

# Dementia Support Service

An information manual for staff working alongside people living  
with memory problems and dementia

Information, Awareness, Understanding and Support



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# 1. Introduction

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# Introduction

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## *Background*

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Age UK Salford's Dementia Support Service (DSS) works with families, individuals and professionals to enhance dementia awareness and information. The service aims to provide community-based advice, guidance and support to people living with memory problems and to their families.

This manual has been produced for the use of the DSS and Age UK staff across Salford. The purpose is to provide a resource for the service to continue to provide high quality awareness, information, understanding and support for people living with dementia and their families.

## *How to use the manual*

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The manual is structured into eight short sections to work through individually and with your team. Included are scenarios for supervision aimed at facilitating discussion and reflection. Further resources provided for the DSS include a PowerPoint presentation, guidelines of peer support groups and the pathway the current DSS uses. The additional materials may help expand upon some of the sources from the manual.

The photographs used in the manual were taken at Age UK peer support groups, and the owner's have given permission for their use.

## 2. Memory Problems

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# Having Memory Problems?

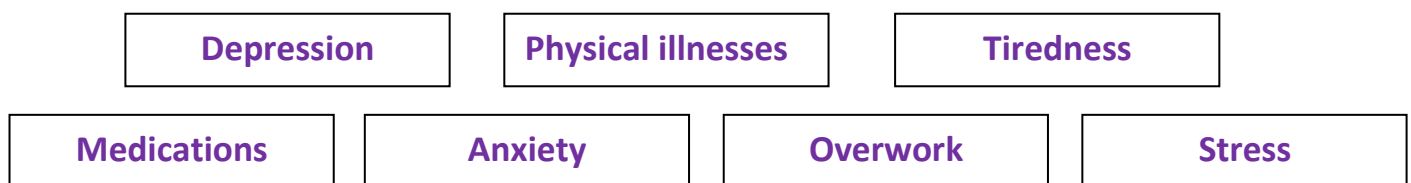
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We all forget things from time to time; we can't remember why we came into a room, where we parked the car and the name of something that's on the tip of our tongue. However, when memory problems start to affect someone's everyday life, it might be worth looking closer (Alzheimer's Society, 2012a).

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## What can affect memory performance?

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If someone feels that their memory is getting noticeably worse and this is impacting on their everyday life, these problems *could* be an early sign of the medical condition **dementia**.

Signs to look out for dementia include:

- Sustained memory problems
- Changes in mood
- Problems thinking and reasoning
- Noticeable communication problems
- Emotional stress and feeling confused

# Memory Assessment Process

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**Within England, only 46% of individuals living with dementia have a formal diagnosis. Early diagnosis can lead to early intervention, access to the right services and support.** (Alzheimer's Society, 2012b)

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## How might you approach talking about memory problems?

Ask the person to make notes of times when they have been concerned about their memory - this can help create a picture of what the problems may be. If the individual has not been to his/her GP, encourage them to do so.

Be positive about seeing a GP – they can help confirm what the problems are and could rule out dementia or refer the person for more help from the memory assessment team and other relevant services.

### Example Questions:

*'I'd like to chat about how you've been feeling lately?'*

*'I've noticed you've not been yourself lately, shall we talk about it?'*



# Diagnosis and Assessment of Dementia

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Getting a diagnosis can take some time. This is because it should only be given after a full assessment involving the following steps:

## 1. History Taking

Personal history, whether they would like to know their diagnosis, previous medical conditions and medication.

## 2. A Cognitive Assessment

Examination of attention, concentration, orientation, short and long term memory, praxis, language and executive function.

## 3. Medical Screening

Screening for other medical conditions and other psychiatric features associated with dementia such as depression.

## 4. Physical Examination

Including: blood tests, biochemistry tests, thyroid function, vitamin B12 and folate levels. A urine test may also be undertaken.

## 5. Structural Imaging

This is used if dementia is suspected and the person has a probable diagnosis. This may be done through having a CT, MRI, or SPECT scan. The scan may also indicate the type of dementia i.e Alzheimer's, Vascular.

(National Institute for Health and Clinical Excellence, 2006)

# Waiting for a diagnosis

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Many people experience a long wait for a diagnosis. This can be for a variety of reasons, such as length of waiting lists for assessments and clinical tests. The nature of some of the tests and assessments can be distressing for people. It is only natural that people undergoing or having completed an assessment for a diagnosis of dementia may feel anxious and worried about the future. It is very important to encourage them to carry on living life in the way that they want to and give them the support they need during this difficult time (Alzheimer's Society, 2010).

## **Tips to help cope with everyday memory problems**

- Make 'to do' lists
- Break up tasks into smaller more manageable chunks
- Focus on one thing at a time
- Establish a routine
- Take your time

Encourage people to stay active, eat a balanced diet, exercise regularly and socialise. These things are all important to live well with or without a diagnosis of dementia.

# Mild Cognitive Impairment

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Mild Cognitive Impairment (MCI) is defined as a cognitive decline greater than expected for an individual's age and intelligence. It is not a diagnosis of dementia but in some cases may lead to dementia.

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## Symptoms may include

- Poor memory functioning (most common)
- Planning
- Language
- Attention
- Visuospatial skills

People who fall within this category may get better, stay the same, or deteriorate. One of the main benefits of diagnosing MCI is that it helps to identify people who are at increased risk of developing dementia. They will then have earlier access to treatments as well as practical information, advice and support.

# 3. What is Dementia?

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# What is dementia?

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*‘Dementia is a general term used to describe a syndrome that affects the workings of the brain and causes a decline in brain functioning. It is caused by physical changes in the brain creating symptoms that affect thinking, memory, language and reasoning’* (Australian Government Department of Health and Ageing, 2006)

## Who does it affect?

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Dementia affects 820,000 people in the UK.

1 in 14 people over the age of 65 have a dementia.

1 in 6 over the age of 80 have a dementia.

25 million people in the UK have a close friend or family member with dementia.

In Salford 1,322 people have a diagnosis of dementia, a further 1201 do not have a diagnosis but do have dementia.

(Alzheimer’s Society, 2012d), (Office for National Statistics, 2011)

# **National Dementia Strategy – England**

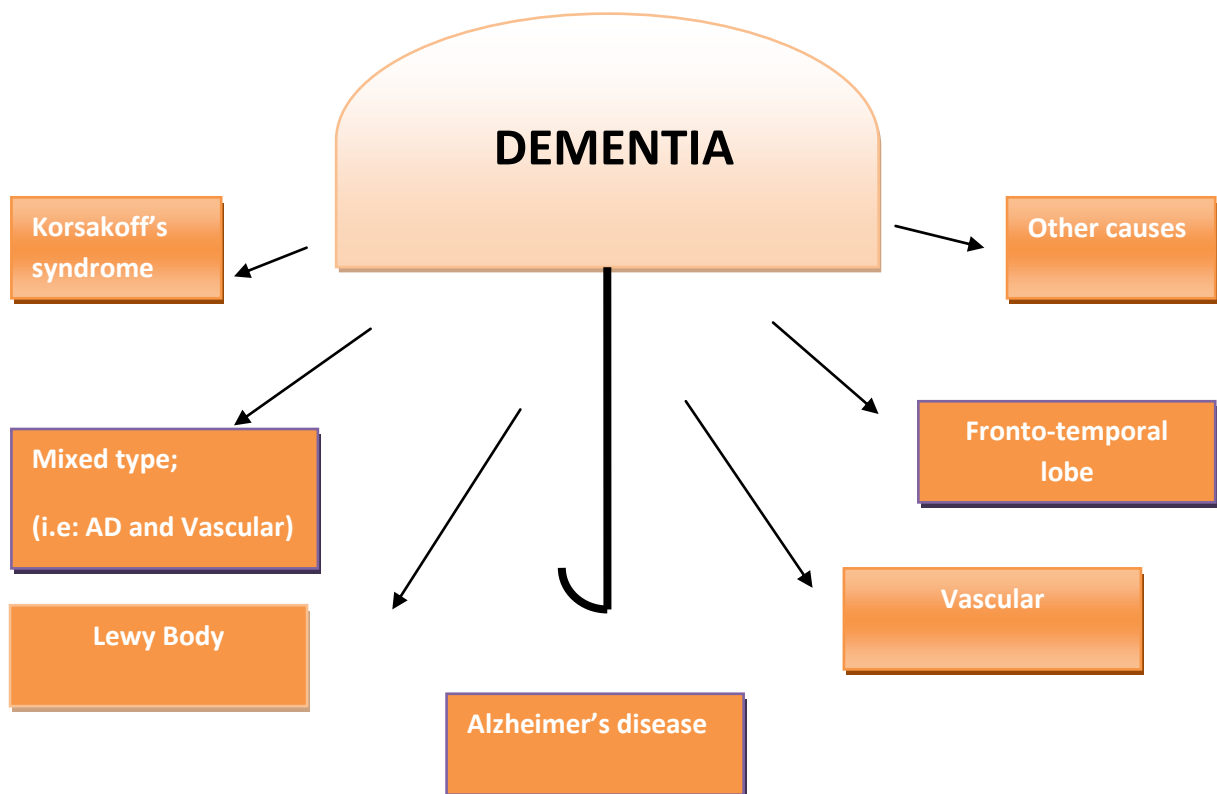
In 2009, the Department of Health launched the National Dementia Strategy 'Living well with Dementia' (Department of Health [DH], 2009). The objectives of the National Dementia Strategy are listed below as a reference for you.

## **National Dementia Strategy Objectives**

- 1. Improving public and professional awareness and understanding of dementia**
- 2. Good quality early diagnosis and intervention**
- 3. Good quality information**
- 4. Enabling easy access to care, support and advice following diagnosis**
- 5. Development of structured peer support and learning networks**
- 6. Improved community personal support services**
- 7. Implementing the Carers' Strategy**
- 8. Improved quality of care in general hospitals**
- 9. Improved intermediate care**
- 10. Potential for housing support, housing-related services and telecare**
- 11. Living well with dementia in care homes**
- 12. Improved end of life care**
- 13. Informed and effective workforce**
- 14. Joint commissioning strategy**
- 15. Improved assessment and regulation of health and care services**
- 16. Clear picture of research evidence and needs**
- 17. Effective national and regional support for implementation of the NDS**
- 18. Reduce the use of anti-psychotic drugs**

# Different Types of Dementia

Dementia is an umbrella term and it is important to identify which type of dementia the person is living with. This is because different types of dementia affect the brain in different ways. Knowing what type of dementia someone has will help draw a clearer picture of the challenges they may face in their individual journey. This section is intended to show the scope of dementia and the challenges and differences that people living with dementia face.



## Examples of the different types of dementia

Dementia Type	Characteristics	Symptoms may include:
<b>Alzheimer's disease</b> (62% of dementia diagnoses)	Alzheimer's disease is characterised by changes to the structure of the brain leading to less brain cells and neurotransmitters. This shortage causes problems to communication pathways in the brain affecting its function.	<ul style="list-style-type: none"> <li>▪ Memory loss.</li> <li>▪ Language difficulties.</li> <li>▪ Communication problems.</li> <li>▪ Recognition problems.</li> <li>▪ Changes in mood and behaviour.</li> <li>▪ Visual-spatial awareness problems.</li> <li>▪ Being more withdrawn.</li> </ul>
<b>Vascular dementia</b> (17% of dementia diagnoses)	Vascular dementia is caused by a problem in the supply of blood to the brain, normally caused by a stroke or multiple strokes. This affects how the blood circulates around the brain and can cause some cognitive impairment.	<ul style="list-style-type: none"> <li>▪ Memory problems.</li> <li>▪ Concentration problems.</li> <li>▪ Communication problems.</li> <li>▪ Increased likelihood of emotional difficulties.</li> <li>▪ Visual mistakes and hallucinations.</li> <li>▪ The abilities affected will depend on the area of the brain affected.</li> </ul>



Syndrome	Characteristics	Symptoms may include:
<b>Dementia with Lewy bodies</b> (4% of dementia diagnoses)	Dementia with Lewy bodies is related to protein deposits found in nerve cells in the brain. Their presence in the brain disrupts normal brain functioning and chemical message pathways.	<ul style="list-style-type: none"> <li>▪ Parkinson type symptoms such as tremor, muscle stiffness and slowness.</li> <li>▪ Possible auditory and visual hallucinations.</li> <li>▪ Disturbed sleep.</li> <li>▪ Problems with attention and alertness.</li> <li>▪ Spatial disorientation.</li> <li>▪ Difficulty in planning ahead and coordinating mental activities.</li> <li>▪ Memory not as affected as in other forms of dementia.</li> </ul>
<b>Frontal-temporal dementia</b> (2% of dementia diagnoses)	Frontal temporal dementia covers a range of conditions including picks disease, frontal lobe degenerations and dementia associated with motor neuron disease. The damage caused to the frontal and temporal lobes in the brain result in the symptoms of the disease.	<ul style="list-style-type: none"> <li>▪ Changes to personality.</li> <li>▪ Obsessive compulsive behaviours.</li> <li>▪ Inappropriate behaviour and lack of insight.</li> <li>▪ Change in eating habits.</li> <li>▪ Language difficulties.</li> </ul>

Syndrome	Characteristics	Symptoms may include:
<p><b>Rarer forms:</b></p> <p><b>Korsakoffs syndrome</b> (3% of dementia diagnoses)</p>	<p>Korsakoff's syndrome is linked to heavy alcohol consumption over a sustained period of time. The effects lead to a lack of thiamine (vitamin B1), which affects the brain and nervous system. If this is suspected, immediate treatment is essential, which can reverse some symptoms if carried out in time. However, if left untreated, a person may become permanently brain damaged.</p>	<ul style="list-style-type: none"> <li>▪ Memory loss (particularly short term).</li> <li>▪ Struggle to learn new things and take in information.</li> <li>▪ Personality changes.</li> <li>▪ Confabulation – creating events which may not have happened.</li> </ul>
<p><b>Parkinson's disease Dementia</b> (2% of dementia diagnoses)</p>	<p>It is not fully clear how dementia occurs in Parkinson's disease. Dementia associated with Parkinson's disease is similar to dementia with Lewy bodies. The main difference is that movement problems occur before cognitive symptoms in Parkinson's dementia.</p>	<ul style="list-style-type: none"> <li>▪ Memory loss.</li> <li>▪ Loss of quick actions.</li> <li>▪ Obsessive behaviours.</li> <li>▪ Lack of emotional control.</li> <li>▪ Visual hallucinations.</li> </ul>

Syndrome	Characteristics	Symptoms may include:
<b>Mixed type dementia</b> (10% of dementia diagnoses)	Many people acquire a mixed form of dementia usually Alzheimer's disease coupled with another form of dementia or stroke. Around 10% of people with dementia have a mix of some of the forms of dementia.	

Based on information from: Alzheimer's society (2012c) and Alzheimer's Association (2013).

The next section (section 4) is designed to give you advice and tips on helping and supporting people living with a diagnosis of dementia.

# 4. Management of Dementia

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# Supporting People with Dementia

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There are many ways people can adapt to life with dementia so they can carry on enjoying the things that they want to do.



## How might someone with memory problems feel?

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Think about the kinds of emotions people facing memory problems may be feeling. The examples below are designed to help you think about ways to talk to people about their dementia and keep in mind ways to help them:

### Emotions

Anxiety *'I can feel anxious, depressed or angry about my forgetfulness.'*

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Bewilderment *'I can have problems thinking and reasoning.'*

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Frustration *'I can find it difficult to follow conversations or programmes on TV.'*

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Disorientation *'I can feel confused even when in a familiar environment.'*

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Sadness *'I can find that other people have started to comment on my forgetfulness.'*

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Realisation *'I can repeat myself and lose the thread of what I am saying.'*

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# Pharmacological Treatments

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Medications that can slow down the development of Alzheimer's disease are *donepezil* (Aricept), *rivastigmine* (Exelon) and *galantamine* (Reminyl). These medications work between the nerve cells to send chemical messages in the brain.

Another drug treatment is *memantine* this works by protecting brain cells from further damage caused by excessive amounts of glutamate (Alzheimer's society, 2012e).

These treatments can temporarily improve or stabilise the symptoms of somebody with Alzheimer's disease. They were originally developed to treat Alzheimer's disease and so it is unclear whether they can help other forms of dementia. They may also not be suited to everyone with Alzheimer's disease. All drug medication is prescribed by the consultant or GP.

## Antipsychotic medication

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Antipsychotic drugs may be prescribed when there is a need for further help for the management of behaviours that challenge (see section 6).

Antipsychotic drugs eliminate or reduce some symptoms of dementia such as delusions, hallucinations and can also help calm the person. For many the use of antipsychotics is a necessary part of their care.



In 2009, it was reported that 180,000 people with dementia were being prescribed antipsychotics, of which **two-thirds were inappropriate** (Alzheimer's Society, 2011). Between 2008-2011 prescriptions for antipsychotics to treat some symptoms of dementia has reduced by over 50%.

**Risperidone** is the only antipsychotic drug prescribed for people with dementia. Some GPs may prescribe a different form of antipsychotic, but this is only in exceptional circumstances. **Due to the possible side-effects this treatment is only meant for the short-term (12 weeks).**

**Table 2: Possible side effects of antipsychotic medication**

- |                             |                                       |
|-----------------------------|---------------------------------------|
| ▪ Sedation/drowsiness       | ▪ Parkinsonism/shaking                |
| ▪ Higher risk of infection  | ▪ Increased likelihood of blood clots |
| ▪ Problems with circulation | ▪ Stroke                              |
| ▪ Heart problems            | ▪ Falls                               |

**If any of these symptoms are reported, ask the person to see their GP as soon as possible.**

# Non-Pharmacological Treatments

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Aside from medication there are alternative ways of coping with a dementia diagnosis. The following are suggested by the National Institute for Clinical Excellence (NICE) guidelines (2006).

## Alternative approaches

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- **Validation therapy:** Focusing on the person's inner reality based on current feelings.
- **Reminiscence therapy:** Reliving past experiences of the person promoting understanding and respect of the things they have achieved in life.
- **Complimentary therapy:** Using alternative medicine such as aromatherapy or massage together with medication to compliment their effectiveness.
- **Multisensory stimulation:** Snoezelen is a stimulating and soothing room environment to help stimulate each sense.
- **Music or art therapy:** Uses physical, emotional, mental, social and spiritual qualities to help provide meaningful stimulation.
- **Animal-assisted therapy:** Involves animals as a form of treatment to improve a person's social, emotional, or cognitive functioning.
- **Cognitive behavioural therapy:** A technique used to help people understand how thoughts and feelings can lead to certain behaviours.

Further options and assisted therapies will be available through contacting the local Community Mental Health Team. [<http://www.salford.gov.uk/mentalhealth.htm>]

# Environmental Adaptions

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Below are some suggested home adaptations you may be able to advise carers with, that may help people live well with their dementia at home.

## In the bedroom

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- Place a label on the door clearly indicating it is the bedroom.
- Use a fairly bright main light of at least 200 lux (check lightbulb) and provide a traditional bedside lamp for additional lighting.
- Fix labels with both text and images to drawers to assist finding.
- Position photographs, pictures and furnishing in safe places (firmly fixed on walls) to re-familiarise people.

## In the Kitchen

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- Keep taps individual with 'Hot' and 'Cold' on them.
- Have bright lighting (around 600 lux).
- Keep open shelving to allow easy recognition of items.
- Clearly label any cupboards, fridge etc.
- Electric ovens and hobs are safer than gas- with lid covers for recently used hobs.

## Around the house

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- As much as possible contrast floors, walls and doors to provide good visual contrasts for way finding.
- Fix down all rugs and loose furniture.
- Keep electric nightlights.
- If there is any incontinence do not use electric blankets.

*The University of Stirling, 2012: Available at: <https://dementia.stir.ac.uk/files/Kitchen.swf>*

# Peer Support

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Attending support groups and gaining practical help can benefit both the person living with dementia and their loved ones. Age UK Salford is an excellent point of access to gain peer support.

## Attending peer support services can provide interventions that:

- Delay moves into residential care
- Keep people active
- Prevent social isolation and depression
- An opportunity to find something enjoyable and important
- Enable carers to have a break
- Let people share their experiences in a non-threatening environment
- Expose people to more information
- Help people come to terms with their diagnosis
- Allow people to take ownership of themselves and help shape services

## Being open and talking about dementia

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If you feel it is appropriate - *talk to the person and their relatives about dementia*. Many people do not want to talk about it, they feel it is something to be ashamed or embarrassed about. Taking the stigma away from the illness by being open and approachable may help people talk about dementia more and come to terms with their diagnosis.



# 5. Communication

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# Communication

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Having problems with language can be distressing for people with dementia. This can be when the person may be unable to find the right word, or they may use words that do not always 'fit' into the flow of a conversation. In some cases, communication problems may mean that someone can no longer communicate verbally. Using non-verbal skills can help maintain good communication to help understand needs and wishes.

## Tips for communication

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- Approaching somebody face on where they can see you
- Speak slowly and clearly
- Give them time to respond - you do not have to fill the silences
- Use simple language and ask one thing at a time
- Try and keep your tone of voice friendly and positive
- Give them space and try to stay at eye level
- Use non-verbal language, such as gestures and objects
- Repeat yourself to let them know what it is you are doing or what you are asking them to do (Burrow, Elvish and Keady, 2012)





# Life Story Work

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Life Story Work is an activity involving developing an individual biography of a person's life. It is used in dementia care to help develop an understanding of a person's past experiences and how they have coped with changes in their life.

## How to conduct life story work

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This template for putting together Life Story books has been developed by Dementia UK and the Central and North West London NHS Foundation Trust. (Dementia UK, 2012).

### Life Story template

1. Introduction to my life (date and place of birth, parents, siblings etc)
2. My childhood
3. My working life
4. Significant life events
5. Significant places
6. Significant people
7. Social activities and interests
8. Later life and retirement
9. My life now (likes, dislikes)
10. My wishes for the future

The process should help staff understand the person better, collaborate well with families and facilitate enjoyable activity with the person living with dementia and their relatives.

# 6. Behaviours that Challenge

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# Behaviours that challenge

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Changes to the brain caused by a person's dementia can affect that person's behaviour. These symptoms are often referred to as behaviours that challenge. It is estimated that between 60%-90% of people living with dementia will experience some type of behaviour that challenges throughout their illness (Shega et al, 2007).

## What behaviours may be a challenge?

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Restlessness

Wandering

Aggression

Less Inhibition

Agitation

These situations can become unmanageable quickly. Often they can be dependent on the context of where the behaviour takes place and can be related to the setting in which the person lives. For example, it is more likely for someone in a care home to experience these symptoms compared with people living in their own homes (Lawlor, 2002). These behaviours are also more likely to occur as the dementia becomes more severe.

We call behaviour that challenges a 'challenge' because it challenges us as staff. It is important to remember that the person living with dementia is not at fault when this kind of behaviour is complex for us to deal with. It is also thought that the behaviour is an attempt at communication and as a result of unmet needs. Creating a plan to manage this behaviour will support you (page 43), the person with dementia and those who care for them.

# Aggression

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Many people caring for those with dementia may have times when they are faced with aggressive behaviour. This includes verbal and physical aggression and this can be very **distressing** (Dagnan, Grant & McDonnell, 2004).

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Understanding the reasons a person's behaviour may be aggressive can help underpin the potential problems and ways to counteract this. Using the four step guide below can help identify the possible triggers (Alzheimer's Society, 2012f).

## Step 1: How do you think the person is feeling?

- Frightened
- Embarrassed
- Frustrated
- Worried
- Disorientated

## Step 2: Physical changes in the brain may have caused:

- Decline in judgement and self-control
- Loss of inhibitions
- Pain

### **Step 3: What triggers the aggression?**

Noting down when the behaviours occur, who with and at what time can help establish what the possible triggers may be, i.e physiotherapy appointment, during personal care, morning hunger.

### **Step 4: Prevention**

If an aggressive situation does arise, don't blame yourself. Instead, concentrate on handling the situation as calmly and effectively as possible. As far as possible avoid the confrontation, reassure the person and try to distract away from the problem. If the person is physically aggressive give them space, look after yourself and seek support.

### **In the future**

Try to behave normally, and be as reassuring as possible. Punishing a person living with dementia will not help them change this behaviour. If this is a frequent worry speak to their GP or social worker.

## Example 2: Joe and Paula

---

*Joe is an 80 year old man and has been married to Paula for 60 years. Joe has always been a quiet man. Recently, Joe has become increasingly verbally aggressive towards Paula. Joe and Paula's daughter reported that Joe has hit Paula several times, although Paula denies this. Paula is becoming more withdrawn and has stopped going to her gardening classes, something that she enjoys.*

.....

***What would you do?***

.....

# Agitation

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**Agitation is a state of anxiety that can be both psychological and physical. Factors which are shown to affect agitation include the environment, a person's personality and other medical factors. Often agitation can be the result of boredom or the need for activity and stimulation** (Salzman et al,

2009).

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If someone is feeling very agitated reassure them of where they are, who you are and ask them if there is anything you can do. It is important to consider the physical and social environment to identify the underlying causes of the agitation (Moore et al, 2013). When agitated some people prefer to return to a more familiar environment, some wish to be left alone whereas others may benefit from more interaction. Effective agitation treatments focus on one-to-one interaction, such as aromatherapy and hand massage. Other activities could include familiar music that the person can relate to or reminiscence about. Knowing the person's life story is very important here. Personalised activities are also a great way of reducing the levels of agitation, without the need for pharmacological interventions.

### Example 3: Betty and Karen

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*Betty is a 76 year old woman who has four grown up children and really enjoys attending her local singing group. Karen who leads the singing group has noticed that Betty gets very agitated around 3pm. She noted she would become wander-some, put her coat on and try and leave the building even though she was not due to be picked up until 4:30pm. Karen would ask Betty to rejoin the group as she would distract other members. There was also limited staff to support the group. Karen didn't want to let Betty go outside for her own safety and would escort her back to her seat sometimes up to five times in one afternoon. Betty would get very upset and on some occasions scream at Karen.*

.....  
***What would you do?***  
.....



# Excessive Walking

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From time to time, people feel compelled to get out and about. It is very natural. Keeping active and walking is good for our health and can relieve stress and boredom. However, when someone with a more advanced dementia goes out walking, problems with their orientation can create difficult situations for both themselves and their loved ones (Alzheimer's

Society, 2012g).

## Reasons that someone may 'wander'

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- Out of habit- they have enjoyed being active so far in life.
- Boredom- seeking entertainment or fulfilment.
- Agitation and anxiety- feeling worried or restless can make someone want to pace/wander.
- Relieving pain- do they have any medical conditions? Are they on any medication that this could be a side effect of?
- Responding to an uncomfortable environment- are they too hot/cold, light/dark?
- Feeling lost in an unfamiliar environment.
- Walking to get something- food, cigarettes etc and then forgetting what they want/how to get there.
- Walking to find someone- possibly a current carer or reliving past experiences, such as going to work.

## What to do to help

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Try as far as possible to walk together and avoid confrontation or telling them to sit down. Identify safe areas to walk outside and offer to walk with him / her. If walking outside is not appropriate (for example, due to the time of day or the weather) relieve boredom by engaging the person in an alternative physically or mentally stimulating activity.

If you feel someone is wandering because they are agitated reassure them and let them know where they are and that they are safe, familiarise them with the room/ toilets. If they are searching for someone who isn't here, such as a carer or someone who isn't alive, encourage the person to talk about it to see what it is they need. This could be for feelings of safety or reassurance for example. Check there is no underlying pain or discomfort that may be causing wandering behaviour, e.g. arthritis or restless leg syndrome.

If a carer speaks to you about this being a repetitive problem you could advise them to install an alarm or bell at the front and back door. This may help to alert the carer to wandering activity. See <http://www.salford.gov.uk/telecare.htm> for more information.

## Example 4: Anwar and Mohammed

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*Both Anwar and her brother Mohammed are in their eighties and have lived together since both of their partners died over 10 years ago. Both enjoy the outdoors and used to go on walking holidays with their partners. Dressing herself appropriately, Anwar has been attempting to open the front door during the early hours of the morning, which is causing great distress to Mohammed, who is consequently sleeping in the lounge chair to make sure Anwar does not leave the house.*

.....  
***What would you do?***  
.....

## Planning out how to help

---

- ✓ Look if there are any obvious signs as to what may be distressing the person living with dementia.
- ✓ **Talking to relatives** will help gain a sense of that person's history, lifestyle, likes and dislikes. This may identify on anything that has changed which may be upsetting the person.
- ✓ Confirm with carers/relatives what **medication the person is currently on** (if any) and what possible underlying physical illness they may have. If you notice that the behaviour occurs during movement they may be in some kind of **pain** or **discomfort**.
- ✓ Finding the root cause of a problem can be very difficult it may help to write down when the behaviour occurs, who with, what time of day and during what kind of activity.
- ✓ It is always worth checking that the person's **needs** are met as they may not always be able to **communicate** them in ways that we understand.
- ✓ Many people with dementia suffer from incontinence, are at a higher risk of infection and struggle with eating and drinking; these could be key areas causing them distress.
- ✓ **Reassure them** of where they are and who you are; they may feel lost or afraid.
- ✓ As many people living with dementia are over the age of 65 they may have other health concerns. Be aware that not every symptom may be directly due to the dementia.
- ✓ For most people changes to their **lifestyle, environment** or **physical health** may have caused the change in behaviour.

## Example 5: Tom and Harry

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*Tom is an 80 year old male who regularly attends a local coffee morning. Harry is a staff member at the coffee morning notices that Tom is moving his money around from the table and back to his pocket. Tom shouts Harry over to ask him where his money is. Harry shouts from behind Tom that he has just put it back in his pocket. Tom asks Harry again where his money is and gets increasingly agitated standing up to find it. Harry shouts at Tom to sit down and that his money is in his pocket. Tom becomes verbally aggressive to Harry and other people attending the coffee morning.*

*Gail another worker at the coffee morning who knows Tom well comes in to see what the noise is about. Harry sends Gail away as he wants to help deal with the situation himself.*

.....  
**What would you do?**  
.....

# 7. Sexual Expression

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# Sexual Behaviour

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**Sex and dementia can be a complex issue that is often not spoken about. Nevertheless, it can be an important area in which to support those living with dementia and their carers** (Alzheimer's Society, 2012h).

## Intimacy

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We all have the right to express our sexuality. Be open to talk about sex with carers and with people living with dementia. Getting a diagnosis of dementia does not mean that their sex life must end. Remind them that their relationship may change as all relationships can change over time. It is also important to share that as a couple they may re-define ways of being close and intimate.

Due to structural changes in the brain a person with dementia's sexual feelings can change unpredictably. This can involve changing interests in sex, changing ability to perform sexually, lack of inhibition and changes in sexual manners. While some people adapt to these changes well, many people will feel upset, loss, embarrassment and frustration. As the relationship changes, there may be issues with partners of people living with dementia being unsure of their capacity to consent to sexual activity. The Sexual Offences Act (2003) and the Mental Capacity Act (2005) can throw light on this difficult area. However, due to the complex nature of this issue, every situation must be viewed individually.

Further help and advice can be sought from:

- Alzheimer's Society's Helpline for confidential advice (0300 222 11 22).
- Relate ([www.relate.org.uk](http://www.relate.org.uk)) (0300 100 1234) Offers various support and advice on sex and relationships through face to face and website support.

## Inappropriate Sexual Behaviour

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Sexual behaviour can be implied in many ways. This can involve sexually inappropriate behaviour such as talking about sex (where it makes others uncomfortable), acts of a sexual nature, and implied sexual acts. Often these types of behaviour have the potential to cause offence. They also cause conflict between the need to protect the person and maintain their dignity, while preserving the person's desire to fulfil their sexual needs (Benbow & Beeston, 2012).

Making a plan of action can help identify; the problems, personal beliefs, and the person's best interests. Sometimes what appears to be sexual is actually an indication of a need such as:

- Needing the toilet
- Discomfort
- Agitation
- Misunderstanding other people's needs or behaviour
- Mistaking someone for their current (or previous) partner

Whatever the behaviour this can be very distressing for the carer and the person living with dementia. If you notice this type of behaviour occurring possibly facilitate a conversation with the carer to see if they have the right support available.





# 8. Helping and Supporting People Living with Dementia

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# Supporting staff

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Although it can sometimes be difficult, it is important to see past the diagnosis of dementia and concentrate on the person. Think how you might feel in their situation. Reflect on how they might perceive the environment when dealing with symptoms. Do not always assume that all behaviour is a direct consequence of the dementia. Getting to know the person behind the diagnosis will help you to be more aware of when they are acting out of character and could help you signify an underlying issue.

Remember that you cannot always help in every situation and if you find the situation unmanageable then take yourself out of it and seek support and assistance from your team. It is also important to reflect on difficult challenges and discuss how you might handle similar situations in the future. Being a staff member in this area of work can be difficult. You may see people with dementia change in their cognitive functions over time and this can be very difficult, have an effect about how you feel about them and about your role. It is important to be able to talk about these feelings with your supervisor. Never be afraid to say how you feel.



# Supporting Carers

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There will be worry and sadness seeing someone you love start to have less control over their lives. There may be changes to the relationship and some sacrifices. Remind carers that being positive can really help people live well with their dementia. There are ways of adapting daily life and activities to make the challenges more bearable.

## Practical Support

It is much easier to cope if carers care for themselves too, this includes their own health and well being. Remind them that they can still meet their needs without compromising the needs of the person they care for. Making time to relax and using respite can be beneficial for both the carer and the person living with dementia.

### **Alzheimer's Society National Dementia Helpline**

Provides information, support, guidance and signposting to other appropriate organisations.

**Tel: 0300 222 1122**

### **PRT Salford Carers Centre**

Offers a range of support especially for carers.

**Tel: 0161 833 0217**



## Example 8: Don and Margaret

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*Don is Margaret's husband and her primary carer. They share a long and close marriage and Don found it very distressing when Margaret usually friendly and positive was upset. Margaret would ask Don 'have you seen my mum?' Don would sometimes correct Margaret and tell her that her mother was no longer with them. This resulted in Margaret becoming very upset and Don would also feel distressed at bringing this news. Don didn't want to lie to Margaret but he found himself very depressed by her illness.*

.....  
***What would you do?***  
.....

# Supporting People Living with Dementia

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Helping people remain as independent as possible will help them to keep enjoying the things they like. Remind them when they have a bad day that there is help. Make sure their choices are clear and that they feel respected and valued. Give them access to information that can sort any legal or financial affairs in the way that they want to.

## Support at Diagnosis

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Dealing with a diagnosis can be very stressful and each person's experience of dementia will be unique to them. Like any illness a person's journey will make them feel different at different times. They will have times that are harder than others but with the right support and information they can adapt. People react to a diagnosis very differently; some feel great relief that the diagnosis allows them to take action where others may never accept their illness and find a way to live with it that way (Alzheimer's Society, 2010).



## Practical Support

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Having a care plan in place will help people living with dementia be more in control of the kind of support they want for in the future. Sorting out financial and legal matters early on into a diagnosis can relieve stress knowing that specific wishes will be respected later on into a diagnosis.

### Driving and Dementia

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DVLA: People must let the DVLA know of their diagnosis immediately, however this does not necessarily mean that they have to stop driving. The DVLA will then assess how safe driving is for that person and other road users. Many people with dementia retain learned skills and are able to drive safely for some time after diagnosis. The DVLA then contacts the person's doctor (if permission is given) and based on medical information will be advised of whether that person is safe to drive.

### Lasting Power of Attorney

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Creating a lasting power of attorney document early in diagnosis can be a way of sorting out affairs in the way they would like. This can be related to property, finances and affairs. It enables someone they trust to make decisions on their behalf around these issues at a later date when they may no longer be able to make those decisions themselves.

### Benefits

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Once benefits have been arranged it may be appropriate to set up an appointee for the future. This person can then arrange, collect and administer benefits in the way the person living with dementia prefers. To do this they need to contact the department of work and pensions (Age UK, 2012).

## Trusts

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If there are financial assets, it may be worth setting up a trust. This ensures that assets are managed in the way a person chooses, but they must be done in the early stages of diagnosis.

## Writing a Will

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We should all write a will- it ensures that after death financial assets go to the people of our choosing. A person must have a testamentary of capacity to make or change a will and a solicitor can decide if they have this usually by seeking medical advice.

Contact your local citizens advice bureau for further information and advice to pass on to those who you support.





# Keeping well

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It is important for us all to look after our health and wellbeing.

This is the same for people living with dementia staying healthy will have a positive impact upon their physical and mental health (Alzheimer's Society, 2012i).

## Physical Health

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### Exercise

Finding a form of exercise that suits individual needs can be an enjoyable part of a routine and beneficial towards their health. Exercise encourages; movement, keeps people active, improves circulation, aids relaxation and reduces stress. <http://www.salfordcommunityleisure.co.uk/>

### Eating well

Keeping a healthy balanced diet will help people build up a resistance to further illness. Make sure people remember to eat, have the right atmosphere and support at meal times. Try to advise them to limit foods that may cause further health problems.

## **Keep warm**

Older adults may feel the cold more than younger adults. Keeping warm is important to avoid risk factors such as hypothermia. There are cold winter payments available for older people.

## **Regular bowel movements**

Constipation can be a major problem in older people and it can cause pain and discomfort. While a GP can prescribe laxatives you can also suggest; high fibre foods, vitamin supplements and regular movement.

## **Limiting Alcohol and Smoking**

Limiting alcohol and smoking are ways to ensure better health and well-being. It is also important to remember the safety of people living with dementia. Smoking does also pose a fire risk and alcohol consumption may confuse and disorientate the person further making their already difficult symptoms worse. Where appropriate, suggest limiting smoking and alcohol consumption as it may significantly improve upon their wellbeing.

## Mental well-being

Maintaining meaningful relationships and having someone to listen to their worries can greatly help the well being of people living with dementia.

Reducing other types of stress as much as possible will help people feel less burdened by their illness. Suggesting appropriate activities can help people stay mentally stimulated.

## Sleep

Some symptoms of dementia such as disorientation and confusion between night and day can affect sleeping habits. This can cause stress and have a detrimental effect on mental well being. Avoiding day time naps, reducing stimulants such as coffee in the evening and eating at set times can help create a stable routine for sleeping.

## Depression

25% of people with dementia also have depression. If you feel someone is showing lower than normal mood, interest, appetite and fatigue then you should raise this with their GP and relatives (Burrow, Elvish, Keady, 2012).



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