay negative symptoms and promote positive aging;
6. Experience pleasure, life satisfaction and enhance the quality of life.

Essential elements for appropriate activities

1. Have specific goal and meaning to the person with dementia;
2. Able to motivate patient for participation;
3. Fit the physical and mental capabilities of the person with dementia;
4. Suitable to the need, interest, age, social & educational background and former life styles of the person with dementia;
5. Provide opportunities for enjoyment during the process of participation;
6. Provide opportunities for the sense of control and satisfaction;
7. Does not pose threat or sense of failure;
8. The process and content should be flexible and easily adapted to meet various needs of the person with dementia.

Choice of activity programs

1. Self-care activities

A safe and relaxing environment, simplified workflow, and the use of tools or adaptations could help the person with dementia to develop sense of control, competence and maximize independence in self-care activities such as dressing, bathing, grooming and dining etc.

2. Household activities

Participation in familiar household activities encourages continuous life experience. When meal planning, cooking and money management become too demanding for the persons with dementia, simple tasks like folding serviettes, table-setting and sweeping the floor in a safe environment could be considered.

3. Leisure activities

Leisure activities that encourage active participation and social interaction are valuable for the person with dementia. Sing-a-long, listening to radio, playing chess, physical exercise, keeping pets and craft work are common examples of leisure activities that provide opportunity for pleasure and enjoyment.

4. Reminiscence activities

Through a process of recollection of the past and life reviews for the unresolved conflicts, persons with dementia could achieve more consistent and positive evaluations of their past, accept personal losses and preserve a sense of usefulness and satisfaction with their lives. Carer(s) could simply use a photo of the past event or a familiar song to encourage the person with dementia to relive his/her past experience. If several persons with dementia are grouped together to do the reminiscence activities, social interaction and emotional release could be further facilitated.

5. Reality orientation activities

Reality orientation is the strategy to orientate the person with dementia to the "time", "place" and "person" of their immediate environment. The use of large face clocks and calendars in different rooms, maps and signs to indicate places of their living environment, frequent greetings etc. are common strategies to help persons with dementia to cope with their daily living. This can also be organized with specific themes such as food, body parts, festival events or community facilities etc.

6. Memory training activities

Recent memories are commonly lost first but older memories are better preserved for the person with dementia. Memory games such as cards matching, reviewing TV drama plots and news discussion are good opportunities for them to realize their memory potential and for social interaction and enjoyment.

7. Sensory stimulation activities

Through focusing on a specific sense, the person with dementia could be assisted to explore familiar smells, movements, textures, sights, sounds and tastes that relate to his/her previous life

experiences. Sensory stimulation could be used to improve level of alertness and awareness to the environment and arouse appropriate responses from the person with dementia. The taste of fruit, the sound of birds, the smell of flowers and texture of toys are day-to-day stimuli that could provide comfort, encourage social interaction and minimize challenging behavior.

Conclusion

There are endless examples of activities that are suitable for persons with dementia. Carer(s) should ensure a safe environment, match the activity carefully with the need and ability of the person with dementia, so as to encourage and support continuous life experience and enhance the quality of life and dignity of the person with dementia.

4. LEGISLATION AND GUIDANCE RELEVANT TO INDIVIDUALS WITH DEMENTIA

4.1 *Understand the legislation and guidance relevant to individuals with dementia:*

Relevant issues Human Rights Act 1998

- The rights most relevant to adult's services are:
- Article 2: the right to life.
- Article 3: no-one shall be subjected to torture or to inhuman or degrading treatment or punishment.
- Article 5: the right to liberty and security of person.
- Article 6: the right to a fair trial.
- Article 8: the right to respect for private and family life.
- Article 14: freedom from discrimination in the enjoyment of Convention rights.

This scenario was produced by: Social Services, Customer Services Unit, Castle Court, Shire Hall, Cambridge, CB3 0AP

DECISION MAKING CHECKLIST - EXAMPLE

Mary is an 83-year-old woman who lives alone in her own home and suffers from senile dementia. She has a pattern of leaving her home and wandering the streets and on two or three occasions in the last month she has been found in the gutter on freezing cold nights. Fortunately, Mary has been found by a neighbour or Police and returned home. Social Services provide 7 hours a day domiciliary care but following a reassessment wish to provide 24 hour care or move her to a residential care home. The residential care home is the better option because Mary, although suffering from senile dementia, enjoys the company of other people. She has said that she feels very lonely at home.

Mary's daughter, Elizabeth, categorically refuses to allow her mother to go to a residential care home or to have any more care because of the cost to her mother. It is suspected that Elizabeth is trying to protect her inheritance. After much discussion the social worker is so concerned about Mary and her nocturnal wanderings, as well as her isolation and the need for care, that she approaches her manager for advice.

Application of the Human Rights Act 1998

1. Does what you are doing / propose to do interfere with any of the Convention Rights? (N.B. check whether you are proposing to take action or leave things as they are)

The plan is to take action to remove Mary from her home and place her in a residential care home. The article that is relevant in this situation is Article 8 - The Right to Family Life.

2. Is there a victim?

Mary is the most obvious victim but although her capacity is limited she does seem to be agreeing to move. Elizabeth should also be considered as well.

3. Can the Convention Rights be legitimately interfered with?

Assess Article 8. The right to family life is subject to an implied limitation. The first question to ask is whether the interference is in accordance with the law or prescribed by the law. The interference is removing Mary from her home and placing her in a residential care home. Mary is consenting to this action and a Social Services authority has the legal power to provide residential care and therefore the proposal to provide such care for Mary is in accordance with the law.

4. Have you followed the rules laid down by the domestic legislation or do you have a legal basis in domestic law for the interference?

Mary has been assessed under the National Assistance Act 1948 for community care services. Her needs have been identified by a way of an

assessment. There is therefore a basis in law for the interference.

5. Is the step you propose to take necessary in a democratic society? (i.e. does it fulfil a pressing social need?)

Yes, because Mary is in danger if this does not take place.

6. Does the interference pursue a legitimate aim under the Article?

Check what Article 8 says: It refers to whether it (the interference) is necessary in a democratic society to achieve one of the specified aims. The relevant social aim relevant here is the protection of health. The objective that is being pursued is ensuring that an elderly person who is suffering from senile dementia is not left alone in her house when she has the tendency to wander or put herself in danger. A residential care setting is more structured and would always have staff on hand to make sure that if Mary did wander, the situation would be dealt with effectively and quickly. It should therefore be possible to show that the intended interference does pursue a legitimate aim because it would safeguard Mary's health.

7. Is the extent of the interference proportionate to the aim proposed?

It is possible to say that it is proportionate because the only alternative would be to put into place a 24-hour care package. That would not be effective from the local authority perspective given the cost of such a package, the number of similar cases and the pressure on resources. Mary lives alone and her family life need not be disrupted by the move into residential care, which she would prefer to a domiciliary package. The Council's resource considerations therefore are not in conflict with the right to family life considerations for Mary.

8. Is the step you propose appropriate to achieve the end?

Yes, because Mary will be safer within a residential care setting and will also receive 24-hour care.

9. Is the step the least restrictive means to achieve the end?

It is arguably less restrictive to allow Mary to remain in her own home but there is not much to choose between the two options. It is known, however, that Mary would prefer to have company and she would have this in a residential care home.

10. Is there relevant and sufficient justification for the interference?

Yes, the reasons are that Mary requires an increasing level of care due to her senile dementia and is putting herself at risk by wandering the streets on cold nights. If she is resident in a care home, both the risk of her not getting the care that she needs or wandering into danger are kept at a minimum.

11. Does the interference involve discrimination against people?

No.

This process should be gone through again in respect of Elizabeth. As Elizabeth does not live with Mary, it is difficult to see how her right to family life would be disrupted by Mary going to live in a residential care home unless of course the proposed home were some distance from where Elizabeth lives and therefore visiting would be more difficult than it is now.

From Age Concern

Extending the Human Rights Act to private care homes (16.01.06)

We are calling on the Government to close a legal loophole that is putting the lives of thousands of older people at risk of malnutrition.

Older people in private care homes are not protected by the Human Rights Act, which gives individuals the right to be treated with fairness, dignity and respect.

Having access to food is a basic human right, yet older peoples' nutritional needs are routinely overlooked as up to a fifth of people in care homes are at risk of malnutrition.

Our Director General, Gordon Lishman said: "Too many older people are currently treated as second-class citizens and older people in care homes are some of the most vulnerable members of society. All older people must get the same level of protection, regardless of who provides their care. It's time to end this lottery of protection once and for all."

- **Mental Capacity Act 2005**

The Mental Capacity Act 2005 provides a statutory framework to empower and protect vulnerable people who may not be able to make their own decisions. It makes it clear who can take decisions in which situations and how they should go about this. It enables people to plan ahead for a time when they may lose capacity.

Guidance on the Act will be provided in a statutory Code of Practice.

Five key principles

The whole Act is underpinned by a set of five key principles stated at Section 1

- A presumption of capacity - every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
- The right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
- That individuals must retain the right to make what might be seen as eccentric or unwise

decisions;

- Best interests - anything done for or on behalf of people without capacity must be in their best interests; and
- Least restrictive intervention - anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.
- **Enduring Power of Attorney Act 1985**

If you lose mental capacity because of dementia, you will need someone else to manage your legal, financial and health affairs. Currently, you can make an 'enduring power of attorney', which means a person of your choosing will be able to manage your finances for you, or someone can apply for 'receivership' on your behalf. In 2007, you will be able to make a 'lasting power of attorney'; this will enable you to choose a person to make decisions regarding your health and welfare, as well as your finances.

It is sensible to make an enduring power of attorney (EPA), as this enables you to select one or more people to act for you now, if you wish, and in the future, should you become mentally incapable. It gives you the opportunity to have a say about your future; it will also make it easier for your carers to act on your behalf in the future.

You can set up an EPA as long as you are aware of what is involved and can show that you understand the process.

If you have a query or complaint about an EPA or receivership, contact the public guardianship office (see below).

What is an EPA?

An EPA is a legal process in which you, the 'donor', give the legal right to one or more people, the 'attorneys', to manage your financial affairs and property.

This power can come into effect immediately, and has the same status as an ordinary power of attorney. This means that your attorneys can manage part or all of your financial affairs for you, or you can continue to manage them yourself while you are able to and hand over responsibility later.

The difference between an enduring power of attorney and an ordinary power of attorney is that an ordinary power of attorney becomes invalid if the donor becomes mentally incapable, whereas an enduring power of attorney becomes effective, providing the necessary steps are taken.

If you become mentally incapable, your attorneys will apply to register your EPA with the public guardianship office. While the registration is being processed, they can use your finances for essentials on your behalf, such as food or payment of regular bills. However, they are not able to arrange larger transactions, such as the sale of your house, until the EPA has been registered.

You can specify that the EPA can only come into effect once you become mentally incapable. However, there are drawbacks to restricting the EPA in this way. For example:

- Even if you are not mentally incapable, you are likely to find it more and more difficult to deal with financial affairs as your dementia progresses. No one will have the authority to take over your responsibilities if you need them to do so.

- Once you do become mentally incapable, no one will be able to act on your behalf during the time that it takes for an EPA to be registered.

Community Care Act 1990

The Community Care Act (1990) is a piece of legislation which governs health care and social care in the United Kingdom. It sets out how the National Health Service should assess and provide for patients based on their needs, requirements and circumstances.

The Act states that it is a duty for local authorities to assess people for social care and support. This is to ensure that people who need community care services or other types of support get the services they are entitled to. Patients have their needs and circumstances assessed and the results determine whether or not care or social services will be provided.

Local authority resources can be taken into account during the assessment process, but if it is deemed that services are required, then those services must be provided by law: services can't be withdrawn at a later date if resources become limited.

Mental Health Act 1983

The Mental Health Act 1983 is an Act of the United Kingdom Parliament but applies only to people in England and Wales. It covers the reception, care and treatment of mentally disordered persons, the management of their property and other related matters. In particular, it provides the legislation by which people suffering from a mental disorder can be detained in hospital and have their disorder assessed or treated against their wishes, unofficially known as "sectioning".

Its use is reviewed and regulated by a special health authority known as the Mental Health Act Commission (MHAC).

Care Standards Act 2000

Care Standards Act 2000 (CSA) is an act in the United Kingdom which provides for the administration of a variety of care institutions, including children's homes, independent hospitals, nursing home and residential care homes.

The CSA, which was enacted in April 2002, replaces the Registered Homes Act 1984 and parts of the Children's Act 1989, which pertain to the care or the accommodation of children.

The aim of the legislation is to reform the law relating to the inspection and regulation of various care institutions.

National Minimum Standards for Care Homes for Older People

Note

This document contains a statement of national minimum standards published by the Secretary of State under section 23(1) of the Care Standards Act 2000. The statement is applicable to care homes (as defined by section 3 of that Act) which provide accommodation, together with nursing or personal care, for older people.

The statement is accompanied, for explanatory purposes only, by an introduction to the statement as a whole, and a further introduction to each group of standards.

Each individual standard is numbered and consists of the numbered heading and numbered paragraphs. Each standard is, for explanatory purposes only, preceded by a title and an indication of the intended outcome in relation to that standard.

The Commission may conclude that a care home has been in breach of the regulations even though the home largely meets the standards. The Commission also has discretion to conclude that the regulations have been complied with by means other than those set out in the national minimum standards.

Structure and Approach

The National Minimum Standards for Care Homes for Older People focus on achievable outcomes for individuals – that is, the impact on the individual of the facilities and services of the home. The standards are grouped under the following key topics, which highlight aspects of individuals' lives identified during the stakeholder consultation as most important to individuals:

- Choice of home
- Health and personal care
- Daily life and social activities
- Complaints and protection
- Environment
- Staffing
- Management and administration

Each topic is prefaced by a statement of good practice, which sets out the rationale for the standards that follow. The standards themselves are numbered and the full set of numbered paragraphs needs to be met in order to achieve compliance with the standard. Each standard is preceded by a statement of the intended outcome for individuals to be achieved by the care home.

Data Protection Act 1998

Purpose

The purpose of the Act is to protect the rights of the individual about whom data is obtained, stored, processed or supplied rather than those of the people or organisations who control and use personal data. The Act applies to both computerised and paper records.

The Act requires that appropriate security measures will be taken against unauthorised access to, or alteration, disclosure or destruction of personal data and against accidental loss or destruction of personal data.

Scope

The 1998 Act applies to:

- Computerised personal data
- Personal data held in structured manual files

It applies to anything at all done to personal data (“processing”), including collection, use, disclosure, destruction and merely holding data.

Principles of Data Protection

The Act is based on eight principles stating that data must be:

1. Fairly and lawfully processed
2. Processed for limited purposes
3. Adequate, relevant and not excessive
4. Accurate
5. Not kept longer than necessary
6. Processed in accordance with the data subjects rights
7. Secure
8. Not transferred to other countries without adequate protection

How does it affect me?

Employees can also be prosecuted for unlawful action under the legislation. Fines of up to £5000 could result if you use or disclose information about other people without their consent or proper authorisation. You could even be committing an offence if you give information to another employee or student who does not need the details to carry out their legitimate duties. You should take particular care when using the Internet, e-mail and the internal network. Special care must be taken with sensitive data such as ethnic origins, religious/political beliefs, health data, disabilities, details of offences or alleged offences, sexual life or trade union membership.

Individual Responsibilities

All staff and students have a duty to observe the Principles of the Act. Individuals who do not handle data as part of their normal work have a responsibility to ensure that any personal data they see or hear goes no further. This includes personal data and information extracted from such data, thus, for example, unauthorised disclosure of data might occur by passing information over the telephone, communicating information contained on a computer print-out or even inadvertently by reading a computer screen.

General Guidelines

- Do not leave people’s information on your desk when it is not in use,
- Lock all filing cabinets,
- Do not leave data displayed on screen, do not leave your computer logged on and unattended,
- Do not give your password to anyone under any circumstances,
- Do not choose a password that’s easy to guess,
- Never send anything by fax or e-mail that you wouldn’t put on the back of a postcard.
- Disability Discrimination Act 1995

The Disability Discrimination Act (DDA) 1995 aims to end the discrimination that many disabled people face. This Act has been significantly extended, including by the Disability Discrimination Act 2005. It now gives disabled people rights in the areas of:

- employment
- education

- access to goods, facilities and services
- buying or renting land or property, including making it easier for disabled people to rent property and for tenants to make disability-related adaptations

The Act now requires public bodies to promote equality of opportunity for disabled people. It also allows the government to set minimum standards so that disabled people can use public transport easily.

The Department for Work and Pensions (DWP) website offers further information, including details on the changes made by the Disability Discrimination Act 2005.

The Disability Rights Commission (DRC) website also has plenty of information, including a brief overview with the key points of the Act. It also provides full versions in PDF (both Acts) and word (DDA 2005 only) format.

- **Health Act 1999**

The Health Act 1999 came into force in April 2000. It includes the latest attempt to pull down the “Berlin Wall” that divides health services funded and provided by the NHS from social services run by local councils.

What is the point of the Act?

The distinction between health and social care is often unclear to individuals, who complain of being pushed from pillar to post in sorting out different parts of their care package. There is confusion over who does what. If a client is given a bath is it a “health” bath or a “social” bath? (If a health care assistant is giving it, then it is probably a health bath; a social care assistant, then it is a social bath. But as far as the bathed client is concerned, it is still a bath, although they may have to pay a means-related fee for a social bath while a bath provided by the NHS is free.) These types of artificial boundaries can lead to a lack of continuity of care and funding disparities. Another classic problem arises where NHS beds are “blocked” by people who no longer need hospital care but whose social care packages have yet to be organised because of social service funding problems.

What exactly does the legislation change?

Joint working is not new. But new “flexibilities” have been introduced to remove perceived obstacles. These include allowing health bodies and local authorities to:

- set up pooled budgets;
- delegate functions, by nominating a lead commissioner or integrating provision; and
- transfer funds between bodies.

Which services are involved?

There are very few restrictions. But the focus has so far been on older people, people with learning difficulties (or learning disabilities), children or mental health.

- **National Service Framework for Older People**

NSFs have been issued for mental health and coronary heart disease, diabetes, renal services, children’s services and neurological disorders.

An NSF is a document, which is intended to drive up standards and reduce unacceptable variations in health and social services. It basically sets standards for services that the commissioners and providers of healthcare must meet. NSFs will not always be prescriptive in every detail, but the standards in them will be monitored by the Healthcare Commission.

Key Standards

The NSF for Older People, which can be viewed as a pdf document at the bottom of this page, has eight standards, concerned with the following;

- Rooting out age discrimination
- Person-centred care
- Intermediate care
- General hospital care
- Stroke
- Falls
- Mental health in older people
- The promotion of health and active life in older age

Person-centred care

The aim of this standard is to ensure that older people are treated as individuals and receive appropriate care, which meets their needs, regardless of health and social services boundaries. A key method of achieving this will be the introduction of the single assessment process. This was originally announced in the NHS Plan for England and will operate across health and social services to ensure a full assessment and evaluation of the needs of the older person. It is to be introduced by April 2002. It is intended to eliminate duplication in information collection and assist information sharing between professionals.

All older people should receive a good needs assessment, but the NSF recognises that some older people will benefit from a fuller assessment across a number of areas, and some may need a more detailed assessment in one or more specialist areas. Although the intention is that one front-line professional should carry out the fuller assessment, it is recognised that other professionals may need to come in to perform specialist assessments.

The fuller assessment includes the older person's senses (sight, hearing and communication), and may identify the need for further investigation by an appropriately qualified professional - such as an optometrist.

Falls

The aim of this standard is to reduce the number of falls, which result in serious injury and provide effective treatment and rehabilitation for those who have fallen. The NHS is expected to work with local councils; one feature of this is to be that older people and their carers can receive advice from a specialised falls advice service.

The NSF specifically identifies visual impairment as one of the five major intrinsic risk factors in falls. It sets out a model for a falls service, as part of the overall specialist services for older people in hospital and community settings. The NSF specifies that the team should include a consultant in old age medicine, nurses, physiotherapists, occupational therapists, social workers, pharmacists and podiatrists, and goes on to state that this team should have access to a range of other

professionals, including optometrists. The NSF suggests that these non-core team members are likely to only work part-time in the falls service. The falls team will play a part in the discharge arrangements for older people. Optometrists may also be able to play a role in the identification of older people in the community who are at most risk of falling.

Local health care providers were required to have audited their procedures and put in place risk management measures to reduce the risk of older people falling by April 2003. The integrated falls service was to be included in the HImP by April 2004, and the last date for the introduction of such a service was April 2005.

Department of Health Document 'How can we help older people not fall again? Implementing the Older People's NSF Falls Standard: Support for commissioning good services

This document, produced in July 2003, aims to provide guidance for commissioners to implement the NSF for Older People Standard 6 on falls prevention - the pdf document may take a short while to download as it contains graphics.

AOP Document on Falls

The AOP produced a paper (November 2003) on falls in the elderly which sets out what LOCs and individual optometrists can do to highlight the role they can play in the prevention of falls in the elderly. This can be viewed in the pdf document at the end of this page.

College of Optometrists & British Geriatric Society

The College of Optometrists, along with the British Geriatric Society, produced a paper (November 2003), endorsed by the Royal College of General Practitioners, entitled 'The Importance of Vision in Preventing Falls'. This can be viewed below amongst the pdf documents.

Better Health in Old Age - A Progress Report

This report highlights progress since 2001 under the National Service Framework for Older People and sets out a vision for the future. It can be viewed below as a pdf document.

Better Health in Old Age - A Resource Document

This document aims to provide a resource for NHS and Social Care staff involved in the implementation of the National Service Framework for Older People. It should be read in conjunction with 'Better Health in Old Age - A Progress Report'. The Resource document details how national and local initiatives have delivered improved outcomes for older people since the introduction of the NSF. It provides examples of good practice through case studies, which may be adapted locally to improve the health, independence and well-being of older people. Finally, the document outlines work underway to drive forward further change and improvement for the future of Older People's Services.

N.B. This list of legislation and guidance is given as examples. Legislation and guidance is subject to change. It is important when designing learning packages, in-house training, etc., that the most recent legislation and guidance is included.

4.2 Understand the organisation's policies and procedures and how to apply them with regard to people with dementia, for example, visitor policy, no secrets policy

VISITOR POLICY

The Home operates an 'open door' policy with regard to visitors but if staff are unsure or have concerns as to a visitor's identity or motives that person will be challenged. Identification of unrecognised visitors will be requested at all times. The Person-in-Charge is under no obligation to admit anyone who has no authority or does not carry a document of authentication.

Staff will respect the client's wishes with regard to visitors. If a client does not wish to see a visitor this will be explained and the visitor will be asked to leave.

Should a visitor refuse to leave and is causing a disturbance, the Person-in-Charge take appropriate action including informing the Police.

The safety and well-being of client's will be maintained at all times.

Client's maintain contact with family / friends / representatives and the local community as they wish.

Client's are able to have visitors at any reasonable time and links with the local community are developed and/or maintained in accordance with client's' preferences.

Client's are able to receive visitors in private.

Client's are able to choose whom they see and do not see.

The registered person does not impose restrictions on visits except when requested to do so by client's, whose wishes are recorded.

Relatives, friends and representatives of client's are given written information about the home's policy on maintaining relatives and friends' involvement with client's at the time of moving into the home.

Involvement in the home by local community groups and/or volunteers accords with client's' preferences.

About No Secrets

In March 2000, the Department of Health published the document No Secrets - guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. The Department of Health instructed that all statutory agencies work together to help ensure vulnerable adults are protected from abuse. A committee had to be formed, made up of all relevant agencies and procedures to be in place by October 2001 to help and protect vulnerable adults.

POLICY STATEMENT

All Vulnerable Adults have the right to live their lives free from abuse of any description. All agencies and individuals that have contact with Vulnerable Adults have a duty to protect them from abuse.

Where abuse is reported to, or suspected by, any person in any agency, the response will be prompt and in line with the Multi Agency Procedures.

The response will:

- Recognise those individuals to which the procedures apply.
- Take the matter seriously.
- Be timely, sensitive and maintain confidentiality as appropriate to each situation.
- Be co-ordinated between agencies.
- Be consistent with the service principles and practice of each agency and this policy.
- Promote human rights and every citizen's access to the law.
- Support the rights of individuals by respecting self-determination and informed choice.
- Acknowledge risk as an integral part of choice and decision-making; Ensure that risk assessments are completed and that these assessments are recorded and reviewed in order that risk can be minimised.
- Be effective in providing or negotiating solutions that are as simple and practical as possible and aim to prevent the risk of abuse recurring.
- Be sensitive to every individual's identity including culture, beliefs and ethnic background, gender, disability, age and sexuality.

The Principles of the Policy and Procedure

The overriding consideration at all times will be the appropriate protection of vulnerable adults. Appropriate protection takes place alongside the need to ensure that individuals have self-determination and autonomy of choice.

- All staff have a duty to ensure that vulnerable adults receive the protection of the law.
- All staff have a duty of care and must take professional/personal responsibility for responding to any concerns about possible abuse.
- All staff have a duty to share information appropriately, to act and to co-operate with colleagues across all agencies, consistent with this policy, • Action taken must reflect a commitment to anti-discriminatory practice, to ensure that services are culturally appropriate, and to promote human rights.
- As far as possible all action taken must be with the knowledge and consent of the individual concerned.
- The procedures are intended to support good practice and sound professional judgement.

4. The Purpose of the Policy and Procedure

- To provide a coherent and consistent framework for recognising and taking action to prevent the abuse of vulnerable adults.

- To recognise and promote the benefits of effective multi-agency working through dialogue and co-operation, to form a collaborative partnership between the agencies that have contact with vulnerable adults.
- To describe the common values, principles and law that underpin the protection of vulnerable adults.
- To define the different types of abuse, signs, symptoms and indicators.
- To define the roles of each agency.
- To ensure that information on allegations and incidents of abuse is collected, monitored and reviewed in order to inform future practice.

3. KEY WORDS AND CONCEPTS

Advocacy

Giving active support to the individual(s). An advocate is a person who intercedes on behalf of an **individual**.

Care planning

The process of producing a **care plan** using a team approach and including the individual, their family and friends.

Care plan

A required document that sets out in detail the way daily care and support must be provided to an **individual**. It may also be known as an “individual plan”, “plan of support”, etc.

Dementia

A state of serious mental deterioration of organic or functional origin.

Individual(s)

The person or people receiving care and support.

Person centred approach

An approach to care planning and support which empowers **individuals** to make decisions about what they want to happen in their lives. The decision then forms the basis of any plans that are developed and implemented.

CONFUSIONAL STATES AND DEMENTIA

In linking both Confusional States with Dementia, with some of the former ending up as the latter, and by treating all known dementia's under one heading, it may help to understand that whatever the causes, there are similar patterns of behaviour and similar signs and symptoms. Each individual will have a range of symptoms and not all will be the same.

CONFUSION IN DEMENTIA

Chronic in nature, irreversible and continuously deterioration is usual.

TOXIC CONFUSION

Internal toxins such as bacteria or viral conditions or an illness or ailment which causes the body to be out of equilibrium such as Uraemia, and external toxins such as chemicals or toxic wastes can cause short or long term confusion. Constipation can also in nit's extreme cause confusion.

DRUG INDUCED CONFUSION

Overdosing on almost any medication can cause confusion, equally taking a moderate amount of a medication initially may cause confusion. The label on the medication may state that it may cause drowsiness and that may in extreme lead to confusion. Toxic drugs like LSD cause an altered cognition and confusion and disorientation may take place.

ALCOHOLIC CONFUSION

Either as an acute phase where too much alcohol is taken and this may lead to confusion, or on a long term chronic basis where alcohol has caused dementia.

HYPOXIC CONFUSION

Especially in the elderly, an acute viral or bacterial illness and usually associated with the lungs, i.e. chest infection, or a long term chronic problem such as emphysema may cause confusion.

CONCUSSION

A fall or a blow that injures the head may cause confusion for a short or sometimes prolonged period. Boxers are likely to suffer this in the short term, and this may develop into an ongoing Dementia

DEMENTIA

ALHEIMER'S DISEASE

Once described as a Pre-Senile Dementia, it is now classed as the predominant dementia in either early or late age onset. It is characterised as a progressive degeneration of brain function. The degeneration of neurones is accompanied by changes in the brains biochemistry. At present the condition is irreversible and there is no effective treatment.

PICKS DISEASE

This is a disease first discovered by a German neurologist, Arnold Pick in 1892. It is similar to Alzheimer's in that it is a progressive degeneration over several years. It is a pre-senile Dementia with a 50-60 years old onset that causes atrophy of the frontal lobes of the brain and loss of cortical cells. Its condition can be identified after death by the characteristic differences to Alzheimer's in cell configuration.

CREUTZFELD JAKOB DISEASE (CJD) AND SPONGIFORM ENCEPHALOPATHY

Creutzfeldt Jakobs Disease is a rare and ultimately fatal condition, caused by an infectious agent which dominates in the brain and causes continuous mental and physical deterioration until death occurs. At the end stage, the individual is bedridden and has dementia, usually death following pneumonia, or similar infection. It may be dormant in the body for many years before activating, but once identified, death follows within one year. Discovered in 1920 by two German doctors, who both give their names to the disease, it now is said to affect 50 people a year, usually affects those over 55 years old.

Spongiform Encephalopathy is a 'New Variant' of CJD or 'Mad Cow disease' which is thought to be a condition caused in the 1980s by feeding cattle feed made up from infected animals such as sheep, which has a similar disease called Scrapie, which does not pass from sheep to man, but may have passed from sheep to cow, and then to man. It has caused the deaths of younger people in their teens, twenties, thirties and forties which although only about 10 cases a year, is a major concern for the future. Symptoms are similar to all dementias, but slow or slurred speech becomes noticeable and vision is often affected. Later symptoms show jerk like movements, tremors, incontinence and eventually an inability to speak or walk.

HUNTINGTONS CHOREA

A rare inherited progressively degenerative brain disorder characterised by profound Chorea movements which involuntarily throw the body into jerks, with torso and limbs affected. Initially these are mild and are disguised by performing a natural movement, i.e. an arm involuntarily moves, so the person brings their arm up and wipes their brow. In later stages the movement may be so profound that a head can be thrust against a door frame at either side because of the involuntary movement. Dementia is accompanied with this. Because of its severe form, Depression and Suicide are common.

ARTERIO-SCLEROTIC

Loss of elasticity of the artery walls, due to thickening, furring and calcification. In brain function it limits the supply of nutrients and oxygen which causes dementia.

AIDS DEMENTIA

HIV sufferers are prone to many differing forms of Auto Immune Disorders. Dementia is one of the categories for this.

GENERAL PARALYSIS OF THE INSANE (GPI)

Not seen so often today because of Antibiotic therapy, the condition is caused by sexual transmission of syphilis which attacks the body, and can lead to Dementia. Due to Central Nervous System degeneration the most noted aspects are Tabes Dorsalis, where the person does not recognise that they have their feet on the ground and push their feet down causing a distinct walking characteristic, and Rombergs Sign, where there is an inability to stand still when their eyes are closed, therefore they 'sway in the wind' and Argyll Robertson's Pupils, in which the eyes have an absence of response to light but not of accommodation.

ALCOHOLIC DEMENTIA

Memory, Learning and Other Cognitive Skills

Excessive drinking over a period of years may lead to a condition known as Alcohol Dementia, which can cause problems with memory, learning and other cognitive skills.

Alcohol has a direct effect on brain cells, resulting in poor judgment, difficulty making decisions and lack of insight. Nutrition problems which often accompany long-time alcohol abuse can be another contributing factor, since parts of the brain may be damaged by vitamin deficiencies.

Those suffering from dementia, may have very little ability to learn new things, while many of their other mental abilities are still highly functioning. Along with the decline in cognitive skills, sometimes noticeable personality changes take place.

CEREBRAL VASCULAR ACCIDENT (CVA) (STROKE)

Commonly known as a stroke, major blood vessels in either a blockage in the arteries of the brain or the brain blood vessels exploding causing death of brain cells. Dementia may be a characteristic, but also paralysis of limbs which may disable the individual. The paralysis is usually down on side of the body, and may cause problems with speech and communication.

BRAIN INJURY

Any brain injury which causes trauma and death of brain cells can have an effect on the mental ability of the individual to think, talk and understand. The injury may also have physical components as discussed above.

CEREBRAL VASCULAR ACCIDENT (CVA) (STROKE)

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MULTIINFARCT DEMENTIA (MID)

Vascular disease as seen in heart disease is not just specific to the coronary arteries. It affects all the arteries and depending where the weakest point is, the disease will cause the greater amount of illness. If the arteries are 'furred up', they lose the ability to maximise the oxygen content of blood that organs need to survive. With MID an individual may suffer many minor strokes, and show signs of dementia through areas of brain death. The effect of these mini strokes may make the individual experience 'dizzy spells', and with each mini stroke will come the increasing effect of dementia.

SIGNS AND SYMPTOMS

Loss of Memory - People - Places - Objects

AGRAPHIA

Inability to write cogently, absence of the ability to express thought in writing, due to muscular coordination or cerebral malfunction.

AGNOSIA

Difficulty in recognising well known objects

APHASIA

Difficulty in finding the right words. In conversation words either of a known kind, or neologism may be included in a conversation that makes the context difficult to understand. It may be in some cases that the individual may have a pain and is trying to say so, but nonsense is spoken. It is important to listen and think further than the words spoken

APRAXIA

Inability or difficulty in performing purposeful organised tasks or similar skilled activities. It is not uncommon to see someone taking a piece of clothing, such as a jumper, then see them trying to put the jumper on as a pair of trousers.

AGITATION

Mental and physical distress causing extreme restlessness, both in mental processes and in physical inability to relax. The individual can be distressed with the agitation, which may make the agitation worse. They may also make others in their company, distressed because of it.

DISORIENTATION

In time, place and person. Cannot recognise day from night, which may cause nocturnal wandering, they may not know where they are or where they should be, and therefore are a danger to themselves, as they may sustain injuries either by their actions, by perhaps getting lost and taking

a route which is not normally taken by others, or the actions of others, such as being run over by a vehicle or being assaulted for being in the wrong place at the wrong time. Painfully for their families, they may not recognise those around them, including their spouse who they may have lived with for 50 years.

LACK OF AWARENESS OF SURROUNDINGS

Some cope remarkably well inside their own Home, as they know where everything is. It is when they are taken out of a known environment that they tend to be unable to find their way around. It can be seen as a serious deterioration from how they were from home, yet it is only the change of environment that is the trigger. Knowing where the toilet is at home may have prevented incontinence which may be experiencing in an unfamiliar environment.

FORGETFULNESS

Is probably the first symptom of dementia, often joked about initially, then often the person will write notes in order to remember what to do until eventually they forget to write a note, or have written it but cannot find it.

FRUSTRATION AND ANGER

Not being able to comprehend or fulfil activities may leave the person a sense of their own limits which well up into a sense of frustration. Mood variations can also take place, causing emotional changes such as anger, which may or may not be for any known situation. That anger may well end up as aggression unless it is defused.

AGGRESSION

Out of frustration and anger of not being able to comprehend what is going on around them. Feelings of not being in control of what is going on may trigger the 'flight, fight and fear of an anxiety reaction. It may also be a symptom of a Paranoid reaction. This can be a symptom of constipation.

EMOTIONAL LABILITY

They may laugh inappropriately or cry for no apparent reason.

INAPPROPRIATE ACTIONS

The person may act in a way that is not appropriate to the situation. May put the umbrella in the toilet, or clean windows with oil. They are partly able to understand that something needs to be done, but the result is an inappropriate solution.

INCONTINENCE

In the early stages it will be evident that incontinence is happening, bedwetting may be a sign. The person may not realise until it is too late that they need to go to the toilet, it may be because they have forgotten where the toilet is or that they simply have no idea what is happening with their own body.

FIRE RISK

Because of their forgetfulness, gas or electric cookers or fires may be left on, food may be left burning on hob or fire may be out of control. If they smoke, they may forget what they have done with a cigarette, and set furniture alight.

SELF HARM RISK

Because of the memory failure, it is possible for mistakes or misinterpretations to be made. The individual may misinterpret one fluid for another, so metal polish may be seen as milk as it is the same colour. It is also possible for a variety of household aids, bleach, insect repellent, shampoos to be added to any meal. In the early stages this may be a crucial sign. Poor personal hygiene may be a risk, especially if their toileting skills have been lost, it is possible to sustain urine burns if the individual lays in a wet bed for long periods.

TREMORS

Because of the general disintegration of the brain and its cognitive function, especially in Parkinson's disease, tremors are common.

DEPRESSION

Depression may be a cardinal symptom of dementia, with possibly the realisation of what is happening to the person that their mental functions are diminishing. It may first appear to be a Reactive Depression, then later memory problems occur

SUICIDE

It is possible, either prior to diagnosis, or after diagnosis for the person to commit suicide. This may be as a result of a severe depression, or because the person feels they do not wish to burden their family, or even as a matter of pride.

TREATMENTS

REALITY ORIENTATION

A system of assisting confused or demented people to stay as much as possible in touch with the world on a day to day basis. Such items as large clocks, notice-boards with the day and date in large type, daily newspapers and large signs assisting them to the toilet with arrows to show the way. In more depth groups are held and conversations and discussions held in order to enable their mental functions to remain. Television, News, Pictures and Films are also part of this process.

REMINISCENCE THERAPY

This therapy enables the confused to stimulate long term memory, using old newspapers, pictures of a bygone age, memorabilia, songs, films and CD ROM historical events meaningfully relating to the time of their lives. Used often in conjunction with Reality Orientation.

DAY CARE

Where the confused or demented need more care than can be given at Home, Day-care Centres can be accessed to give a change of environment, which can also be used for Assessment which also gives carers a break. The amount of Day Care will be decided on need and or on any financial abilities or constraints of a particular budget, either of the Authority or of the family.

DIET

Many elderly confused fail to eat adequately, so their mental and physical deterioration is heightened. A full range of Proteins, Carbohydrates and roughage should be given as well as plenty of fluids.

MEDICATION

A variety of medications for the mind may be required, depending on the presenting problems. If there are behavioural or aggressive problems a Major Tranquilliser such as Chlorpromazine, or Melleril may be prescribed. Night Sedation may be required to ensure that the individuals body clock does not slip into nocturnal mode, Zopiclone may be prescribed. Diet Supplements may be given if the individuals appetite is poor, or if there is a difficulty swallowing. Vitamins/Iron may be prescribed on top of this. To prevent constipation, which tends to make the situation worse, Senakot may be prescribed. Where there is an underlying depression, Anti-Depressants may be prescribed.

DEMENTIA CARE BEST PRACTICE

Dementia is a syndrome in which progressive deterioration in intellectual abilities is so severe that it interferes with the person's usual social and occupational functioning. An estimated 5 to 10 percent of the adult population ages 65 and older is affected by a dementia disorder, and the incidence doubles every 5 years among people in this age group. Despite its relevance, dementia often goes unrecognized or is misdiagnosed in its early stages. Many health care professionals, as well as patients and family members, mistakenly view the early symptoms of dementia as inevitable consequences of aging. Dementia symptoms include: anxiety, paranoia, personality changes, lack of initiative and difficulty acquiring new skills.

Alzheimer/Dementia care requires a commitment to providing quality care.

It focuses on the person and always recognizes the individual with respect and dignity.

The following dementia best practices focus on early recognition of symptoms and what care providers, routines, activities and environments must do, to change and not the resident who is doing their best with diminished capacity.

Does the person have increased difficulty with any of the activities listed below?

Knowledge of the resident's previous levels is invaluable in assessing symptoms and interpreting results. Positive findings in any of these areas generally indicate the need for further assessment for the presence of dementia.

Report results to the attending physician.

Learning and retaining new information.

For example: Is more repetitive; has more trouble remembering recent conversations, events, and appointments; more frequently misplaces objects.

• Handling complex tasks.

For example: Has more trouble following a complex train of thought, performing tasks that require many steps such as balancing a cheque book or cooking a meal.

• Reasoning ability.

For example: Is unable to respond with a reasonable plan to problems at work or home, such as knowing what to do if the bathroom flooded; shows uncharacteristic disregard for rules of social conduct.

• Spatial ability and orientation.

For example: Has trouble driving, organizing objects around the house, and finding his or her way around familiar places.

• Language.

For example: Has increasing difficulty with finding the words to express what he or she wants to say and with following conversations.

• Behaviour.

For example: Appears more passive and less responsive; is more irritable than usual; is more suspicious than usual; misinterprets visual or auditory stimuli. In addition to failure to arrive at the right time for appointments; the clinician can look for difficulty discussing current events in an area of interest and changes in behaviour and dress. It might also be helpful to follow up on areas of concern by asking the patient or family members relevant questions.

Focused Dementia Care

Focus I. Assessment and Care Plans

Assessment is crucial to the development of a useful care plan. The abilities and needs of the resident with dementia change throughout the disorder at a rate and in a course that is highly individual to that person.

Families can provide information regarding the resident's prior life, customary routines, preferences, behaviour triggers, and results of attempted interventions. They can help interpret language, nonverbal interactions and the meaning behind the behaviour's affected by major life events and traditions. Include carer's in the assessment process, as they are an integral part as they notice subtle, individual cues they've come to understand.

Ask questions in a systematic way, write down the answers, and observe. Also, describe a situation and then ask why the situation exists.

Occasions For Assessment

Preadmission/Admission

- How long might this person stay at this level of need and ability?
- What is this person's history and current status?
- What are this person's preferences, habits, and daily routines?
- How will this person fit in socially with other residents?
- Is this person and our program a good fit?

Care Plan Development

What does this person need from us to meet his/her own life goals?

Who needs to help residents with efforts to meet those goals?

How can we operationalize goals into concrete, measurable objectives?

How can we adapt our care and services to the resident's schedules and needs rather than expecting that the resident adapt to ours?

How can staff carer's be flexible and adapt care to the changes this resident may go through?

How can we compensate for deficits and build on the abilities a resident has retained?

Ongoing Documentation

What is the "baseline" level of ability, functioning, and behaviour for this resident?

How can we measure the overt and subtle changes occurring daily?

As the resident's abilities and needs change, how should our care plan change?

What is the impact of the initiation of an intervention?

What is working and what isn't?

What differentiates good from bad days?

Problem Analysis and Resolution

Why is this behaviour occurring in this resident at this time?

Is this behaviour consistent with the past?

What needs or desires are evident in the behaviour?

What is occurring in the environment, in interactions with this resident, and within this resident

at the time of the behaviour?

Does the behaviour reflect changes in the resident's physical/medical status or the effects of medications?

Situational Decision Making

What is the most urgent at this time?

Why is the resident doing this?

What is triggering this in the environment, the interactions with this resident, within this resident at this time?

How is the resident experiencing this event right now?

What are the response options?

Focus II. Ongoing Resident Care

Day to day care should be individualized based on the resident's capabilities, physical health, behavioural status, and personal preferences. Goals should include:

- maintaining maximum independence in ADL's,
- safety and security, minimizing
- discomfort,
- special attention to medical conditions,
- special attention to skin, feet, teeth, gums, the perineal area and bowels; promotion of nutrition and hydration,
- provision of physical conditioning and fresh air;
- appropriate level of stimulation,
- achievement and maintenance of a good mood,
- maintenance of dignity, family
- involvement/satisfaction and promotion and support of functional skills of bowel and bladder continence.
- Ongoing treatment and management of behavioural symptoms is a major element of the care and in the effective treatment of the disease.

Five general modalities are available for the treatment of behaviours are:

- Address difficult behaviours analytically. Assess the resident in the situation in which the behaviours are occurring.
- Analysis of the behaviour and its causes should precede any consideration of the use of medication or physical restraints to control the behaviour.

Problem Solving Outline For Challenging Behaviour

Assess The Behaviour To Discern Why The Resident Is Engaging In The Behaviour

1. Describe in detail the behaviour

Include what occurs, when it occurs, how often it occurs, and who else tends to be involved in the situation in order to discern the pattern of the behaviour. Be very specific and use objective terms (e.g., "Mrs. S struck caregiver's shoulder with open hand when the carer was leaning over to tie Mrs. S's shoe," rather than "Mrs. S was combative during her care").

Describe conditions regarding the behaviour. Identify what preceded and what resulted from the behaviour.

Document the occurrence and conditions of the behaviour for a period of time to establish a baseline.

2. Examine the extent to which the behaviour is a problem

Identify who is raising the concern about the behaviour (family member, carer, staff, the person with dementia, or other residents).

Who experiences the behaviour as a problem? Is anyone in physical or other danger as a result of the behaviour?

Can the problem be solved by reducing others' exposure to the behaviour rather than changing the behaviour itself or by changing others' tolerance level for the behaviour (such as staff perceptions and tolerance for sexual invitations or swearing)?

3. Try to discern why the resident is engaging in the behaviour, by examining 1& 2 above

To what extent can the behaviour be explained by understanding the way the individual with cognitive deficits experiences and reacts to the situation? For example, does hitting or screaming during undressing occur because the resident feels threatened?

Did something in the environment trigger or cause the behaviour? For example, is there too much, too little, or an inappropriate type of stimulation? Is there a change in the environment?

Is the task too difficult? Are there too many task steps to keep in order?

Is there something about the resident's preferences, habits or expectations that has been affected? For example, is the resident used to eating breakfast before taking a bath?

To what extent is the resident's health or emotional status playing a role?

4. Identify the interventions attempted to date that have and those that haven't worked. Examine the conditions under which interventions are more likely to be effective.

Modalities For Treatment Of Behaviours

1. Prevention of the problem through care staff education (especially about recognizing what

happens before a behavioural crisis erupts) and the provision of meaningful activities.

2. Behavioural management through changing the environment, i.e., identification and removal of triggers of disruptive and replacement with more pleasant stimuli. For example: unpleasant stimuli (noise, commotion, or sun glare).

3 Behaviour modification directed at discouraging unwanted behaviour and/or rewarding desired behaviour, but this may not be a useful approach in the late stage of the disease.

4. Distraction (e.g., preventing biting by giving food) or engagement in meaningful activities.

5. Medication

Focus III. Programmes

The challenge of designing a program that meets the needs of residents with dementia and fits the interests, habits, values and abilities of these individuals is the responsibility of the care staff. The purpose of programming is to help a resident express herself as the person he/she knows themselves to be in a way that accommodates their disability and honors their abilities, values, habits and familiar roles.

There are activities that help one feel safe, in charge, a part of a group, loved, and loving come from the day-to-day, moment-by-moment events and encounters of life.

A full balanced life depends on successfully performing activities from the following three domains:

- Productive Activities (work) - That make us feel useful and needed
- Leisure Activities - Relaxation and entertainment that are fun
- Self Care Activities - Personal and instrumental activities of daily living through which we express our independence and the intimate personal aspects of our personality.

The amount of satisfaction one gets from doing things that make each day goes a long way to determining our overall satisfaction with life.

To be meaningful, an activity will meet the following criteria:

Activity Programming

1. Have a purpose that the resident can appreciate and endorse. Does the resident know what he is doing and why?

2. Be done voluntarily. Does the resident really want to do this or is she being coerced?

3. Respect the resident's age and social status. Avoid activities that feel or look childish or socially inconsistent with resident's status. The product of any activity must also be appropriate to adults. For example, instead of making figurines with plasticine, use gingerbread dough and bake them into cookies.
4. Take advantage of the resident's retained abilities. Security depends on being in control and control depends on being able.
5. Ensure an opportunity for success.
6. Feel good. When the resident is unable to remember or anticipate, there is no place for "present pain for future gain." The actual activities that will meet the above criteria differ from individual to individual.

Each individual needs and deserves individualised program planning based on the best possible evaluation of his abilities, interest, habits and needs.

When presenting an activity don't ask; direct and inform and phrase it politely. Give strong, concrete cues. Point to the thing or demonstrate the action. Initiate the activity with the resident watching so he/she can see what is expected. Trigger an automatic reaction. For example, it is easier to respond when one is simply handed an article instead of being told to find it and pick it up. Be sure that the activity is within the resident's ability to understand and perform. If the person is truly refusing to participate, respect his/her right to refuse. Minimize distractions, turn off TV's and radios, and avoid "crossfire" conversation, in which staff members are talking to one another over the resident's head.