NHS Ealing

# Dementia

## Awareness Handbook

NHS
Ealing

# Introduction

**It is likely that you are reading this handbook because you, a relative, friend or someone you work with in a professional capacity has, or may have, dementia. And so, this is likely tobe a worrying and difficult time for everyone involved. This handbook draws on the wide experience of those caring for people with dementia, so we know that much of your concern or fear may come from not knowing how to cope, what to expect, or what is likely to happen in the future.**

We recognise every person is different, and so the experiences of those with dementia, and their carers will vary. This guide aims to address a variety of your concerns, by providing information about dementia, and what to expect along the way.

The handbook contains a great deal of information that covers issues that may arise at different stages of the illness, and it may feel overwhelming to read the whole handbook. Instead, you may prefer to re-refer to the handbook from time to time.

You may also want to look further into some of the issues that are raised in the handbook, so please see Chapter 12 *'Useful Contacts & Services'* for other resources available to you.

In 2008 Ealing NHS assessed the current health and social care system for dementia taking a 'whole system' approach. In line with the National Dementia Strategy 2009, a local Ealing strategy was developed, incorporating public health initiaives of which this handbook is a key element.

This handbook was developed within NHS Ealing's Older Peoples Mental Health Group in close partnership with Alzheimer's Concern Ealing (ACE), West London Mental Health Trust and Ealing Council.

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ALZHEIMER'S CONCERN EALING ACE
West London Mental Health NHS Trust
Ealing
NHS Ealing

*"I rely greatly on my wife and my carers... I'd be in terrible trouble without them"*

(person with dementia)

# 1. What is dementia?

**Dementia is a group of related symptoms that is associated with an ongoing decline of the brain and its abilities. It is a common disease that is not an expected result of ageing.**

The term 'dementia' is used by doctors, to describe the different diseases that affect the brain and how it works, in areas such as:

- *thinking*
- *language*
- *memory*
- *understanding*
- *judgement*

We all tend to become more forgetful as we age. But dementia is different. It is a brain disease which often starts with memory problems but goes on to affect many other parts of the brain, producing:

- *difficulty coping with day-to-day tasks*
- *difficulty communicating*
- *changes in mood, judgement or personality*

People who suffer from dementia can still have a good quality of life for many years; whilst the ability to carry out your daily activities will continue to deteriorate. In the later stages the person will begin to lose some of their independence, and will need to rely on others for help.

Dementia is a disease that often goes undiagnosed due to poor awareness and understanding of what it is; combined with the stigma attached to both mental illness and old age.

# 2. What are the general signs & symptoms I should look for?

**The following difficulties are commonly experienced in the earlier stages of dementia. If you recognise that you, or someone you know, are experiencing 3 or more of the following, please speak to your GP regarding your concerns.**

**They include:**

- *Memory loss, such as regularly forgetting recent events, names and faces.*
- *Regularly misplacing objects or putting them in odd places.*
- *Confusion about the time of day.*
- *Failing to recognise familiar places, and difficulty in finding their way around, especially in new or unfamiliar surroundings.*
- *Problems finding the correct words, or understanding other people.*
- *Poor concentration.*
- *Excessive tiredness after an activity.*
- *Problems learning new ideas or skills.*
- *Constantly repetitive questioning.*
- *Difficulties with thinking and reduced judgement, such as finding it hard to lay a table, and being unaware of danger.*
- *Mood or behaviour change such as becoming irritable, saying or doing inappropriate things, becoming suspicious or aggressive.*
- *'Year of silence' may be experienced before other symptoms appear where it is very difficult to get any response from the person who may have dementia.*

Although the symptoms above may indicate the possibility of dementia, it is also important to rule out other treatable conditions with symptoms similar to dementia. For example, depression and dementia can be sometimes mis-diagnosed.

**If you have concerns that either you or the person you care for is displaying signs of dementia, it is important to speak to your GP to seek advice and support.**

# 3. Who is affected by dementia?

**Dementia is a common disease that can affect anyone regardless of their age, gender, ethnicity, or financial situation.**

It is estimated that there are over 570,000 people in England living with dementia and with increasing life expectancy; the numbers are set to rise.

(Department of Health, 2009)

Dementia is most common in older people, and is called 'late onset dementia'. Research shows that:

- *1 in 20 people aged over 65 have dementia.*
- *This number increases to 1 in 5 people by the age of 80.*

(Royal College of Psychiatrists 2009)

However, dementia can sometimes start in people as young as 40, and it is estimated that there are 15,000 people in the UK under the age of 65 who have 'early onset' dementia.

(Alzheimer's Society 2007)

In 2007 in Ealing, there were an estimated 115 people with early onset dementia and 2,500 people with late onset dementia.

(System Review of Dementia Services in Ealing 2009)

## Dementia affects...

*... both men and women, however in Ealing and the rest of the UK, there are more women affected than men.*

*People with learning disabilities may experience a higher risk of dementia because of premature ageing or increased genetic risk.*

*Black and minority ethnic populations in the UK, have higher rates of 'early onset dementia' compared with the rest of the UK population.*

(System Review of Dementia Services in Ealing 2009)

# 4. What factors can affect whether I develop dementia?

**As with any health issue, there are no set rules that decide who will develop a form of dementia; however there are some factors that may increase the likelihood of it developing. These factors include:**

## Age

As we get older, the risk of developing dementia increases. This is due to factors such as:

- *high blood pressure*
- *weakened natural repair systems*
- *higher risk of certain diseases that cause heart attacks and strokes*

## Genetics

In some families, it is clear that dementia is passed down through the family and 'inherited'. Our genetics also play a part in terms of hereditary diseases such as Huntingdon's disease and Alzheimer's, both of which can cause symptoms of dementia.

## Medical history

Your medical history and certain health issues such as Multiple Sclerosis, Downs Syndrome and HIV can increase the likelihood. Having experienced repeated head injuries is also known to increase the risk.

## Lifestyle choices

Your lifestyle choices such as having an unhealthy diet, smoking, drinking too much alcohol, and not getting enough physical exercise can all contribute.

# 5. What can I do to reduce the likelihood of developing dementia?

**Whether or not you feel you are at risk of developing dementia, there are plenty of things that we can do to improve our health, and help to reduce the likelihood of its onset.**

## Eat healthily

A diet of fruit, vegetables, cereals, some fish, moderate amounts of alcohol, and a little dairy and meat is recommended to help lower the risk of dementia.

## Keep physically active

The recommended level of physical activity is 30 minutes most days. Do things that you enjoy such as:

- *Go for walks alone or with friends and family.*
- *Walk or cycle instead of taking the car.*
- *Gardening, washing the car or cleaning windows.*

## Exercise your mind

Try new things to keep your brain active. Carry on doing things you already enjoy that stimulate your brain, such as reading, playing cards, board games and doing crosswords.

## Watch your blood pressure & cholesterol

Ask your GP to check them regularly so that you receive advice on how to manage any issues that arise.

## Maintain a healthy weight

Obesity has been linked with an increased risk of dementia, so try to stay in shape.

## Don’t smoke

Smoking has a harmful effect on the vascular system, therefore increasing the risk of vascular dementia.

## Maintain your social networks

A recent Swedish study found that having an extensive social network seems to protect against dementia. People with a poor or limited social network had a 60% increase in the risk of dementia so stay involved in the world around you.

(Alzheimer Scotland: Action on Dementia Leaflet)

- *Keep in regular touch with friends and family.*
- *Volunteer for something that interests you.*
- *Join a club or group.*

# 6. What causes dementia?

**Dementia is a term used to describe a group of symptoms that occur as a result of structural and chemical changes in the brain. Individuals may have a number of different forms of dementia.**

## Alzheimer’s

Alzheimer’s is the most common cause of dementia, with 62% of all cases. Alzheimer's disease attacks nerves, brain cells and neurotransmitters (chemicals that carry messages to and from the brain), leading to the death of brain cells.

The damage causes clumps of protein, known as 'plaques' and 'bundles', to form around the brain's cells. The plaques and bundles then start to destroy more connections between the brain cells, which worsens the condition.

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*
- *become more withdrawn, due either to a loss of confidence or to communication problems*

In the later stages, it will cause severe intellectual, behavioural and physical problems, including loss of speech, immobility, incontinence and frailty.

# Vascular Dementia / Mixed Dementia

**Vascular dementia is the second most common cause of dementia with 17% of all cases. It is caused by problems in the supply of blood to the brain.**

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, the cells will eventually die. This can lead to the onset of vascular dementia.

**The main types of vascular dementia include:**

- *One caused by stroke, called either 'singular' or 'multi infarct' dementia.*
- *Another caused by small vessel disease called either 'sub-cortical vascular dementia' or the more severe type 'Binswangers disease'.*
- *'Mixed dementia' where someone experiences dementia caused by Alzheimer's disease, combined with stroke and/ or small vessel disease. This type accounts for 10% of all dementia cases.*

**People with vascular dementia may experience:**

- *difficulties in concentrating*
- *problems communicating*
- *symptoms of stroke, such as physical weakness or paralysis*
- *depression*
- *epileptic seizures*
- *hallucinations and delusions*
- *periods of acute confusion*

They may also experience symptoms being constant for a period of time, and then a sudden deterioration.

# Dementia with Lewy Bodies (DLB)

**Dementia with Lewy bodies (DLB) is a form of dementia that shares characteristics with both Alzheimer's and Parkinson's disease, and accounts for 4% of all cases.**

Lewy bodies are tiny, spherical protein deposits found in nerve cells. Their presence in the brain disrupts normal functioning, interrupting the action of important chemical messengers. Researchers have yet to understand fully why Lewy bodies occur in the brain and how they cause damage.

Lewy bodies are also found in the brains of people with Parkinson's disease, a progressive neurological condition that affects movement.

**They may experience:**

- *issues with attention and alertness*
- *difficulty in planning ahead and co-coordinating mental activities*
- *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*

Although memory is often affected, it is typically less so than in Alzheimer's disease.

# Fronto-temporal Dementia (Pick's Disease)

**The term 'fronto-temporal dementia' covers a range of conditions, including:**

- *Pick's disease*
- *Frontal lobe degeneration*
- *Dementia associated with motor neurone disease*

All are caused by damage to the frontal lobe and/or the temporal parts of the brain, is quite rare and accounts for 2% of all dementia cases.

Typically, during the initial stages, the person's memory is still intact but their personality and behaviour changes.

**People with fronto-temporal dementia may:**

- *Lack insight, and lose the ability to empathise with others. This can make them 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 their inhibitions, for example, exhibiting sexual behaviour in public.*
- *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 disease.*

# Other causes of Dementia

***Korsakoffs Syndrome***
is a brain disorder that is usually associated with heavy alcohol consumption over a long period of time. The main symptom of this type of dementia is memory loss, especially after the condition has started developing.

***Creutzfeld Jacob disease (CJD)***
is extremely rare, and is a part of a group of diseases called Prions disease which affects proteins in the brain causing brain cells to die, and therefore causing dementia.

***HIV-related cognitive impairment***
is sometimes found in the later stages of HIV and Aids, and is caused either by the HIV infection itself, or other infections. The chances of this occurring are reduced by taking medication.

# 7. What should I do if I think a relative or a friend has dementia?

## Seeking a diagnosis

**If you are concerned about a friend, relative or even yourself, then seeking help as soon as possible is advisable, and your GP should be the first point of contact.**

An early diagnosis can:

- *rule out other treatable causes of the symptoms*
- *enable the individual to benefit from treatment*
- *help you to identify sources of support and advice*
- *help you to cope with caring for the person*
- *enable you to plan for the future*

## How is dementia diagnosed?

**Dementia can be diagnosed by a GP, or the person may be referred to a specialist.**

Since all types of dementia have similar symptoms, it can sometimes be difficult to tell which type a patient has. A diagnosis is usually made based on the description of how the person is affected, psychological changes, risk factors and family history.

Older people with dementia are often unaware that they are experiencing symptoms and may be unaware that they need help. Therefore, it is essential for the caregiver, close relative or someone who knows the patient well, to provide an independent history of the person, who may have dementia.

The diagnosis may involve:

- *Memory tests, such as the mini-mental state examination (MMSE), which is a series of questions and tasks that test memory, language and mathematical skills.*
- *A physical examination with blood and urine tests may be done to help exclude other causes of memory problems, and different types of dementia.*
- *Other investigations such as a CT (computerised tomography) brain scan or an MRI (magnetic resonance imaging) brain scan may be carried out.*
- *Being referred to a "memory clinic" that specialises in diagnosing conditions like Alzheimer's.*

## Getting the most from a consultation

- *It may be useful to write down any questions or worrying signs beforehand to take with you.*
- *It can be difficult to remember everything you want to say during an appointment. You may also want to write down the important points.*
- *Don't be embarrassed to ask the doctor to explain any words or phrases that you don't understand.*

Finding out that you or a loved one has dementia is distressing, but understanding that there is a cause for the changing behaviour can be reassuring, and the first step in learning how to adapt to the changes.

## What if a diagnosis isn't given?

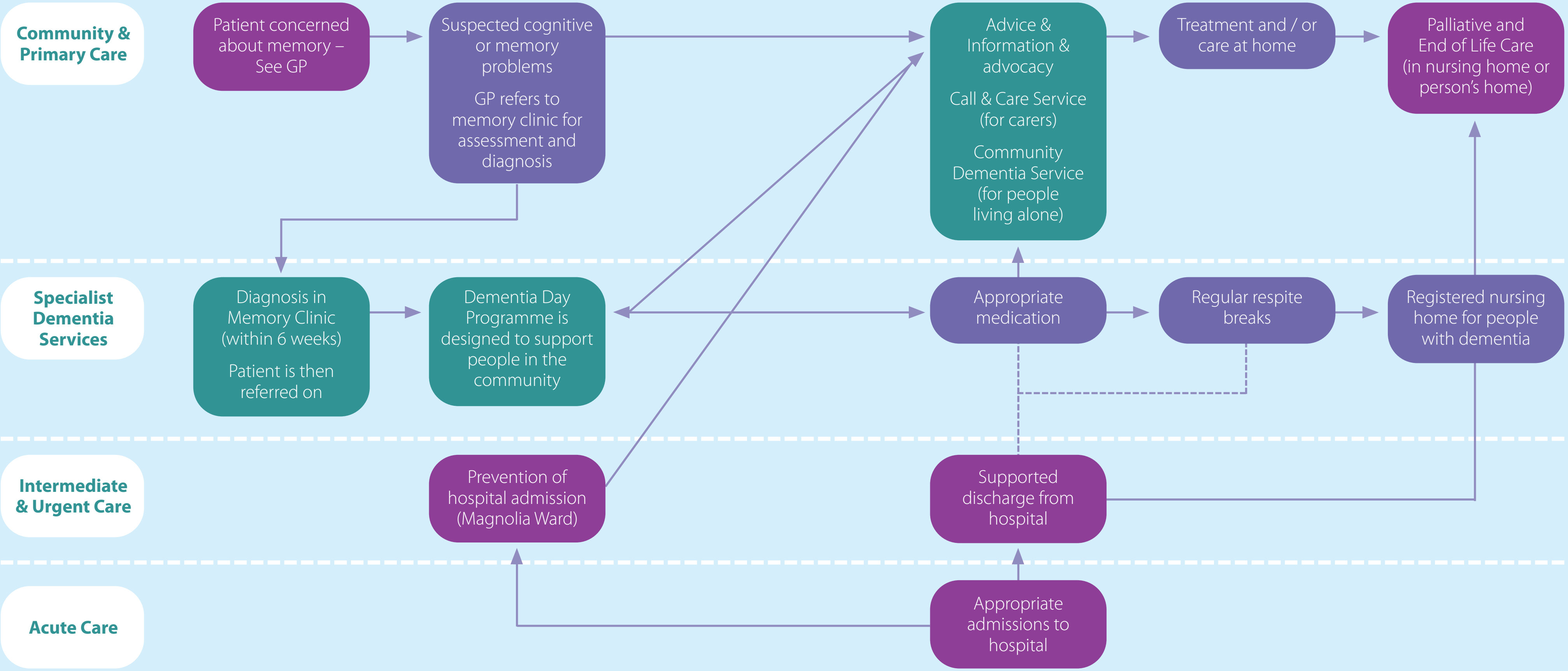
It may be possible that even after raising your concerns to your GP, that a diagnosis or cause may not be found. You are the expert of your situation, and only you know if there is still something wrong. If this is the case, it may be worth asking your GP to be referred to a specialist either through the Community Mental Health Team (CMHT), or the Integrated Day Care Services.

You may need to be assertive when requesting the referral, however you deserve to find out what is causing you problems. If you feel unable to do this alone, you can contact an advocacy service (See Chapter 10 for definition and 12 for contacts), who can advise and help you to speak to your GP about this.

# Dementia Care Pathway

**Pathways help us to highlight a person's path through a health system, emphasising the various forms of support.**

The pathway below indicates the current health and social care system for dementia within Ealing.



**Community & Primary Care**

Patient concerned about memory – See GP

Suspected cognitive or memory problems

GP refers to memory clinic for assessment and diagnosis

Advice & Information & advocacy

Call & Care Service (for carers)

Community Dementia Service (for people living alone)

Treatment and / or care at home

Palliative and End of Life Care (in nursing home or person's home)

**Specialist Dementia Services**

Diagnosis in Memory Clinic (within 6 weeks)

Patient is then referred on

Dementia Day Programme is designed to support people in the community

Appropriate medication

Regular respite breaks

Registered nursing home for people with dementia

**Intermediate & Urgent Care**

Prevention of hospital admission (Magnolia Ward)

Supported discharge from hospital

**Acute Care**

Appropriate admissions to hospital

# 8. What happens after receiving a diagnosis of dementia?

**No one can be fully prepared for receiving a diagnosis of dementia. People describe the mixed emotions they experience at this time as shock, anger, depression, fear, resentment, guilt and despair.**

> *"The worst part was telling the kids. One daughter... just doesn't want to know, the other one is in denial, and my son knows more than I do."*
>
> (person with dementia)

> *"I rely greatly on my wife and my carers... I'd be in terrible trouble without them"*
>
> (person with dementia)

> *"The consultant said 'it's dementia' and I just burst into tears because I was so... I half expected it but it's still a terrible shock."*
>
> (carer)

There are also positive things to come from being diagnosed. Some people experience a sense of relief after receiving a diagnosis, asit can provide an understanding of the reasons for the change in behaviour, experiences, and feelings. It will allow you to learn about the causes of your difficulties, and find ways of adapting to the changes.

It also provides you with the opportunity to plan for you and your family's future; to access appropriate support and services as early as possible; and to find ways to continue to be as independent as possible, and enjoy your usual activities, employment and way of life.

## Talking things over

Sharing your diagnosis with those close to you is likely to be difficult. Informing people is important, as maintaining and improving your support network will be vital in coping with dementia, especially during more difficult times.

People are likely to react in different ways; some may feel upset by the news, whilst others may deny that there is anything wrong. Discussing these matters in a calm way, in a place where you feel comfortable may make this easier.

Children and young people also need to know what is happening. You may want to protect them from difficult or confusing situations, or not be sure how much information to give them. However they can often 'sense' that something is wrong, so it is important to explain to them what is happening, in an honest and clear way. They will need reassurance, which can be given by talking to them, providing the opportunity to ask questions, and by giving them the chance to be involved.

You may also find it beneficial to speak to someone outside of your family or friends, and this support could be gained from counselling or local support groups (See section 12).

## Accessing services & support

It is important to identify and access support and services available to you, as soon as possible. Due to the number of people experiencing dementia, there are often waiting lists for services, as dementia is a disease that varies over time, you may otherwise not be able to access the service when it is most needed.

## Planning ahead / putting affairs in order

It is vital that all important papers are in order and that you know where to find them. These papers might include bank and building society statements, records of mortgage or rent, insurance policies, a will, tax and pension details and bills or guarantees.

## Making a Will / Advanced Directive

In the early stages of dementia, it is usually possible to be fully involved in the planning process, whereas later on this may not be possible. Under the new "Mental Capacity Act", people are strongly encouraged to write an advance decision, also known as a 'living will'. This is a statement that sets out what you would like to happen if you are unable to make decisions in the future. This could include your preferences about:

- *nursing home care*
- *what treatments you do and don't want*
- *whether you want to be resuscitated in an emergency*
- *who you would like to make decisions on your behalf*

If you are a lesbian, gay, bisexual or transgender (LGBT) person, it may be beneficial for you to ensure that a living will is completed to specify your wishes for your partner's involvement in your life, especially where your family or friends struggle to recognise how important your partner is to you. This includes their involvement in your care, but also living and financial arrangements.

Giving a copy of this plan to everyone involved can help reassure you that your wishes will be respected. If you need help with writing an advance directive, a solicitor will be able to advise you.

> *"I need to make those decisions while I have enough mental capacity to be able to do that and to understand the implications of it before I get too far down the line. So it has given me the time to think about that. That is important."*
>
> (person with dementia)

# The Lasting Power of Attorney: A Brief Overview

## What is a Lasting Power of Attorney (LPA)?

An LPA is a legal document that you (the Donor) make using a special form. It allows you to choose someone now (the Attorney) that you trust to make decisions on your behalf about things such as your property and financial affairs or health and welfare at a time in the future when you no longer wish to make those decisions, or you may lack the mental capacity to make those decisions yourself.

It is 'completed' in advance and is then 'kept' until needed. During this period it cannot be used and the person continues to make decisions themselves. It is then 'registered' with the Office of the Public Guardian and from this point on it can be used, and the other people are then able to make decisions on the person's behalf.

Types of LPA are shown overleaf.

### The types of LPA

There are two different types of LPA:

#### 1. Health & Welfare LPA

**Allows the people you choose to make decisions about, for example:**

- *giving or refusing consent to particular types of health care, including medical treatment decisions*
- *you staying in your own home, perhaps with help and support from social services*
- *you moving into residential housing and choosing the right care home for you*
- *day-to-day issues like your diet, dress, or daily routine.*

#### 2. Property & Financial Affairs LPA

**Allows the people you choose to make decisions about, for example:**

- *Buying and selling your property*
- *Opening, closing, and operating bank/building society accounts*
- *Claiming, receiving and using your benefits, pensions, and allowances.*

A person who is chosen to be the attorney for 'Property & Financial Affairs' doesn't automatically become the attorney for 'Health & Welfare' as a separate form will need to be completed.

### How to make an LPA

To make an LPA, you must use a special LPA form, also known as the 'instrument'. You can download the form from the 'forms and booklets' section of the Office of Public Guardian website or get copies from their Customer Services (See section 12).

## Benefits

Claiming benefits can be a long and complex process however they could make a great difference to your life, and should be claimed.

### Things to know about benefits

- *To qualify for any benefit, the person with dementia or their carer will have to meet certain conditions. These vary according to the type of benefit.*
- *Some of the conditions include whether you have paid national insurance contributions over a period of time; how old you are; what your weekly income and savings are; and some of the practical effects of a disability.*
- *Sometimes, getting one benefit may increase your entitlement to another and sometimes it may prevent you claiming another benefit, or reduce the amount you can claim.*
- *As a minimum, someone with dementia will usually claim attendance allowance or the disability living allowance care component.*

## Filling out the forms

There are a number of different ways of getting information and advice on benefits, as well as help filling in forms, which can be complicated.

**They include:**

- *A professional, such as a social worker.*
- *Organisations such as the Carers Centre and Alzheimer's Concern.*
- *Job Centre Plus.*
- *If English isn't your first language, it may be necessary to seek help from someone within your own community; a local group such as the Racial Equality Council; or access telephone translation services.*

## What help may be available?

**Some of the financial help that may be possible for you to claim includes:**

- *Benefits to support your daily living, if you do not work.*
- *Help to pay your rent and/ or your council tax.*
- *Access to a social fund to pay one off expenses.*
- *Payments to help with heating costs.*
- *NHS benefits.*

## Benefits in hospital

Benefits may be affected if either a carer or someone with dementia goes into an NHS hospital for more than a short continuous stay. In this case, it is important to seek advice and inform the local social security office or Job centre Plus office.

# Adapting to change

## Driving

- *By law, you must inform the DVLA, who will gather information about your condition and decide whether to give a limited license or revoke it.*
- *You also need to inform your insurance company.*
- *You can still drive if it is safe to do so, and this can be assessed by participating in a driving assessment test to find out how your driving is impacted by your illness. As dementia progresses, it is likely that you will need to stop driving and use alternative methods of transport.*
- *It may be possible for you to get a Freedom Pass, a discount mainline train card, and also access to a taxi service. You will need to discuss this with social services.*

> *"Everybody I have met has been absolutely amazed that I can still talk and still think, even though I have a diagnosis of dementia."*
>
> (person with dementia)

## Working

- *Eventually, you will need to inform your employer, especially if experiencing difficulties. They may be able to adjust the job role to meet your needs by changing or reducing responsibilities; and providing flexible or reduced working hours. Your employer may also be able to receive funding to support the changes being made.*
- *You may wish to stop working, and so you will need to seek information on your pension and which benefits you may be entitled to.*
- *If you feel you are being treated unfairly at work due to your condition, you can contact the 'Equality and Human Rights Commission' (See Chapter 12 for contact details).*

## Maintaining healthy relationships

Dementia will bring changes to your relationships, especially with your spouse or partner. Good communication between yourself and your partner is essential, as it is with other people, including your friends and relatives.

Sexual intimacy is often not a subject discussed however it is affected by dementia, yet it can be a source of mutual comfort, support and pleasure.

Changes that may be experienced include:

- *more, less or no interest in sex*
- *more or less ability to perform sexually*
- *changes in sexual 'manners', for example, appearing less sensitive to the other's person needs or appearing sexually aggressive*
- *changes in levels of inhibitions*

(Alzheimer's Society 2007)

If this is something that is causing concern for you, many people find it helpful to either talk to those who are in a similar situation, to seek advice on ways of dealing with it; or perhaps speak about it anonymously through telephone support lines ( See Chapter 12).

## Moving

There may come a time when living at home becomes too difficult, and you may prefer to move to a residential home, either as a temporary or permanent measure.

This is likely to be a difficult decision, and issues such as payment can be complex, so it is important to consider it well in advance, especially so you can have a say in how and where you might be cared for.

The local social services will be able to give advice on care homes in your area, and on whether you can get financial support.

# 9. Managing and treating dementia

**Dementia is a disease that, once it has started to develop, it cannot be reversed, and is non curable. However it is possible to delay the progression of some dementias, and can be effectively managed to allow many people to continue living a good quality of life for many years.**

This is achieved through a palliative care approach, which manages not only physical symptoms, but also the psychological, social and spiritual aspects of dementia.

# Staying healthy

**Staying healthy is paramount. There are many things one can do to maintain their health. This includes:**

- *Eating healthily and drink plenty of fluids to maintain general good health and also to prevent malnutrition and dehydration, which are the most common causes of hospitalisation of people with dementia.*
- *Sleeping well by avoiding caffeine before you go to bed, using lavender aromatherapy or room sprays to help you to relax. Your sleep needs change as you get older, and you may not need as much. Also, if you nap during the day, this will affect how much you can sleep at night.*
- *Exercising regularly and participating in daytime activities which will help to maintain your general health, and to sleep better.*
- *Considering the implications of drinking alcohol as it is likely to interact negatively with any medication being taken, but will also worsen confusion.*
- *Visiting the GP regularly for general health checks. You should attend even for minor complaints, as they can have a big impact on your overall well being and ability to cope.*

# Creating a safe home environment

People with dementia will experience a change in their abilities that will increase the likelihood of accidents occurring. It is impossible to create a completely risk free environment, however many things can be done to reduce the chances of an accident happening.

An **'OT'** or **'occupational therapist'** can help you to make the changes in your everyday life and to overcome practical problems.

**They do this by:**

- *providing advice*
- *looking at ways an everyday task can be done differently*
- *recommending alterations or changes to your home*
- *referring you on to other services that can help*
- *helping you to address work-related issues*

www.direct.gov.uk

The changes that need to be made vary depending on individual needs, and may need to be adjusted as the illness develops.

**Some ways your home can be made safer include:**

- *Ensuring the lighting in your home is bright enough, and ensuring there are lights to help the person if they need to see at night.*
- *Preventing trips and falls by keeping the floor clear of rugs, wires and clutter; and installing adaptations such as handrails.*
- *Making sure that dangerous substances such as poisonous liquids are locked away.*
- *Changes to kitchen, which may include moving sharp objects.*
- *Having gas and smoke detectors installed in the home. Both smoking and electric blankets pose a risk to people with dementia as, if forgotten about, they can cause a fire.*

## Speech & language therapy

Speech and language therapists offer assessment, therapy, advice and support with difficulties related to dementia, including:

- *Speech, language and communication.*
- *Memory and information processing.*
- *Eating, drinking and swallowing.*

## Physiotherapy

Dementia can cause reduced mobility and so, based on the individuals needs, the role of the physiotherapist can include:

- *Improving the range of movements.*
- *Reducing the risk of falls.*
- *Promoting health and well being through massage, exercise and movement.*

## Pharmaceutical drugs

Pharmaceutical drugs are used to reduce some of the symptoms of dementia, and slow the progression of the illness.

It is advised that non drug treatments should be tried first, and used as long as possible alongside drug treatments, as appropriate, especially where there is aggression and restlessness.

**The different types of drugs that are used include:**

**Anti-convulsion**
*Used to manage aggression and agitation.*

**Anti-dementia**
*Used to manage aggression and agitation; and used in Alzheimer's to delay onset of behaviour change.*

### Anti-psychotics

*Used to manage restlessness and aggression.*

### Anti-depressants

*They are used to manage the rapid mood swings that can sometimes occur. Often, symptoms of depression are often present after diagnosis; however other approaches such as exercise, and activity programmes, should be tried first.*

## Risks involved in pharmaceutical drugs

### Side effects

The majority of drugs listed above will have side effects, and they all take different periods of time to surface. Speak to your GP about the side effects so that you know what to expect, and so you can make an informed decision whether to take the drug.

### Take as prescribed

It is important to take the drugs as your GP has prescribed them, e.g. every day or at certain times. This is to ensure that the full benefits can be experienced. Many drugs take time to have an effect, so be patient.

### Interaction with other medication

It is possible that some medication given with or without a prescription, could interact with pharmaceutical dementia drugs, and have a negative effect on your health. Ensure you consult the pharmacist or your GP to ensure it is safe to take.

### Review medication regularly

Due to the progressive nature of dementia, the treatments that are effective at the current time, may not continue to be effective a couple of months down the line, due to the continuing changes in the brain. If you have started a new course of medication it should be reviewed every 3 months.

If you are on 4 or more types of medication, it should be reviewed at least every 15 months. Whoever prescribes the medication should be responsible for monitoring it. However if you feel your condition is deteriorating, speak to your GP sooner.

### Keep medication safe and secure

Whilst the drugs you take at the recommended dose are beneficial to you, taking these drugs when you do not need them or in large amounts can be dangerous. Keep your medication in a safe and secure place, away from children and any potentially vulnerable adult.

If the person with dementia decides to stop taking a drug, they should speak to the GP first, if possible, or as soon as they can after stopping treatment.

If someone stops taking their prescribed drug, their condition will deteriorate over a period of about four to six weeks, until their symptoms are no better than in someone who has never taken the drug.

# Complementary & alternative medicine

The aim of complementary and alternative medicine is to provide a different, more holistic way of managing an illness or ailment.

**This includes the use of:**

**Herbal treatments**
*where plants are used to maintain health. They are available in health stores; however people should always consult their GP before taking them, and should always purchase a leading brand.*

**Aromatherapy**
*which is the use of aromatic plant extracts and essential oils to help achieve emotional and physical well being. They are often used either in the bath or in an oil burner to fragrance a room. They are also used with massage. This alternative therapy has been found to help reduce wandering and agitation by promoting relaxation.*

**Art & Music therapy**
*where musical and artistic improvisation between a client and practitioner is used to develop a therapeutic relationship to promote relaxation and improve quality of life.*

**Acupuncture**
*which is based on the idea that illness is caused by the imbalance in the flow of energy. It aims to unblock the energy pathways to restore functioning by inserting small needles into the skin, and is said to have a therapeutic effect.*

More research is being done, looking into complementary and alternative medicines, and the effects they have on dementia. If you are interested in using them, speak to your GP as they may be able to refer you via the NHS, or know of a good quality private practitioner for whom you may have to pay.

# Questions to ask

Regardless of which course of treatment you decide to take, it is important to ask questions, to ensure you have all the information you need to make your decisions.

**Some questions you could consider asking include:**

- *What are the potential benefits?*
- *How long will it be before I see a result?*
- *What side effects can I expect?*
- *What other treatments (prescription and over-the-counter) might interact with these drugs?*
- *Can I drink alcohol while taking the drug?*
- *How might these drugs affect other medical conditions?*
- *What changes in health should I report immediately?*
- *Are there any costs associated with this treatment?*
- *Why have I been prescribed one drug rather than another?*
- *If one drug proves ineffective can I try another?*

## Counselling & support groups

Sometimes, people find it helpful to speak to others who also have dementia, to share their experiences that many others may find difficult to understand. Alternatively, some people prefer to talk to a trained counsellor who isn't involved in the situation. If you feel that talking to someone would help, please see Chapter 12 *'Useful Contacts & Services'* for local services.

## Day-to-day coping strategies

Over the years, people have had to find ways of managing some of the difficulties that arise as a result of dementia. The things people struggle with vary with each individual, and so here are a variety of practical ideas that may help to manage memory loss and retain independence.

- *Gather and read as much information about dementia as you can to ensure you understand the illness.*
- *Give yourself time to adjust.*
- *Use a diary or notebook to keep lists to help you remember.*
- *Set up daily routines.*
- *Use a notice board to record things that need to take place regularly.*
- *Keep important items in the same place so that they are easier to find.*
- *Set up direct debits to avoid missing the deadline to pay bills.*
- *Using a dosette box for medication.*
- *Keep a calendar that can be changed by the day, month and year.*
- *Label rooms, such as the bedroom, with words and pictures.*
- *Keep photos of familiar people and the family on view.*
- *Keep furniture in the same place.*
- *Keep checklists of things to do that day, or lists of expected visitors, which can be ticked off.*

**Other things that may help in daily activities include:**

- *Using equipment for washing and for using the toilet, such as bath seats or raised toilet seats.*
- *Obtaining equipment for eating and drinking, such as specially adapted cutlery or non-spill cups as necessary.*
- *Use mobility aids, including walking frames and wheelchairs.*
- *Make the most of assistive technology such as Telecare devices or systems to reduce risk and help with various tasks.*

# Lesbian, Gay, Bisexual and Transgender (LGBT) people & Dementia

**As an LGBT person with dementia, you and the people close to you, not only face the challenges of learning to live with dementia, but may also have additional challenges to face, perhaps feeling the mainstream services won't understand your needs, be tolerant, or fear that you may encounter discrimination because of your sexual orientation and/or gender identity.**

We hope that the dementia services would treat every person with dementia in a respectful and appropriate manner. However, recognising that some LGBT people may prefer to access specific services, we have identified resources to address this, such as carers training; advocacy services, support lines, which can be found in chapter 12.

# The issue of abuse

Talking about abuse isn't an easy task. However it is important to be aware of what it is, and what to do if it is happening to you, or someone that you know. Both men and women of all ages, with or without dementia, can be at risk of being abused in a variety of ways. These include:

## Physical abuse

**Includes:**

- *hitting*
- *slapping*
- *restraint*
- *pushing*
- *misuse of medication*
- *forcible feeding or bathing*

## Psychological abuse

**Includes:**

- *intimidating by shouting*
- *verbal abuse*
- *humiliation*
- *ignoring requests or conversation*
- *isolation from people & services*
- *denial of choice, opinions, privacy, and religious or cultural needs*

## Financial abuse

**Involves:**

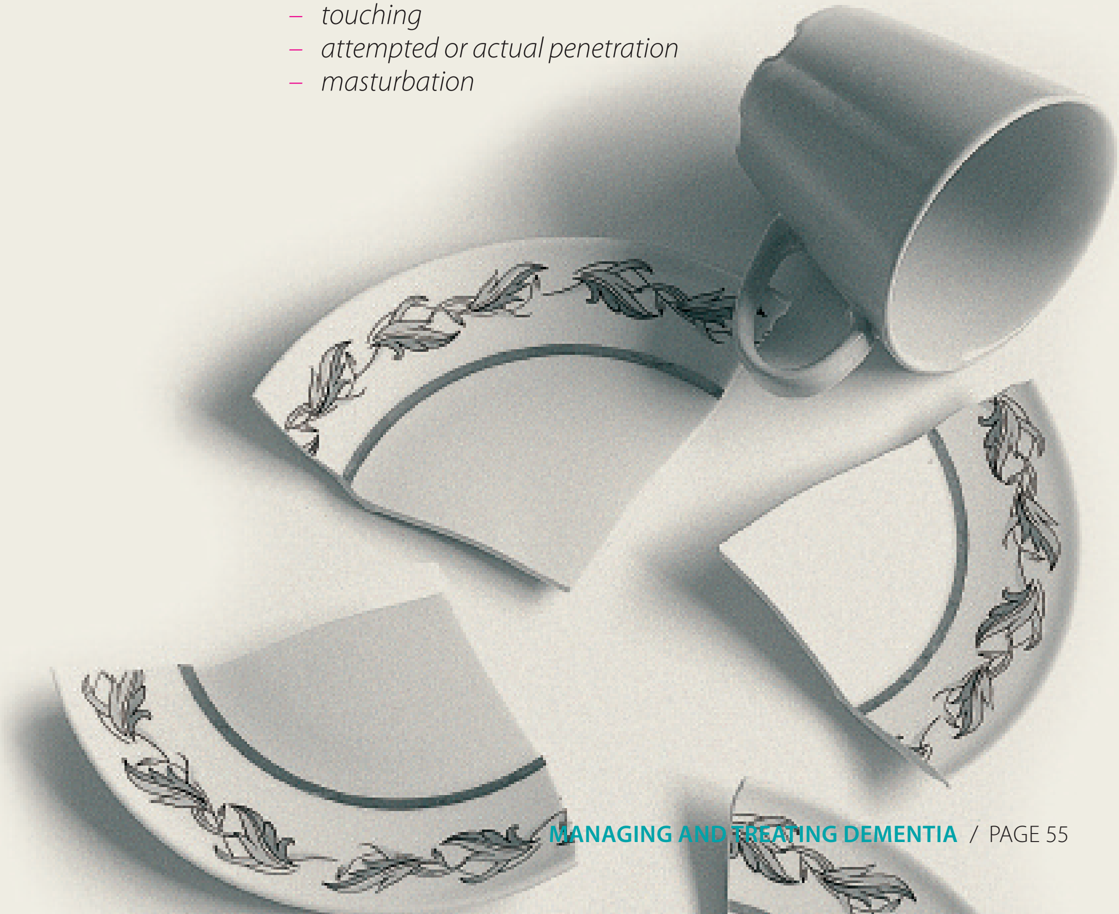
- *the use of money or property without informed consent*
- *stealing*
- *preventing the sale of property that would enable access to domiciliary or residential care*
- *misuse of a persons money, possessions, property, insurance or preventing access to them*

## Sexual abuse

Where the victim is involved in sexual activity or relationships that they do not fully comprehend, or have not given consent. The abuse may also take place within marriage.

**Includes:**

- *inappropriate examinations*
- *indecent exposure*
- *taking inappropriate photos*
- *touching*
- *attempted or actual penetration*
- *masturbation*



# Neglect

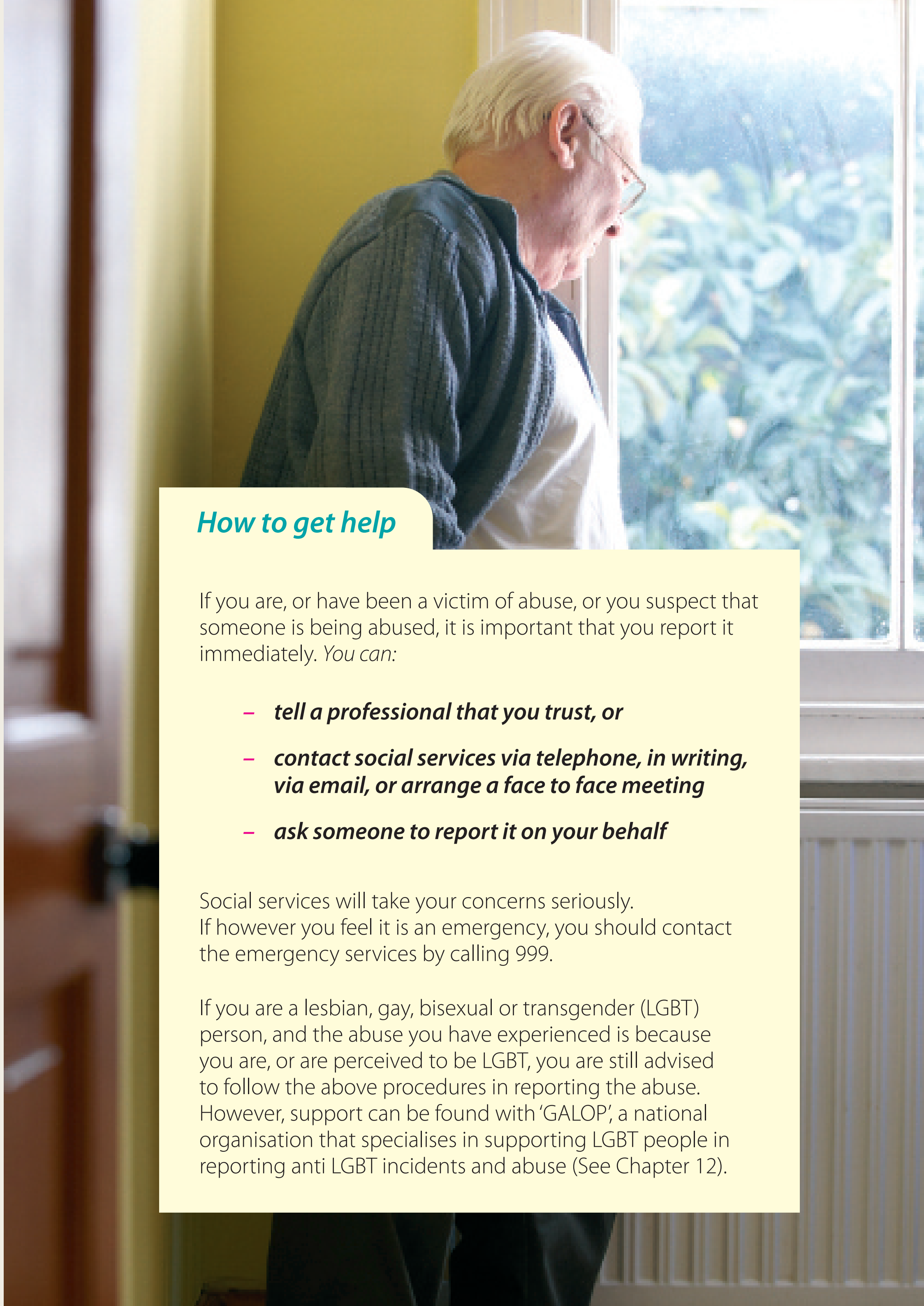
This involves failing to provide care and assistance that a vulnerable adult needs for important activities of daily living, including not intervening when a person's behaviour is dangerous to themselves and others. It may not be deliberate, as they may not recognise or be able to provide the necessary care.

Abuse can occur once, several times, or it can occur many times over a period of days, weeks, months or years. Abuse can occur anywhere including someone's own home; a carer's home; day care; residential care; a nursing home; or a hospital.

The abuser is usually well known to the person being abused.

**They may be:**

- *a partner, child or relative*
- *a friend or neighbour*
- *a paid or volunteer care worker*
- *a health or social worker, or other professional*
- *older people may also be abused by a person they care for*



## *How to get help*

If you are, or have been a victim of abuse, or you suspect that someone is being abused, it is important that you report it immediately. *You can:*

- ***tell a professional that you trust, or***
- ***contact social services via telephone, in writing, via email, or arrange a face to face meeting***
- ***ask someone to report it on your behalf***

Social services will take your concerns seriously.
If however you feel it is an emergency, you should contact the emergency services by calling 999.

If you are a lesbian, gay, bisexual or transgender (LGBT) person, and the abuse you have experienced is because you are, or are perceived to be LGBT, you are still advised to follow the above procedures in reporting the abuse. However, support can be found with 'GALOP', a national organisation that specialises in supporting LGBT people in reporting anti LGBT incidents and abuse (See Chapter 12).

# 10. Carers

**Carers play an important role in the care of people with dementia. A carer is someone who provides help and support, unpaid, to another person who couldn't otherwise manage certain tasks. This means that you could still be called a carer even where you are part of the family – a husband, wife, child, friend, or grandchild. Some of the things that carers do can include:**

- *personal care, such as bathing*
- *cooking meals*
- *dressing*
- *physical help with moving around*
- *carrying out errands, such as shopping or picking up prescriptions*
- *spending time and keeping the person company*

People find themselves looking after a person at home for many different reasons – out of love, from a sense of duty, perhaps because they feel they have no choice. Some find assuming the responsibility relatively easy. Others come to resent it.

(Who Cares: Department of Health 2007)

- *More than one-in-five of people aged 50-59 are providing some unpaid care.*
- *One in ten adults in the UK is a carer.*
- *58% of carers are women, 42% are men.*

(Alzheimer's Society 2007)

Carers can find parts of their task challenging, but most agree that there are strategies which makes caring less of a burden.

## 1. Recognise yourself as a carer

The first step in making the caring role easier is to recognise that you are a carer, that caring is likely to be a sometimes difficult role, and that it is likely you will need support in your caring role. It is important to identify what help is available to you to hopefully prevent you from becoming overwhelmed.

*Tip*

Think about what help you might need, and where you can get it, before you actually need it.

That way, when the time comes, you'll know where to turn.

## 2. Find carer resources

There are many places that you can find resources for carers. They include:

- *Local carer support groups that meet regularly.*
- *Advocacy services.*
- *Information booklets & websites.*
- *Carer help and support lines.*
- *Online discussion forums.*

These resources can provide you with all the support and information you may need in your caring role. Please see Chapter 12 for local and national resources.

### *What is advocacy?*

Advocacy is where organisations, usually charities, provide services and support; take action to help people say what they want; secure their rights; represent their interests; and obtain services they need.

# 3. Telling people

After learning that someone you care about has a diagnosis of dementia, it may take a little time to get your head around it. It is likely that you won't feel able to discuss it straight away; however talking to people will help you to get support and information for your caring role.

## Your GP

By telling your GP that you are a carer, it should encourage them to:

- *carry out regular health checks*
- *offer you the flu jab*
- *give you information about resources that may support your caring role*
- *provide emotional support*
- *give you advice on maintaining your general health*

## Your Employer

By speaking to your employer about your caring role, it may:

- *allow you to discuss what options are available to you*
- *help when making arrangements if you are required to leave in an emergency*
- *provide flexible working options*
- *enable you to check the status of your pension*

## Social Services

Social services may be able to provide you, as a carer, with support and access to resources to help you with your caring role. For this, you will need to have a carer's assessment, which will identify if you are eligible for support from social services.

You are entitled to a carer's assessment if you are aged 16 or over; providing, or intending to provide, a regular and substantial amount of care; and the person you care for is eligible for community care or other services, even if they do not receive them.

The assessment is your opportunity to recognise and discuss what your caring role involves, how it affects your daily life, and what could make this easier. It would be beneficial to prepare for your assessment by thinking about things such as:

- *Is your health affected in other ways?*
- *Are you able to get out and about, or follow your own interests?*
- *Are your other relationships affected?*
- *Do you want information about benefits?*
- *Is the person you care for getting enough help?*

(Ealing Council Website 2009)

## 4. Claiming entitlements

If it is assessed that you are a carer, it is important to identify what financial support is available to you. You will need to contact Job Centre Plus to apply for benefits, and support in doing this can be provided by social services or your local carers centre. More information can be found in Chapter 12.

## 5. Look after yourself

Caring can bring its own rewards. But it can also be hard work. The person you care for relies on you to help them or to carry out daily activities. That's a lot of pressure to be under, and so it is paramount that you take care of yourself, not only for your own personal well being, but so that you can continue to provide care to the best of your ability.

**Tip**

*Be clear about what support it is that you need. Try to be assertive and persistent when seeking support from services as you deserve the support.*

*Ensure you explain how you are affected and the impact this has on your caring role. By doing this you are helping to develop the service for others who may not be able to demand services in the same way as you.*

### Looking after yourself

**Make time for yourself to do something to enjoy or relax you**

Read the newspaper

Do some gardening

Bake a cake

Go swimming

Have a massage

**Try to socialise with family, friends, and other carers**

Give them a call

Meet up for a coffee

Write them a letter or email

Go to a support group

**Involve family and friends in the caring role where you can, right from the beginning**

**Continue to enjoy your usual leisure activities & try to find new interests**

**Make use of respite services available to you**

**Try to attend Carers training where available**

You will have the chance to meet other carers whilst learning new and different ways to care for your loved one.

**Make time to do enjoyable activities with the person you care for**

Play a board or card game

Go for a walk

Watch a film together

## Respite

Respite is a temporary supported break for the primary care giver, to help relieve some of the pressures of the caring role. It can provide the carer with time to themselves to simply go shopping, socialise with family and friends, or pursue a hobby or interest.

Forms of respite can take place in a variety of settings including:

### Day centres

*which provide the opportunity for people with dementia to go and socialise, and participate in activities with others who are also experiencing dementia.*

### Domiciliary respite

*which involves a professional coming into your home to temporarily take over the caring role.*

### Residential respite

*which involves the person with dementia temporarily going to a residential home to be cared for.*

Respite can also be provided in the form of family, friends or neighbours temporarily taking over the caring role.

The type, location, duration and frequency of respite will vary depending on what your needs are. This will be assessed by whoever provides the respite, for example social services.

# 6. Maintaining healthy relationships

Dementia will bring changes to your relationships, especially if it is your spouse who you are caring for. Good communication between yourself and your partner is essential, as it is with other people, including your friends and relatives.

## Sexual Intimacy

Sexual intimacy with a person who has dementia is often not a subject discussed however it is affected by dementia; but can be a source of mutual comfort, support and pleasure.

Whether or not one person within a relationship, or their partner, has dementia, by law, both parties must consent to sexual relations. A person consents if she or he agrees by choice and has the freedom and capacity to make that choice. When someone has dementia, it is often unclear whether the person has the 'mental capacity' to consent to sexual relations.

Some partners find this confusing, and may be left feeling guilty if it is not clear whether the person really wanted to have sex, while others find it normal to continue having sex as before. This situation can raise some complicated ethical as well as legal issues, such as whether or not the person with dementia has the mental capacity to consent to sexual relations.
(Alzheimers Society)

If this is something that is causing concern for you, many people find it helpful to either talk to those who are in a similar situation, to seek advice on ways of dealing with it; or perhaps speak about it anonymously through telephone support lines. There is also more reading material on this subject to be found on the Alzheimer's Society website and the Alzheimer's Scotland website. (See Chapter 12).

## Communication top tips from the perspective of a person with dementia

- *Even if I don't communicate in the same way as I used to, I still enjoy chatting with you.*
- *When you don't understand what I am trying to say, tell me the bits you have understood, to see if we can work it out.*
- *If I seem agitated, you can try distracting me with something else that might interest me, which might help me to forget what is bothering me.*
- *Sometimes, I may find it difficult to understand what you are saying, but please remember that using facial expressions, gesture, posture, and different tones of voice will help to make it easier.*

(Communication Top Tips: Sarah Kramer- Speech & Language Therapist)

# 11. Managing the later stages of dementia

**During the later stages of dementia, the needs of your loved one are likely to have changed to the stage where they can do very little, if anything, for themselves; they may be unable to recognise you or communicate with you which can be very painful. Although the relationship seems very different, you are unable to mourn the changes because the person is still alive.**

# How will the dementia sufferer be affected?

As dementia is an illness that gets progressively worse, the symptoms of the disease that were first experienced, are likely to become more severe, and will result in almost total dependence on those providing care. Some of the decline that is likely to be experienced includes:

- *Severe memory loss, to the stage where they may not recognise who you or your family are.*
- *Communication becomes very difficult, and they may not be able to speak or understand what is being said to them.*
- *Mobility may gradually decline to the stage where they are unable to walk, or carry out simple everyday tasks.*
- *Eating & weight is likely to be affected, either losing a great deal of weight, or putting on weight; depending on the individual.*
- *Incontinence of the bladder and/ or bowel is frequently experienced and therefore they may require personal care.*
- *Behaviour is likely to change, and become difficult to understand. This may include agitation, aggressiveness due to not understanding what is going on, rocking, hallucinations, restlessness, excessive hand activity and using repetitive words.*

# Where will the person with dementia be living?

Most people in the final stages of dementia live in a care home as their needs increase and need more specialised care.

### Stay at home

Some families feel able to continue caring for their loved ones at home, and often do so with support from community services.

### Hospital

Some people are admitted to hospital in the final stages of dementia, often due to illnesses unrelated to dementia.

### Care Homes

The majority of people live through their final stages of dementia in a care home, whether it is a residential care home or nursing care home.

### Hospice

When an illness is no longer treatable, combined with complex symptoms and/or social problems, a hospice can provide palliative care to reduce the physical and psychological distress, and provide support to the family.

# What may cause your loved one to pass away?

Although dementia is a life-shortening illness, another condition or illness such as pneumonia may trigger death and be given as cause of death on the death certificate.

# When your loved one passes away

Some people who have loved ones with dementia find that they grieve so much during the course of the illness that they have no strong feelings left when the person dies. Others experience a range of overwhelming reactions at different times. These may include:

- *numbness, as though their feelings are frozen*
- *inability to accept the situation*
- *shock and pain, even if the death has been expected for a long time*
- *relief, both for the person with dementia and themselves*
- *anger and resentment about what has happened*
- *guilt over an incident that happened in the past*
- *sadness*
- *feelings of isolation*
- *feeling of lack of purpose*

It can take a long time to come to terms with the person's death. Those who have been full-time carers for a long time will be left with a huge void when this role ends.

# Funeral arrangements

Losing a loved one is an incredibly difficult experience to go through. This combined with the many decisions and arrangements that need to take place can make it seem an impossible task to get through. In many cases, people who have been involved with providing care are often able to provide help and support. In the first few days after your loved one passes away, you will need to:

- *Inform their GP.*
- *Register the death at a register office.*
- *Find the will, to note any special funeral requests of your loved one.*
- *Arrange funeral with or without the support of a funeral director.*

Although your caring role may have come to an end, many of the support services you were using previously will still be accessible, and may be of help to you during this difficult time. There are also other bereavement services available to you, and possibly financial assistance with funeral costs. Further information can be found in Chapter 12 ***'Useful Contact & Services'.***

# 12. Useful contacts & services

## Local Organisations & Resources

### Carers Resources

**> Alzheimer's Concern Ealing (ACE)**
**223 Windmill Road, Ealing, W5 4DJ**
**Tel: 020 8568 4448**
**Website www.alzheimersconcern.co.uk**

A local support organisation in Ealing, which specialises in Alzheimer's and other forms of dementia. Services provided include:

- Carers Voice, a bi-monthly newsletter for carers
- Respite Services
- Advice & Information including welfare rights and advocacy
- Counselling & a bereavement support network
- Carers Services

**> Ealing Carers Centre**
**46 South Ealing Road, Ealing, London, W5 4QA**
**Tel/Fax: 020 8840 1566**
**Textphone: 020 8840 568**
**Email: ealingcarerscentre@ealing.gov.uk**

A resource and support centre for all unpaid carers in the borough providing:

- Advice & resource information area with internet access
- Carers training and development
- Holistic therapies
- Support groups

**> Caring with Confidence**
**Tel: 020 8583 6677 Email: cwc@gmipartnership.org.uk**
**Website: www.caringwithconfidence.net**

If you are a Lesbian, Gay, Bisexual and Transgender (LGBT) carer, or those caring for someone from the LGBT community, Caring with Confidence offers free skills and development sessions.

**> Crossroads Care**
**Hillview Surgery, 179c Bilton Road, Perivale, Middx, UB6 7HQ**
**Tel: 020 8728 7000**
**Website: www.crossroads.org.uk/ealing**

Crossroads Care is a registered charity that provides respite in the form of day care services and overnight care services, in order to reduce the stresses experienced by carers.

### Counselling Services

**> Bereft - Bereavement Support for the Borough of Ealing**
**Hawkco House, 35 Horn Lane, Acton, W3 6NS**
**Tel: 020 8896 2800**
**Email: bereftbereavementsupport@hotmail.co.uk**

Provides one to one bereavement counselling to people of the London Borough of Ealing.

**> Ealing Youth Counselling and Information Service**
**55 High Street, Acton, W3 6NE**
**Tel: 020 8992 8182 Email: ealingycis@ealing.gov.uk**

EYCIS offers a free and confidential counselling service to people aged 14-25. Please phone for an appointment.

**> Samaritans**
**26 Junction Road, Ealing, W5 4XL**
**Tel: 08547 90 90 90 Email: jo@samaritans.org**

They provide a 24 hour confidential emotional support for people who are experiencing feelings of distress or despair, including those which could lead to suicide.

## Mental Health Resources

> **Ealing Mental Health and Well-being Service**
**84 Uxbridge Road (3rd Floor), West Ealing W13 8RA**
**Tel: 020 331 35661**
**Website: www.mhws.org.uk**

Providing guided self help for mild to moderate depression, generalised anxiety and panic disorders. Provides supported access to Computerised Cognitive Behavioural Therapy. The service offers one-to-one counselling for all moderately severe and common mental health disorders.

> **Rethink**
**15 Central Chambers, The Broadway Ealing, W5 2NR**
**Tel: 020 8567 0101**
**Email: ealingcarers@rethink.org.uk**
**Website: www.rethink.org**

Ealing Carers Support Project Advice, information, advocacy and support group for carers of mental health service users.

> **Mind in Ealing & Hounslow**
**The Lotus Centre, 48 Hartington Road, Southall, Middlesex UB2 5AX**
**Tel: 020 8992 0303 / Lotus Centre: 020 8571 7454**
**Email: info@mind-eh.org**
**Website: www.mind-eh.org**

Information and support for mental health service users, their families, carers and friends. Also provides advocacy in local hospitals.

## Older People Resources

> **Age Concern Acton**
**216 High Street, Acton, W3 9NX**
**Tel: 020 8992 0898**
**Website: www.ageconcern.org.uk**

Social centre for older people offering lunches, library, health services, advice and activities.

> **Age Concern Ealing & Irish Advice Service**
**135 Uxbridge Road, Ealing, W13 9AU**
**Tel: 020 8567 8017**
**Website: www.ageconcern.org.uk**
**Hours: Mon - Fri, 10am - 1pm and 1.30 - 3.30pm**

Information and advice on services for older people and welfare benefits advice.

> **Age Concern Northolt, Greenford and Perivale**
**Age Concern Centre, Hotspur Road, Northolt, UB5 6TN**
**Tel: 020 8845 1590**
**Website: www.ageconcern.org.uk**

Provides welfare benefits advice, information about services and activities for older people and their carers.

> **Neighbourly Care**
**32 Featherstone Road, Southall, UB2 5AQ**
**Tel: 020 8843 9618**
**Hours: Sun - Thurs, 9am - 4.30pm**
**Website: www.neighbourlycare.org.uk**

Provides general welfare benefits advice, information about services, activities for older people and their carers.

## Legal Advice Resources

> **Advice and Law for All**
**Tel: 020 8600 3100**
**Website: www.lawforall.org.uk**

Advice on problems with housing, welfare benefits, debt, family, employment, immigration, education, mental health and consumer matters.

> **Community Advice Programme**
**Old Stable Block, Ealing Town Hall Annexe, Ealing W5 2UQ**
**Tel: 020 8579 3861**

Provides general advice on areas such as welfare benefits, employment and housing.

### > Ealing Racial Equality Council

**The Lido Centre, 63 Mattock Lane, Ealing, London, W13 9LA**
**Tel: 020 8579 3861**
**Email: info@ealingrec.org.uk**

Provides free legal advice to Ealing residents on all human rights issues.

## Other Resources

### > Ealing Council

**Perceval House, 14-16 Uxbridge Road, Ealing, W5 2HL**
**Tel: 020 8825 5000**
**Ealing Social Services: 020 8825 8000**
**Website: www.ealing.gov.uk**

An A-Z of the services that can be accessed in the borough of Ealing. The adult social care section also contains helpful information.

### > Patient Advice and Liaison Service (PALS)

**NHS Ealing, 119 Uxbridge Road, Hanwell, London W7 3ST**
**Email: PALS@ealingpct.nhs.uk**
**Tel: 0800 783 5208**

PALS is a confidential service for those who would like information, help, or would like to comment about any aspect of the NHS services in the borough.

### > Ealing Community Benefits Team

**Tel: 020 8825 8555**

Provides welfare benefits advice and advocacy service, appeal and tribunal representation. A referral from a health or social care professional is required to access this service.

### > West London LGBT Forum

**Ealing CVS, Lido Centre, 63 Mattock Lane, West Ealing W13 9LA**
**Tel: 020 8280 2286**
**Email: peter@ealingcvs.org.uk**
**Website: www.ealingcvs.org.uk/lgbt**

For signposting and information on local services, forums, activities and groups for LGBT people and their carers.

## National Organisations & Resources

### > Alzheimer's Society

**Helpline Number: 0845 300 0336 | Open Mon - Fri: 8.30am to 18.30pm**
**Website: www.alzheimers.org.uk**

- Talking Point: an online discussion forum
- An extensive collection of factsheets in a variety of languages
- An LGBT support help line staffed by gay men and by lesbians:
  Email: gaycarers@alzheimers.org.uk
  Tel: Patricia: 07973 916335 | Bruce: 01865 847471

### > Alzheimer Scotland

**Website: www.alzscot.org**

Provides information resources on a variety of issues related to dementia.

## Carers Resources

### > Carers UK

**Website: www.carersuk.org**

- Free advice through Carers Line 0808 808 777 on Wednesday and Thursday from 10am - 12pm, and 2pm - 4pm. Interpreters can be provided.
- Online information and advice for carers, available in many languages.
- Online discussion forums for carers only.

### > Carers Direct – NHS Website

**Tel: 0808 802 0202 | Textphone: 0800 988 865**
**Email: CarersDirect@nhschoices.nhs.uk**
**Website: www.nhs.uk/carersdirect**

Carers Direct is a free, confidential information and advice website for carers, including young carers. There is also a free phone Carers Direct helpline and an interpreter service available.

## Benefits / Legal Advice Resources

> **Counsel and Care**
> **Twyman House, 16 Bonny Street, London, NW1 9PG**
> **Tel: 0845 300 7585 (advice line)**
> **Email: advice@counselandcare.org.uk**
> **Website: www.counselandcare.org.uk**

Provides advice, information on benefits and financial support for older people, their families and carers.

> **Job Centre Plus**
> **Benefit Tel: 0800 055 6688**
> **Benefit Textphone: 0800 055 6688**
> **Website: www.jobcentreplus.gov.uk**

Information regarding:

- Benefits available & how to claim for them
- Looking for work
- Work & Disability
- Work & Carers

> **Office of the Public Guardian (OPG)**
> **Tel: 0300 456 0300**
> **Phone lines are open Mon-Fri 9am-5pm (Wed 10am-5pm)**
> **Fax: 0870 739 5780**
> **Textphone: 020 7664 7755**
> **Website: www.publicguardian.gov.uk**

This online resource provides information on Lasting Power of Attorney; Enduring Power of Attorney; the Mental Capacity Act; and what to do if abuse of a vulnerable person is suspected. They also have an extensive list of useful contacts:
www.publicguardian.gov.uk/about/useful-organisations.htm

## Other Resources

> **Alliance Advocacy Limited**
> **Tel: 01253 738837**
> **Email: info@allianceadvocacy.org.uk**
> **Website: www.allianceadvocacy.org.uk**

Specialist mental health advocacy in NHS and independent hospitals.

> **GALOP**
> **Helpline: 020 7704 2040**
> **Website: www.galop.org.uk**

GALOP provides advice and advocacy for reporting hate crime, including anti-LGBT incidents and abuse, to the police and other organisations. They can also refer you to other LGBT organisations that may be of use.

> **London Friend: LGBT Bereavement Helpline**
> **Tel: 020 7403 5969**
> **Website: www.londonfriend.org.uk**

London Friend's dedicated helpline offers support and practical information to lesbian, gay, bisexual and transgender callers who have been bereaved or are preparing for bereavement. Open Tuesdays between 7.30pm and 9.30pm.

> **The Cinnamon Trust**
> **10 Market Square, Hayle, Cornwall, TR27 4HE**
> **Tel: 01736 757900 | Fax: 01736 757010**
> **Email: admin@cinnamon.org.uk**
> **Website: www.cinnamon.org.uk**

The Cinnamon Trust is a national charity which supports the elderly and terminally ill people and their pets. The charity offers:

- Volunteers to provide practical help when any aspect of day to day care poses a problem e.g. walking the dog for a housebound owner
- A national volunteer fostering service is provided for pets whose owners face a spell in hospital.
- Long term care for pets whose owners have died or moved to residential accommodation which will not accept pets.

## Online Resources

> **Alzheimer's Disease International (ADI) Website**
**www.alz.co.uk**

Information resource and contains links to information on dementia in 45 different languages.

> **Care Directory**
**www.nursing-home-directory.co.uk**

This is an online resource which provides information on care homes and nursing homes in the UK; information on which type of care to choose; and the financial aspects of care.

> **Citizens Advice Bureau (CAB)**
**www.citizensadvice.org.uk**
**www.adviceguide.org.uk**

Your local CAB can provide information and advice in confidence or point you in the right direction.

> **Find a Care Home**
**www.yourcarehome.co.uk**

This is an online resource which provides information on care homes and nursing homes in the UK; information on which type of care to choose; viewing a care home; regulatory bodies for care homes; recommended books related to the subject; and the financial aspects of care.

> **NHS Choices Website**
**www.nhs.uk**

A website which provides information on health conditions, treatments, local services, and healthy living.

> **NHS Direct**
**www.nhsdirect.nhs.uk**
**Tel: 0845 46 47**
**Textphone: 0845 606 46 47**

For health advice and information 24 hours a day, 365 days a year. They will assess your issue or concern, and advise you on the best course of action. An interpreter service is available.

> **NICE (National Institute for Health and Clinical Excellence)**
**www.nice.org.uk**
**www.nice.org.uk/cg42 (Dementia Guidelines)**

NICE is an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health, including dementia.

> **Royal College of Psychiatrists Website**
**www.rcpsych.ac.uk**

Contains up to date information regarding older people’s mental health including dementia; the treatments available; and information on bereavement.

> **The Princes Royal Trust for Carers**
**www.carers.org**

Information resource for carers, including an online discussion forum.

> **YC Net**
**www.youngcarers.net**

Young Carers Net is an online resource for young carers aged 18 and under. The website provides:

- Information about caring and how they may be affected
- An email agony aunt, a discussion board & chat room chat room
- A blog & a free monthly e-newsletter

# Reading Resources

> **The Simplicity of Dementia: A Guide for Family and Carers**
> **by Huub Buijssen – Jessica Kingsley Publishers (2005)**

This book explains the causes of communication problems, mood disturbances and different types of behaviours, with particular emphasis and clear guidance on how to support dementia sufferers at every stage and help them deal with the challenges posed by their condition.

> **And Still the Music Plays: Stories of People with Dementia**
> **by Graham Stokes – Hawker Publications (2008)**

It is presented as a series of stories about real people and their experiences of dementia which are set at home, in day centers, care homes and hospitals.

> **Remind Me Who I Am, Again**
> **by Linda Grant – Granta Books (1999)**

In 1993 Linda Grant's mother, Rose, was diagnosed with multi-infarct dementia. In this book she looks at the question of identity, memory and autonomy that dementia raises.

> **The Selfish Pig's Guide to Caring: How to Cope with the Emotional and Practical Aspects of Caring for Someone**
> **by Hugh Marriott – Piatkus Books (2009)**

Hugh Marriot, a carer himself, has written this book to explore what the caring role involves. He aims to bring into the open everything he wishes he'd been told when he first became a carer.

> **Telling Tales About Dementia: Experiences of Caring**
> **by Lucy Whitman – Jessica Kingsley Publishers (15 Sep 2009)**

In Telling Tales About Dementia, thirty carers from different backgrounds and in different circumstances share their experiences of caring for a parent, partner or friend with dementia.

> **Contented Dementia: 24-hour Wraparound Care for Lifelong Well-Being**
> **by Oliver James – Vermilion (2009)**

The SPECAL method (Specialized Early Care for Alzheimer's) outlined in this book works by creating links between past memories and the routine activities of daily life in the present.

> **Keeping Busy: Handbook of Activities for Persons with Dementia**
> **by James R. Dowling – The Johns Hopkins University Press (1995)**

This book describes a variety of activities designed to bring meaning and enjoyment to the lives of persons with dementia.

# Additional information for professionals

**As can be seen in earlier chapters of the handbook, dementia is a disease that can affect every aspect of a person's life, whatever role that person plays. For these people, it is possibly their first time learning what dementia is. At the beginning, it is unlikely that patients and carers will have all the information and support they need to understand and to manage the varied challenges that dementia can cause.**

Therefore, as a professional working with dementia, they may look to you to share your knowledge and experience with them. It is important for you to develop and maintain your knowledge of what dementia is and how it affects people, which can be sought in the first section of the handbook. However, this section aims to provide some basic information on what you can do in your role to make the experience of dementia an easier one. This section will cover:

- *Dignity in Care*
- *Best Practice*
- *Care Planning*
- *Promoting Communication*
- *Safeguarding*

**This handbook only touches on some of the information available; however there is a vast amount of additional information that can be accessed online and in books.**

## Dignity in Care

Each person with dementia is a unique individual with their own individual 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.
Alzheimers Society 2007

As with any other human being, people with dementia and their carers deserve to be treated as individuals, and to receive care and services without the worry of disrespect or abuse. This was recognised by the *'Dignity in Care'* campaign, launched in November 2006.

The campaign is about changing the culture of care services and placing a greater emphasis on improving the quality of care and the experience of people using services including NHS hospitals, community services, care homes and home support services.

Before the campaign launched numerous events took place to find out what *'Dignity in Care'* meant to people. The issues raised at these events resulted in the development of the ***10 point Dignity Challenge*** which depicts what high quality services that respect people's dignity should include:

1. *Have a zero tolerance of all forms of abuse.*
2. *Support people with the same respect you would want for yourself or a member of your family.*
3. *Treat each person as an individual by offering a personalised service.*
4. *Enable people to maintain the maximum possible level of independence, choice and control.*
5. *Listen & support people to express their needs & wants.*
6. *Respect people's Right to Privacy.*
7. *Ensure people feel able to complain without fear of retribution.*
8. *Engage with family members and carers as care partners.*
9. *Assist people to maintain confidence and a positive self-esteem.*
10. *Act to alleviate people's loneliness and isolation.*

When working with people with dementia, and the people involved in caring for them, please practice with these points in mind. For further information, please see the following websites:

DH Care Networks: Dignity in Care
**www.dhcarenetworks.org.uk/dignityincare**

DH Care Networks: Dementia
**www.dhcarenetworks.org.uk/dementia**

## Best practice

### Joint working

*It is important to try and engage in joint working with other professionals of other disciplines and agencies, promote the sharing of knowledge, skills and expertise to improve the quality of the service being provided.*

### Continuity of staff

*Where possible, it would be beneficial to provide continuity of staff to encourage relationships between professionals, and people with dementia and their carers, to develop.*
*This will help to build trust, help prevent confusion created by change, and will allow people to feel more able to seek advice and support.*

### Empower people

*Support people's rights to control their lives and make informed choices about the services they receive. Respect and, where appropriate, promote the individual views and wishes of both service users and carers.*

Please also see **www.scie.org.uk** for the *'Dementia Gateway'* where there are lots of practical tips, tools and activities that will help you with your daily work. There is also *'Social Care TV'* which provides video clips of people's experiences of dementia.

# Care planning

**When care planning for people with dementia, it is important to consider the following points:**

- *Taking the history from the service user should be careful, methodical and detailed.*
- *Talking to the person with dementia alone may be unreliable (due to the dementia), and so include the care-giver, a close relative or someone who knows the patient well.*
- *Discrepancies in the accounts obtained help to assess the presence and extent of anosognosia (lack of awareness by the patient of their symptoms), which is important to know when managing the disease.*
- *When care planning, help people with dementia and their carers to think about their future, what help they might need, and where they can get it, before they actually need it. That way, when the time comes, they will be empowered by knowing where to turn.*
- *Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The palliative care approach is holistic in nature, managing not only physical symptoms, but also the psychological, social and spiritual aspects of non-curable diseases with the aim being to support the achievement of best quality of life.*

# Respecting diversity & culture

Ealing is a multi-culturally diverse borough, and so as a professional, you will work with and care for many people from cultures and backgrounds that are different to your own. It is important to be aware of how this could affect your work, and the care that you provide. For example:

## Dementia not recognised in some languages / cultures

It is acknowledged that in some cultures, the word 'dementia' isn't translatable, and therefore may prevent people from recognising the signs and seeking diagnosis.

## Reverting to first language

Many people with dementia, as they deteriorate, revert back to their mother language. Therefore the use of family, friends or an interpreter may be required to translate. It is also important to have appropriate cultural awareness training, to ensure that the individual's dignity is respected.

## Respecting culture & lifestyle choices

Make sure you record and explain the person's cultural or religious background, and any rules and customs, to anyone from a different background so that they can incorporate it when they are caring for the individual.

**These may include:**

- *respectful forms of address*
- *what they can eat*
- *religious observances, such as prayer and festivals*

- *particular clothing or jewellery that the person (or those in their presence) should or should not wear, any forms of touch or gestures that are considered disrespectful*
- *ways of undressing*
- *ways of dressing the hair*
- *how the person washes or uses the toilet*

This includes recognising and respecting the needs of Lesbian, Gay, Bisexual and Transgender (LBGT) people. For example, LGBT have identified that they sometimes:

- *Fear that they will encounter discrimination or prejudice / not being understood by services / professionals. As a professional, it is your responsibility to be aware of your views, and educate yourself in order to challenge them, and other peoples, to ensure that the service you provide doesn't discriminate against the people you work with.*
- *Feel excluded from mainstream services. Ensure that the organisations policies and procedures recognise and include the needs of LGBT people; and the service and the environment you provide is LGBT friendly, for example, LGBT reading materials on display, and not hidden away.*
- *Feeling forced to come out to their service provider. Consider how it would feel to be expected to explain your personal lifestyle choices to people you barely know. Don't assume that every person you care for is heterosexual. If people choose to 'come out', consider how you would deal with this sensitively. You will also need to discuss confidentiality, as they may not wish for you to share this information with other people.*

## Promoting communication

**Communication can become increasingly difficult as a person's dementia develops, however here are some pointers which may help:**

- *Listen carefully to what the person has to say, giving time and encouragement, and reflecting back what you have understood.*
- *Make sure you have their full attention before you speak by making eye contact, calling the person by name, using touch if appropriate, and reducing other noisy distractions.*
- *Pay attention to your body language and what messages it may be sending. People with dementia are often more responsive to body language than they may have been before the illness.*
- *Be respectful of personal space, and try to speak to a person at the same level, or lower than them to avoid coming across as intimidating.*
- *Speak clearly and calmly, using short sentences. Asking closed questions with 'yes' or 'no' answers can sometimes be helpful.*
- *Consider whether any other factors are affecting their communication.*
- *Communicate with them respectfully e.g. don't speak to them like a child; include them in conversations; and don't speak about them as though they aren't there.*

Different people have different ways of communicating, and this can be recognised through the use of a communication passport.

# Using Communication Passports

Personal communication passports are a way of documenting and presenting information about people who are unable to communicate effectively for themselves. Communication Passports aim to:

- *Describe the person's most effective means of communication and how others can best communicate with, and support the person.*
- *Present the person positively as an individual and reflect the person's unique character, sense of humour etc.*
- *Provide a place for the person's own views and preferences to be recorded and drawn to the attention of others.*
- *To help staff and conversation partners understand the person and have successful interactions.*

(Call Scotland 2009)

We have included parts of a Communication Passport Template from Call Centre 2006 – **www.communicationpassports.org.uk** – where you can learn about communication passports, and to help to inspire and guide you in the creation of a passport.

## Insert Photo

**My name is**

**I like to be called**

Please read this booklet
about me and the ways
I like to communicate.

## Contents

**1)** Key things you need to know about me

**2)** Special People

**3)** My Family & Friends

**4)** How I communicate & how you can help

**5)** Things I like to talk about

**6)** Things that cheer me up

**7)** Things that make me cross!

**8)** I need help with

**9)** Food and Drink

## Key things you need to know about me

**1) I need…**

**2) I mustn't…**

**3) I like…**

**4) I don't like…**

## Special People

These are the most important people in my life:

**Parents**

**Spouse / Partner**

**Children**

**Siblings**

**Pets**

(Include names and some information)

# Life story / reminiscence work

Life story work is based on the fact that each person is unique with their own experiences, relationships, and ways of behaving. By recognising a person's individuality, it fosters person centred care by recognising the person first and dementia second. Person centred care promotes better understanding of the person and leading to improved relationships between staff, patients and family carers. Other reasons for doing life story work include:

- *Helping us to learn more about the person we care for.*
- *To help create communication opportunities for them.*
- *To pass on to other services if the person needs to move on.*
- *To provide the opportunity for the person to enjoy a failure-free, fun activity.*
- *To involve the family and give them a sense of achievement through collecting life story material.*
- *To help to monitor changing needs of the individual.*

Life story work is more in depth than the information provided in a communication passport, as it describes the individuals past and present experiences. Some chapter headlines could include:

- *Introduction to my life*
- *My childhood*
- *My working life*
- *Significant life events & places*
- *Social activities & interests*
- *My life now & my wishes for the future*

For more information about starting a life story, best practice, and issues that may arise in the process please see, ***"And it started with a Seashell: Life Story Work and People with Dementia"*** by Charles J Murphy (1994).

# Multi-Agency safeguarding adults

All individuals and agencies working with vulnerable adults have an essential role to play in ensuring the safeguarding of vulnerable adults from abuse. (Please see chapter 9 for examples of abuse). The primary aim should be to prevent abuse.

Safeguarding is everyone's business, and so as a professional it is important to ensure that you are familiar with what your local safeguarding procedures are. For further information, please see the *'Ealing Multi- Agency Safeguarding Adults Policy and Procedures'* at **www.ealing.gov.uk** in the Adults Services section. Also, *'Safety Matters: Developing Practice in Safeguarding Adults'* by Research in Practice for Adults (RIPFA) - may be helpful, see **www.ripfa.org.uk**.

**Some legislation that may help you in your professional role includes:**

## Mental Capacity Act

The Mental Capacity Act 2005 provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. It makes it clear who can take decisions in which situations, and how they should go about this. It also allows people to plan ahead for a time when they may lack capacity.

### The Key Principles of the Mental Capacity Act are:

- *Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise.*
- *A person must be given all practicable help before anyone treats them as not being able to make their own decisions.*
- *Just because an individual makes what might be seen as an unwise decision, they should not be treated as lacking capacity to make that decision.*
- *Anything done or any decision made on behalf of a person who lacks capacity must be done in their best interests.*

(Public Guardian Website)

A persons capacity is viewed as being decision specific, and so whilst they may not have capacity in one area of their life, it must not be assumed that they are incapable or lacking capacity in other areas too. Each decision needs to be assessed individually.

## The Mental Capacity Act "Deprivation of Liberty" Safeguards

The Mental Capacity Act Deprivation of Liberty safeguards were introduced into the Mental Capacity Act 2005 in 2007. The safeguards are designed to protect the interests of an extremely vulnerable group of service users and to:

- *ensure people can be given the care they need in the least restrictive regimes*
- *prevent arbitrary decisions that deprive vulnerable people of their liberty*
- *provide safeguards for vulnerable people*
- *provide them with rights of challenge against unlawful detention*
- *avoid unnecessary bureaucracy*

# Human rights

Here are some examples of human rights, and how a person with dementia rights could be breached.

**THE RIGHT NOT TO BE TREATED IN AN INHUMAN OR DEGRADING WAY**

- Physical or psychological or other types of harm
- Soiled or unchanged clothing or bedding
- Leaving food for service users or patients when they are unable to feed themselves
- Personal care carried out in view of other people

**THE RIGHT TO RESPECT FOR PRIVATE AND FAMILY LIFE, HOME AND CORRESPONDENCE**

- No support for independent living
- No privacy at home, in a hospital or care home
- Personal information including financial or medical records being shared without permission
- Staff in care homes, supported accommodation or hospital etc controlling mail, phone calls etc without authority.

**THE RIGHT TO A FAIR TRIAL**

- The complaints procedures of public bodies
- Compensation claims
- Appeal procedures in social security, mental health care and treatment tribunals

**THE RIGHT NOT TO BE DISCRIMINATED AGAINST**

- Access to medical treatment or community care services, based on age, disability, gender or ethnic origin etc
- Information or options presented in inaccessible ways
- Failing to offer food that takes account of cultural differences such as kosher or halal foods

**THE RIGHT TO LIFE**

- Do not resuscitate orders placed by medical staff because they consider the patients life to be of low quality. This could be a breach of human rights
- Refusal of life saving treatment
- Advance directives
- Deaths caused by negligence

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