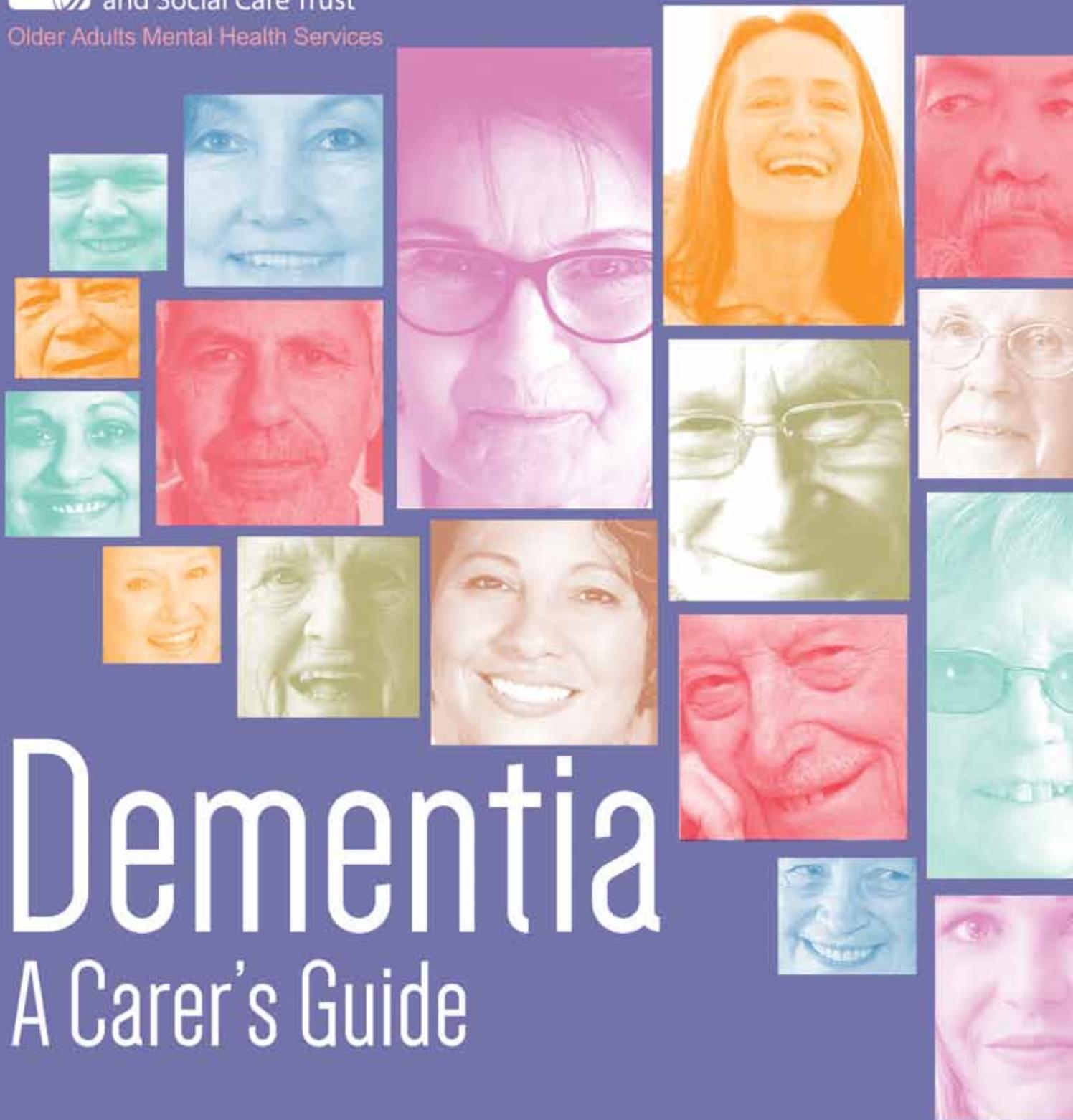




Western Health
and Social Care Trust

Older Adults Mental Health Services



Dementia

A Carer's Guide

A booklet providing tips to individuals providing care to a relative, friend or family member living with dementia.

Contents

Foreword	5
Part One: Understanding Dementia	7
Reaching Their Best Potential	8
Young Onset Dementia	11
Independence	16
Sensory Changes in Older age and Dementia	16
Changes in Behaviour	19
Part Two: Communication	25
Behaviour Staging Model of Dementia	26
Stage One: Malorientation	27
Stage Two: Time Confusion	31
Stage Three: Repetitive Motion	35
Stage Four: End Stage Withdrawal	39
Look After Yourself	40
Some Simple Tips	42
Part Three: Helpful Information Sources and Organisations	43

Foreword

Memory problems can be devastating not only for the individual who experiences them, but also for their family, their friends, and their carers. Family members and carers of those with dementia can play a crucial role in the practical and emotional support and care of those with dementia. However, the impact of the diagnosis can be made worse if carers are not given appropriate information, training and advice at an early stage and throughout the illness.

This booklet was developed as a direct response to requests from carers of those with dementia. Hopefully you will find that this booklet helps you to improve your understanding of the impact of dementia on the person and how to understand different types of behaviour at different stages of the illness. It is hoped that this understanding will allow you to prepare for changes in advance and to improve your communication with the person with dementia.

This booklet is split into three main sections. Part one focuses on factors which can impact upon dementia and also aims to provide a few ideas about how to understand dementia and changes in behaviour. Whilst a diagnosis of dementia at any age will understandably have an impact on the person

diagnosed and their family, when someone under the age of 65 develops dementia the challenges can be very different. With this in mind part one of this booklet also focuses on some of these issues which are more specific to people of young onset dementia. Part two of this booklet focuses on communication within dementia and how to improve communication when memory and language skills are reduced.

Further information sources and organisations which can help carers are listed at the back of the booklet in Part three.

This booklet accompanies the post diagnosis education programme on dementia run by the Mental Health service for older people.

Older Adult Mental Health Services



Understanding Dementia

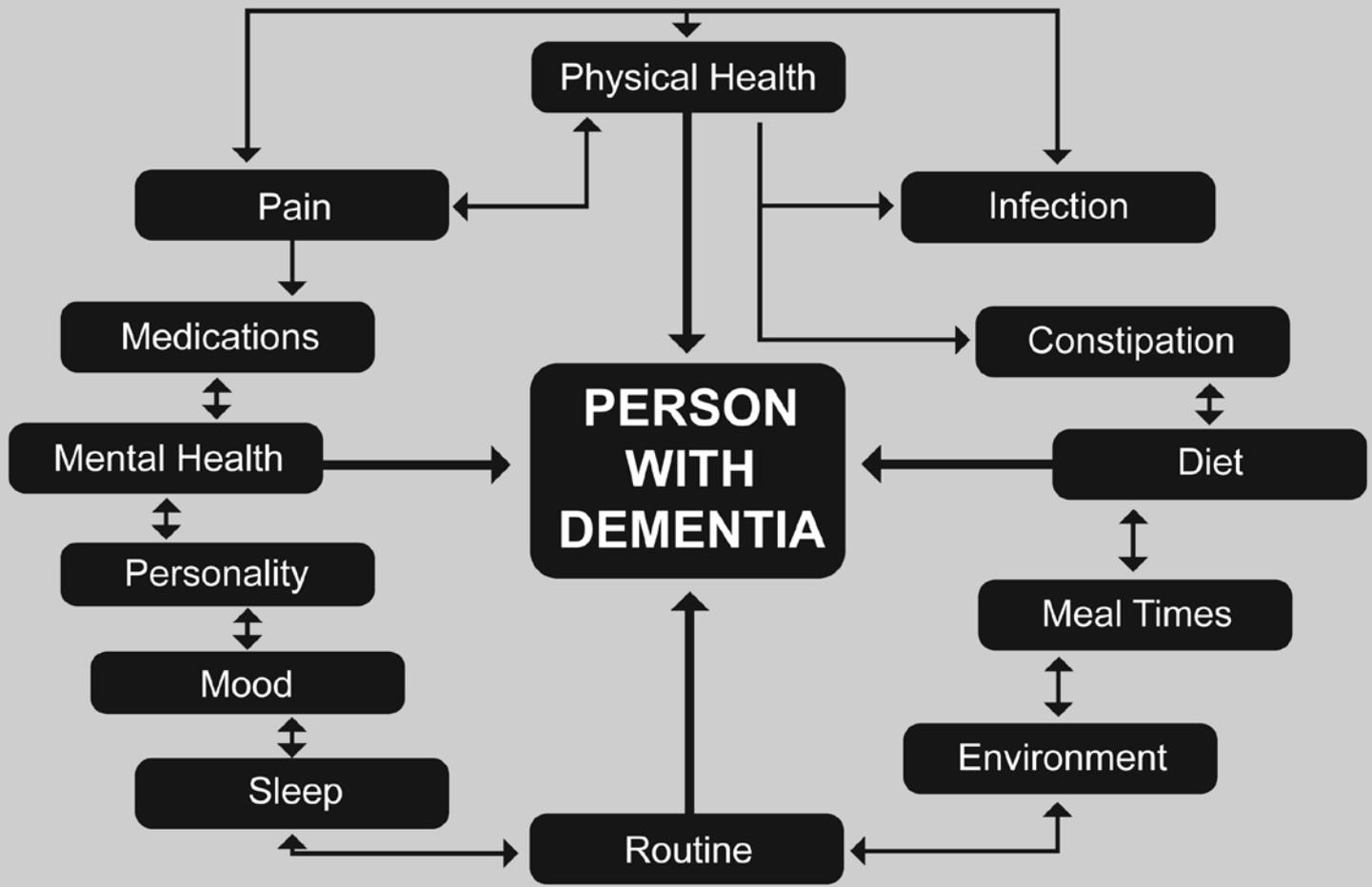
The term 'dementia' describes a set of symptoms that includes loss of memory. However a person with dementia will also experience problems with communication and language (e.g. finding the right word or understanding words that are said or written down). They will also experience difficulties with solving everyday problems (getting dressed, making a cup of tea) and may find it difficult to know how to act correctly in social situations. Individuals with dementia may also experience changes in their mood and are less able to control their own emotional reactions.

There are many types of dementia. The most common types are Alzheimer's disease and vascular dementia. However your relative may be diagnosed with Dementia with Lewy Bodies or Frontotemporal Dementia or one of the other rarer types of dementia. At the time of diagnosis you will be told which type of dementia that your family member or friend has been diagnosed with. Each type of dementia will affect the person in slightly different ways. However all dementia is progressive, which means the symptoms will gradually get worse.

When someone has been diagnosed with dementia there are lots of factors which can affect the person's day to day abilities and can also affect their behaviour. Some of these will be explored in this booklet and the education groups.

The diagram on page eight gives an example of some of the factors that can impact upon the person's ability to reach their best potential.

Various Factors that can Impact Upon the Person With Dementia



PART ONE

How to allow the person with dementia to reach their best potential ...

If you are ever in doubt regarding your relative's mental or physical health always contact your GP. It may be the case that they are suffering from a physical infection that can cause a change in their behaviour. It can be surprising just how much factors such as an infection

can impact upon an individual's mental state. Infections are common in older adults and if you notice an unexpected or sudden change in your relative's behaviour such as an increase in confusion, agitation, delirium or aggression, it is often due to infection. It is very important that you are aware of this change and seek medical advice quickly. It is also common for some people with dementia to experience pain although they may not be able to communicate this.

Diet has an important influence upon how the person with dementia will perform on a daily basis.

If the person does not have enough fluid they can become dehydrated and therefore more prone to a urinary tract infection. Also if the person does not eat enough foods that are high in fibre they can become constipated and therefore suffer pain and discomfort which will increase their agitation and irritability.

Fruits (strawberries, apples and oranges), cereals (rice, whole grain bread) and vegetables (broccoli, carrots, potatoes etc) are important and useful to prevent this. By introducing food on red plates or liquid in red cups this may help the person with dementia to feed themselves or drink more fluids as they are more able to see the prepared food or drink. If your relative finds it difficult to eat at meal times, ensure that they are with you, where possible, for the preparation and cooking of the food. Simple tasks such as setting the table or peeling the vegetables may not be completed correctly, but will allow the person with dementia to feel valued and important. Being in the area where the food is being cooked will also stimulate the senses

(particularly smell) and the appetite and will give the person a sign that it is time to eat. In order to reduce stress during mealtimes, reduce the amount of cutlery placed on the table for each course being served. Trying to use a knife and a fork can make eating more frustrating. Consider serving more finger foods or specially adapted cutlery to promote independence during mealtimes.

Routine is extremely important and can impact greatly on the person with dementia's ability to reach their best potential if it is changed. Visiting new places or going on holiday can be extremely difficult for the person with dementia and they become more dependent on family members or carers to help them find their way about which can lead to frustration and agitation. Creating and continuing a daily



routine will help reduce the risk of confusion and also reduce the risk of potential conflicts and agitation.

Always encourage your relative to use the toilet often as holding urine in the bladder for too long can make them susceptible to infections. If you are not always with your relative, consider putting up a sign on the bathroom door (including both words and a picture) or leaving the toilet or bathroom door open. The route to the toilet should be well lit, especially at night. Changing your toilet seat to a contrasting colour e.g. blue will make it easier for the person with dementia to see. Sometimes a person is believed to be incontinent when the real reason is that they are unable to find the toilet. By using colours (orange, bright pink, yellow) that allow the person with dementia to see better, to highlight a toilet door or toilet seat, the person may manage to find the toilet on time. Some men who have poor mobility or balance, or who can no longer direct their penis when urinating, may find it easier to sit rather than stand. If your relative uses a urinal bottle (designed for men and women) or commode because they are

unable to make it to the toilet on time, especially at night, make sure this is always available.

Individuals who have dementia can often display behaviours that are confusing and difficult for carers and family members to understand and deal with. As a carer it is important for you to try and understand what has triggered this behaviour and the meaning behind it.

- Repetition

Memory loss can cause an individual to repeat the same statement or question over and over again within a matter of moments and can be frustrating for others. This can occur as a result of many reasons such as boredom, anxiety about coping or simply having forgotten completing a task or having forgotten that they have recently asked the question already.

If this happens; be patient and encourage the person to find the answer themselves such as the time or the date. Repetition occurs often in situations such as an appointment or a visitor arriving, it may help if you don't mention the event until just before it is about to happen. Introduce a notice board in a

room that is always used, in a very prominent place. Clearly write the day and date. Add any appointments for that day, as near to the time of the event as possible. Place a large easy to read clock near the notice board.

- **Restlessness**

People with dementia are often restless and this can be a sign of something other than memory loss like an infection, hunger/thirst, pain, constipation, needing the bathroom or anxiety. The individual may not be comfortable and is unsure how to express themselves. If this is the case, try to find the reason, offer them reassurance and contact your GP if you feel something physical is troubling them. Offer them something to do such as an activity to occupy them.

- **Asking to go home**

This is common in people living with dementia and can occur whilst they are still at home. This can be a sign of anxiety, insecurity, fear or even low mood. It happens because they no longer recognise their current environment as “home” and this can be very upsetting. They can be recalling memories

of people and things from years ago that aren't there now which can in turn provoke anxiety and low mood. It is difficult for you to understand as you know that this is their home but try to reassure them that they are safe and loved and you are here to help them. The reason that this happens is explained more fully in behaviour stage 2 of the communication section.

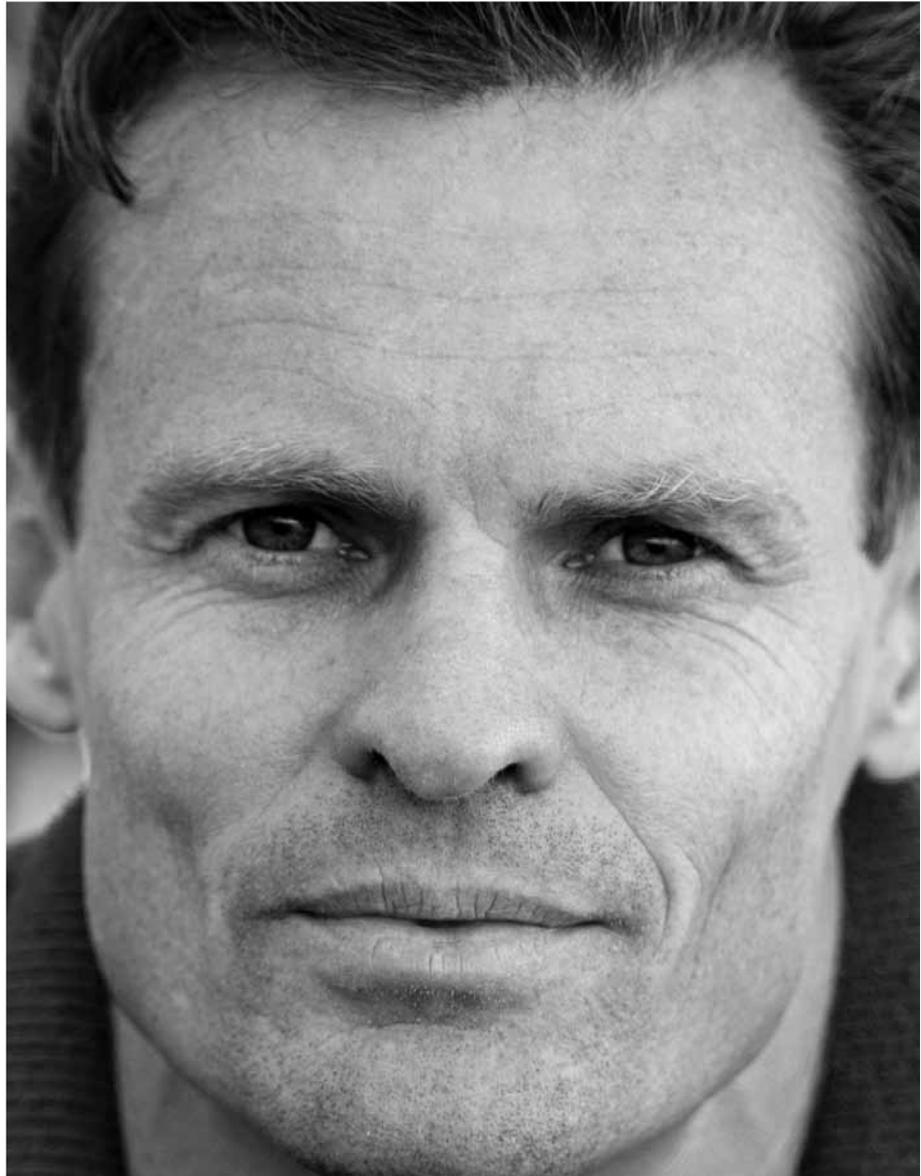
Young Onset Dementia

Dementia does not just affect older people. Whilst age remains the greatest risk factor for dementia about 5% of people diagnosed with dementia are under the age of 65. Young onset dementia, also known as ‘early onset’ dementia or ‘working age’ dementia affects adults between the ages of 30-64.



Young onset dementia is more often due to rarer causes, unusual presentations of the common dementia and genetic causes and because of this can be more difficult to recognise. Memory problems may not always be the main complaint. Younger people can also be very reluctant to accept that there is anything wrong when they are otherwise fit and well and may put off visiting their doctor.

Even when the younger person visits their doctor, a diagnosis of young onset dementia may be delayed for a number of reasons. Rarer causes of dementia are often more difficult to diagnose. There may be a reluctance on the part of the referring doctor to consider dementia in people under the age of 65 and unusual or uncharacteristic behaviour may be ignored or put down to stress or tiredness. Furthermore, understanding the cause of dementia in a younger person is quite rightly a relatively intense and a more lengthy process and more specialist investigations, including brain scans, further memory and other cognitive



or thinking assessments and home observations may be necessary.

A diagnosis of dementia, at any age will understandably have an impact on the person diagnosed and their family. However, when someone under the age of 65 develops dementia the challenges can be very different.

- Financial

Younger people with dementia may still be working at the time of diagnosis. An early and accurate diagnosis is important for many reasons.

For someone of working age, there may be heavy financial commitments, such as a mortgage, a pension, or life insurance etc. A diagnosis of dementia will mean a drastic change in circumstances.

If the person is still working when diagnosed, retiring from work due to ill health rather than because they are making mistakes in their job will affect what pension rights and benefits they are entitled to.

Some people with dementia may choose to stay on at work. It is therefore important that their employer is made aware of their diagnosis, so that they can identify if there are ways that the working hours or level of responsibility could be reduced, in line with the new diagnosis.

The person with dementia and their spouse or partner may need information to help make appropriate legal, financial, occupational and welfare decisions. It is important to talk

to someone about what benefits you may be entitled to.

As a carer you may also have to leave employment to care for a loved one, which can lead to further financial problems.

- Emotional

While the symptoms of dementia in younger people are the same as in older people, emotional responses may vary a lot. The younger person with dementia may feel more anger and frustration or may find it harder to come to terms with their reduced ability to take part in day to day tasks. It is important not to make assumptions about how the person is feeling or what they might be going through. Each person's experience of living with dementia is different. The same is true for the spouse or partner, the family or the carer of the person with dementia.

For many younger people with dementia and their family this is a very traumatic time, when feelings of uncertainty, grief and loss are particularly acute.

Both the person with dementia and their spouse or partner may feel robbed of their future. They may have had dreams

and ambitions to fulfil up to and beyond retirement. They may lose their sense of identity through giving up work or their role within the family. There may also be elderly relatives to care for which may lead to further feelings of guilt and stress.

Because dementia is so strongly associated with older people, younger people can feel extra stigma and discrimination. A younger person may not be believed when they say they have been diagnosed with dementia. This reaction can add to a person's problems.

- **Family Relationships**

When someone is diagnosed with dementia it obviously affects the whole family and not just the person who is diagnosed. There may be young children or teenagers living at home. There may be grandchildren or other family members who do not understand what is wrong. The kind of information and support which is required will depend on the age of the family member and their relationship to the person diagnosed.

Sometimes there can be changes within the relationships of family and friends. Some people may unfortunately drift away e.g. former work colleagues, although new friends can be made through support groups. After such a long period of uncertainty, relationships between the person diagnosed and the family can improve, with the new understanding of what has been wrong and in making plans for the future, whether in more formal ways, such as financial, or making plans for holidays and more family time.

It is important that the person with dementia is encouraged to communicate the changes that they are experiencing. Children and young adults especially will need help in understanding what is happening to their parent or relative.

When communicating a diagnosis to children or teenagers, it is important to share it in a way that is easy to understand, making sure that they are aware that any changes in the person is to do with the condition and that no-one is to blame. Young children may need particular reassurance and some time to understand what they have been told.

- Physical Activity

Physically younger people with dementia are usually fit and healthy. It is important that a younger person is helped, where required, to maintain their physical health and wellbeing for as long as possible. A younger person with dementia will still have more energy and may enjoy walking and sport. Encouraging physical activity will allow the person with dementia to continue to feel a sense of independence

and self-worth and purpose. It may also have a positive effect on mood and sleep, which can all be affected with dementia.

It is certainly acknowledged that compared to older people, younger people with dementia may experience more difficulty in accessing services appropriate to their needs. The lack of age specific services or activities for younger people makes having the disease more lonely and isolating for both the person with dementia and their carer. The needs and interests of someone in their 40s or 50s will inevitably be different from those in their 70s and 80s.

However, despite the progressive nature of dementia, many people do find ways to cope with their diagnosis and get on with their lives. Some people find a sense of purpose after diagnosis by joining local support groups and talking to people in the same position as themselves and coping with similar changes. There are a number of these running within the Western Trust area for both the person with dementia and their carers.

As with any age, it is important to remember that young onset dementia is not the defining



aspect of someone's identity. They are a person first and should always be described and treated as such. Life does not stop when dementia starts.

Independence

As a carer it is very important that you try to encourage the **individual** to do as much for themselves that they can possibly do. This helps retain their skills and **promotes their independence**.

This also enhances their physical, psychological and emotional well being as they gain a sense of achievement from completing activities.

It can be frustrating to watch someone struggle but **offer help** rather than doing the activity for them.

Don't let your frustration and upset show, if necessary leave the room as it will be more upsetting for them to see you upset.

Always **be mindful of their strengths** and give them praise and encouragement for what they can do.

Offer help in a **sensitive** manner, even try breaking the activity down into smaller sections and suggest small breaks.

Be careful about your **tone of voice and body language**. Instructions should be short, simple and helpful and not patronising, abrupt and rushed!

Most importantly – **Do things together!** It maintains a bond; integrate adapted activities into your daily routine.

Sensory Changes in Dementia and Ageing

• Sight (Vision)

There is a reduction in the sharpness (acuity) of vision. A younger person will have to bring things closer to the eye to see clearer. However, when we get older, we must move objects away from our eyes to improve our vision. Visual acuity starts reducing from around the age of 40 on average. By changing the toilet seat to contrast with the toilet pedestal (e.g. white pedestal dark blue seat) this will allow the person to see it better.



As normal ageing occurs, the lens of the eye gets coloured browner as a person gets older. Think of it like wearing a pair of sunglasses inside. If the day is already dark outside due to the weather, the person with dementia will not be able to see properly. Make sure that lights are on and that there is plenty of lighting in the room to make sure that the person is able to see properly. By the age 80-85, only 30% of light reaches the retina compared to age 25

The visual field (peripheral vision or seeing something 'out of the corner of your eye') reduces after the age of 25 years old. At age 80-85 years, peripheral vision has reduced by an average of 30-35% on

both sides. As the person's dementia progresses, ensure that you are not standing to their side when communicating or assisting with activities of daily living such as feeding the person as they will not see you. Make sure that you do not place their favourite or reminiscence objects too high on a wall or a sign too high on the door as they will 'disappear' to the person with dementia.

Colour vision is also decreased. The blue/purple colour spectrum is lost in older age. In Alzheimer's the colours of blue, purple and green are affected and may be perceived as grey.

Colours that are best seen are yellow, orange, pinks and reds. These colours can be used to highlight particular rooms (by painting the doors to the rooms), for example the toilet, bedroom and the lounge. This allows the person with dementia to find these rooms, without having to be told by someone else. This allows the person to preserve their dignity.

The person with dementia's reading speed also reduces and their ability to read and follow the television screen will reduce as the dementia progresses.

Make sure that the person with dementia also has regular eye examinations, where possible, to rule out any cataracts.

- Smell

For people with dementia the sense of smell is affected. There is some reduction to the sense of smell in Alzheimer's disease (recognising certain smells without being told). Sensory gardens should focus on stimulating the visual sense rather than just the smell.

- Taste Receptors

There are five taste receptors in the mouth. These are bitter, sweet, salty, sour and savoury. As a person gets older their ability to perceive or identify certain senses is reduced. The person's ability to taste salt reduces first followed by their ability to perceive a bitter taste. Sour perception stays the longest. A person's ability to taste sweetness is very poor as they get older.

- Hearing

As we age, there is a loss in the ability to hear particular sounds. The ability to hear high frequency noises is lost first. Make sure that the person with dementia can hear what you are saying as sometimes a misheard comment may lead the person to become angry or aggressive.

- Touch

Both hand massage and therapeutic touch can be effective as a method of relaxation for individuals living with dementia and the carer. This is dependent upon the stage of dementia they are experiencing (people with dementia in stages 2, 3 or 4 may appreciate this better). In stages 2, 3 and 4 it is invaluable, especially where the person's verbal communication is limited.

For people living with dementia, they are not as able to detect coldness. Make sure that they are kept warm and offered a cardigan or a jumper if you believe that they might be cold. Do not wait for them to ask.

What if your relative or friend shows changes in behaviour?

- Agitation

When an individual shows signs of agitation there is always a reason for it. You will be one of the people that know them best so you may already know how to help remedy this situation.

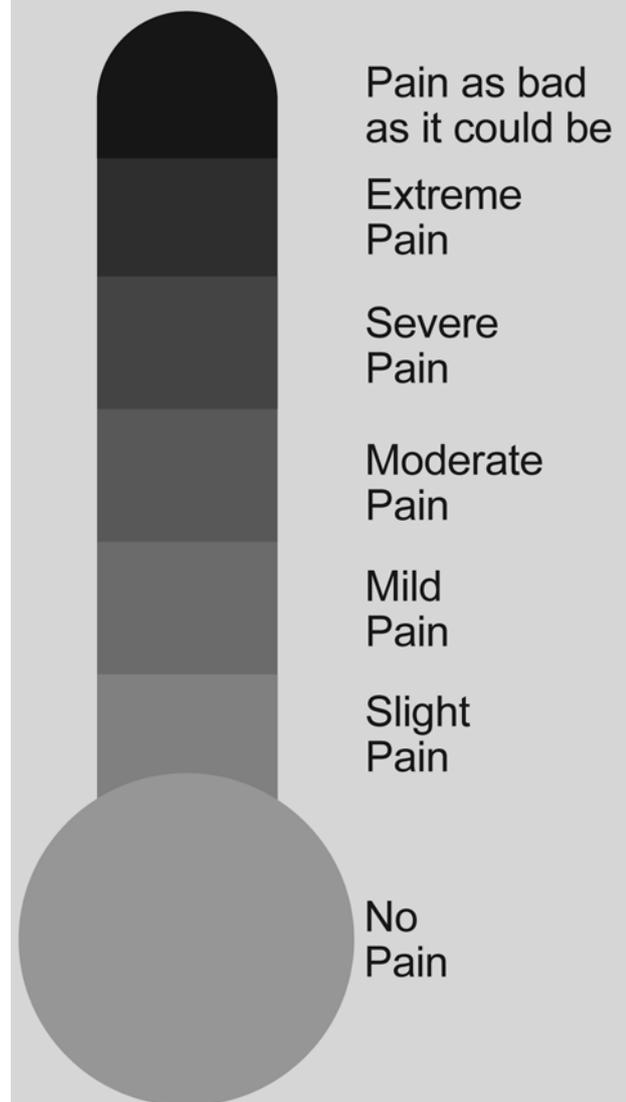
Always be sure to check if there is an underlying physical reason why this agitation has occurred, as it is possible that they may have other illnesses or infections whilst also experiencing dementia. It may be that they have misheard or misinterpreted a situation or may have become scared or frightened.

If the individual is agitated and/or pacing do not try to stop them, restrain them or make them sit down as this will only increase their agitation. Instead offer them purposeful exercises such as going for a walk or simple household tasks that they may have once previously enjoyed. Not only will this tire them out and ensure that they sleep well, but it also provides a form of exercise for them and you might get a good night's sleep too!

If the individual becomes angry it may be necessary for you to leave the room. By doing so, you are giving them time and space to calm down. It may not have been your fault that they have become agitated and angry, but by leaving the room you are reducing the possibility of them blaming you.

Thermometer Pain Scale

(Adapted from the Assessment of Pain in Older People National Guidelines)



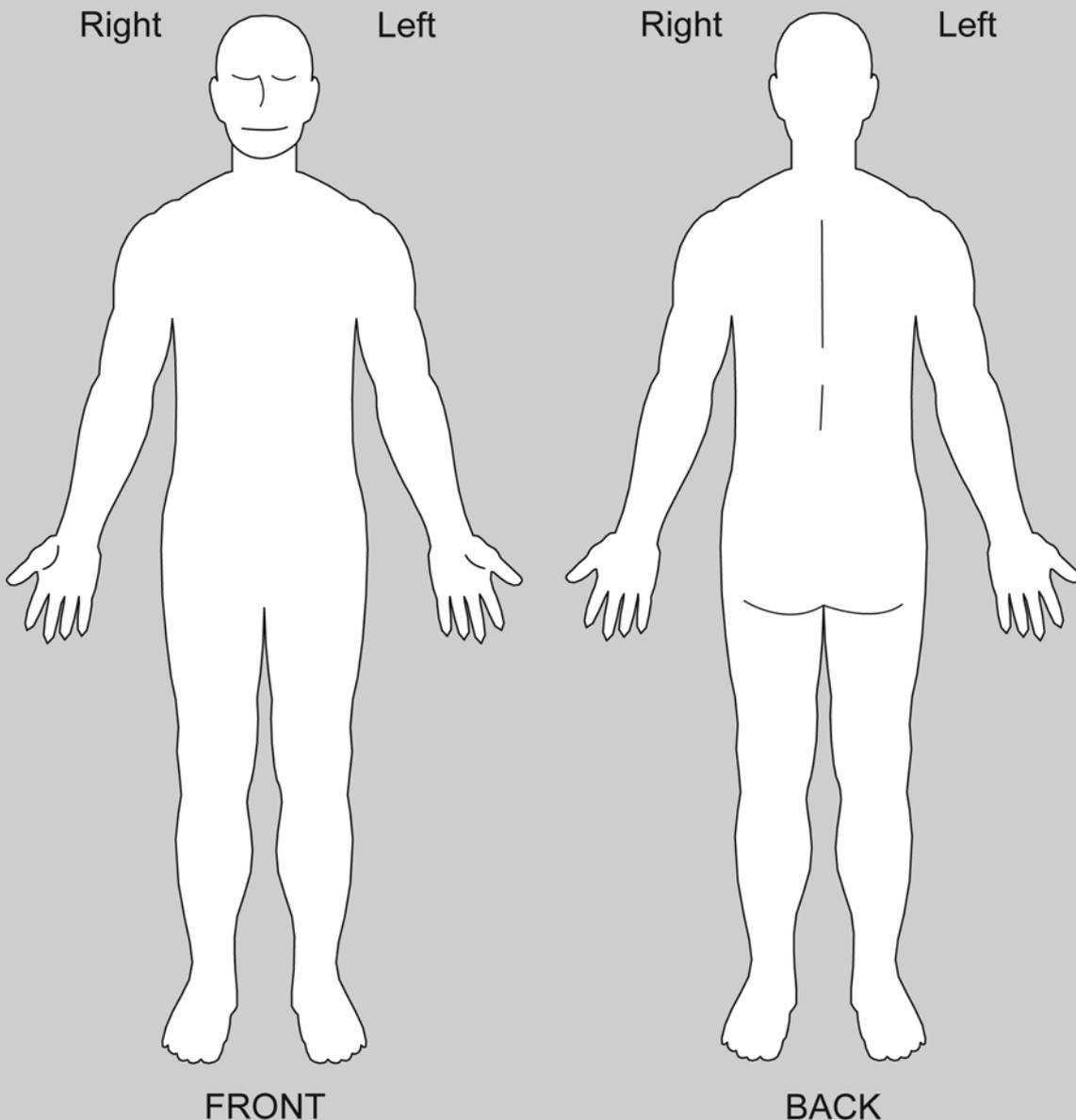
- Pain

Ensure that the reason for the agitation and anger is not pain. Individuals' living with

dementia experience pain just as everyone else does but may be unable to tell you that they are in pain. Pain or discomfort is a very common reason for

Body Pain Map

'Where is your pain? Please mark where you feel pain on the drawings.'



agitation or aggression in people with dementia.

Gently take the person's hand and ask them are they in pain using simple questions that require 'yes' and 'no' answers. If the person remains agitated and this does not work remove yourself from the situation whilst ensuring that you have reduced the risk of the person falling.

Use the two pain assessment tools (body map, on the left and the pain thermometer on page 19) to help identify if the person with dementia is in pain.

If the person with dementia is no longer able to communicate that they are in pain by answering 'yes' and 'no' or by using the pain thermometer or the pain body map, check their body language. Some other symptoms to look out for are whimpering, groaning or crying; looking tense, frowning or grimacing; perspiring or looking flushed; refusing to eat or increased confusion. If you think that the person experiences any of these symptoms or the person has other physical conditions which may cause them to feel pain, seek medical advice but also

consider pain relief given in appropriate doses and following medical instruction.

• Low Mood

Low mood is one of the least diagnosed mood disorders in individuals living with dementia, but it is very common. It is entirely possible for an individual to experience a flattening of mood but it may be masked by the symptoms of memory loss. It may appear to you that their memory has got worse when in fact they are going to bed or are getting agitated or are emotional because they are low in mood. By treating the symptoms of low mood you can also improve aspects of their memory.

If your relative or friend is also suffering from low mood there are a few things that you can do to help them.



Speak to your GP or community nurse to begin with.

Activities can help to relieve boredom or even insecurity as the individual has had to deal with a lot of change in their life. It is possible that they are dwelling on this fact so something such as a run out in the car or listening to their favourite music, or dancing can be beneficial.

Reminiscence is a helpful strategy for managing low mood. Looking over old photographs together and discussing them, or remembering things you used to do together is a great way of not only spending time together but keeping your friend or family member's mind active.

It is extremely difficult when living with someone with dementia who is convinced that they are still 21 years of age and trying to go to work when in fact they are 85 and haven't worked in 25 years. Instead of telling them their real age and that they are wrong make use of a technique called 'validation'.

Validation is a helpful technique that encourages you to explore the meaning

behind what the person is saying. This technique lets the person know that their opinions are acknowledged, respected and heard. Instead of saying "No, you are 85, you don't work" say something like "Where have you worked?", "Did you enjoy your job?", and "What was your role?" By doing so you are giving the person with dementia a means of comfort and the chance to reminisce. You are also allowing them to feel valued and important. The person will therefore not feel silly or frustrated for having forgotten the time period that has passed between the ages of 21 and 85.

Don't argue if it doesn't matter. Your friend or family member will forget a lot of things and be wrong quite a lot regarding names, dates and places for example. There is no point in disputing these mistakes as it becomes exhausting and upsetting not only for them but also for you.

Exercise and mild physical activity such as walking short distances are beneficial for a low mood. It occupies the individual for a short period of time and promotes a sense of achievement.

Low mood = decreased sleep, feeling sad/worthless, anxious, irritable, decreased energy, poor appetite etc.

Aggression

An individual can behave in an aggressive manner for a variety of reasons and for you as a carer this can be very distressing. They may be aggressive verbally or physically and even threaten violence to you or others.

There are numerous reasons as to why this may occur including:

- Fear
- Embarrassment
- A break down in communication
- If the person feels their dignity or independence is threatened
- Over stimulation – too much noise, too many people or a changed routine.
- A change to their physical health, for example infection, pain or constipation.

When an individual displays aggressive behaviours it can be stressful for you. It is important to understand reasons why this behaviour has occurred and to find helpful ways to deal with it that suits both you and the person with dementia. Remember that the person with dementia is trying to communicate something.

- Don't take it personally!!

It is hard to deal with but remember it is not intentional. You may feel like it is directed at you but that is only because you are there.

- Take a step back.

By leaving the situation you are giving the individual and yourself a chance to calm down. Take a deep breath. Walk into another room for a short while when you know that the person is safe to be left.



- Don't argue!!

It's not worth it and will probably make the situation worse than what it already is.

- Acknowledge that they are upset.

Reassure them and try to distract their attention from the current situation. Try to understand how they are feeling.

- Give them space.

Leave the room. If the person becomes physically violent it is important that you walk away unless it is necessary that you stay. Do not try to restrain or hold the person. If the aggression has started because you were trying to take the person to the toilet, help them into the shower, get them dressed, etc, then consider if you really need to complete this task at this moment. If you try it again later and approach the situation slightly differently, the person might be okay with it then.



Communication

Or how to “understand the message and engage with the need that is not being met”

(Goudie & Stokes, 1989).

Part 2 of this booklet gives tips and advice to help improve your communication with someone with dementia throughout the progression of the illness. The information within this next section is based upon the work and teachings of Dr Gemma Jones and uses the behaviour staging model of dementia.

We all need to communicate with other people. Communicating our needs, thoughts and feelings is extremely important – not only to maintain our quality of life, but also to preserve our sense of identity.

Communication is not just talking. Much of our communication is non-verbal, which takes place through gestures, facial expressions and touch. Non-verbal (or non-speaking) communication is particularly important when a person with dementia is losing their language skills. This may also mean that a person with dementia behaves in ways that those caring for them find difficult. This may be because they are trying to communicate something. Losing the ability to speak or understand can be

both frightening and frustrating for the person with dementia. There may come a time when the person can hardly communicate accurately or successfully through language. This may be distressing for friends or family members, but it's a normal aspect of their memory loss.

Other factors may also affect the ability of a person with dementia to communicate – including pain, discomfort, illness or the side-effects of medication. If you suspect that this might be happening, talk to the person's GP. If appropriate, make sure the person's glasses are the correct prescription, that their hearing aid is working properly, and that their dentures fit well and are comfortable.

The Alzheimer's Society has produced a good factsheet (Factsheet 500LP) on communication. This may be downloaded from www.alzheimers.org.uk.

For those people who find it more difficult to understand verbal (spoken) language, communication through the use of pictures may be helpful. A useful visual communication book may be purchased from www.visualcommunicationaid.com (Tel: 01937 558426).

The Behaviour Staging Model of Dementia

All behaviour has meaning. It should never be seen as senseless, crazy, stupid or unprovoked.

The course of dementia usually consists of a series of slow but progressive changes. Therefore it is helpful to have points of reference along the way. 'Behavioural staging' is a simple way of describing this. Behavioural staging allows you to see the person with dementia's current needs and abilities within the larger context

of what is happening to them throughout their illness. Behavioural staging is also a method of helping you focus on the many ways in which a person with dementia tries to adapt to their own changing circumstances. Each person with dementia will experience or react to their illness in their own individual way. This model can make you as a carer aware of the stage that someone is experiencing during this complex illness. You can then start to use helping strategies that are most appropriate to each particular stage, to help your friend or family member live as full and as enriched a life as possible.

The Behavioural Staging Model consists of five stages. Each of the stages from one through to four will be described in some detail within this booklet, along with suggestions which you or other family members may wish to use to enhance communication with the person with dementia at each stage. Stage Zero occurs when the person starts to experience mild problems with their thinking and memory. Not all people at stage zero will go on to receive a diagnosis of dementia. Communication remains largely unchanged at this stage.



Stage One: Mal-orientation

During stage 1 the person with dementia will start to make noticeable mistakes, in the way that they try and communicate. The person may experience some word finding difficulties and forgetfulness. They may start to become confused by changes in routine e.g. at family gatherings having to set the table for six instead of the usual two. Although these errors are noticeable, the person with dementia may still try and hide them, which can take a considerable amount of effort on their part.

You will start to notice problems with the person's memory, attention and their ability to think in a logical way due to the

damage in their hippocampus (the part of the brain that is involved in memory forming, organising and storing information). In Alzheimer's disease, the hippocampus is one of the first regions of the brain to suffer damage. An easy way to recognise these difficulties is to look at the quality of excuses the person is making.

Stage one can last up to 5 years in Alzheimer's disease. This stage can last much longer in vascular dementia depending on when the next stroke occurs. People in stage 1 will lose the thread of the story they are telling, so will confabulate. Confabulation is a term used to describe a plausible but imagined memory that fills in the gaps in what is remembered. It is distinguished from lying as the person does not intend to deceive you as they are unaware the information is false. They may also confabulate if they are caught off guard and will come up with something probably not as plausible. Relationships can become undermined very quickly by pointing out this confabulation. Families can create more stress and upset by confronting someone in this stage.

People in stage 1 have awareness that they are making mistakes and are worried that if others find out they will be labelled as crazy or put in a care home. There are different levels of defensiveness about making mistakes. The person may be in a muddle, trying to ensure that they do not lose the respect of other people, by admitting to their confusion. It is important to remember that the person with dementia still takes pride in their accomplishments and where possible, they will try and protect this by hiding what they cannot do from you. Their adrenalin levels are raised, and they are constantly in a state of stress. They will use up a lot of energy covering up their errors all day. If you as their carer notice this and offer to help, they may push you away and will think that they have got to try harder. The person in stage 1 may ask for help at one point and then push you away again.

People in stage 1 are still trying to follow social manners. A way to understand what that means is to think of an example using a colour-coded traffic light system.

People who do not have dementia or any other problems with their thinking can decide

what information to share with other people. They may decide not to tell someone the truth about something to prevent hurting their feelings, or so that they do not get into trouble. In these circumstances the traffic light system moves from red to amber, which gives the person time to think and consider whether to share the information or to keep it to themselves, before the light turns to green. People at stage 1 are still able to stop and consider whether to share information or thoughts with other people (they still have an amber light).

People in stage 1 can be distrustful of other people as they are hearing critical comments all the time about their forgetfulness or their ability to perform tasks that they have



always managed. The person in stage 1 will desperately be looking for one person to understand them. They will only trust one person who will take them seriously. Therefore they find it difficult to handle noisy discussions with family members. Children (or other carers) can feel betrayed, or that they are being played one against another by the person with dementia. Family carers should not take this personally. If possible, take time out, walk into another room if you feel upset. Involve another family member to give you time to step away from the situation or re-charge your batteries.

It is important for carers to understand the person with dementia's view of the world. If the person with dementia mishears, they might interpret what is being said to them according to the way they view the world.

People at stage 1 can plan or exhibit deliberate behaviour, unless diagnosed with fronto-temporal dementia when problems with their planning ability occurs early in the illness.

Evening time can be difficult for carers of the person in stage 1 as the person with dementia may be tired in the evening, go to bed early and then get up during the night.

Helpful 'tips' to improve communication for people at stage 1:

- Keep your distance unless or until you are invited to get closer.
- Do not expose the person's weaknesses or errors. They are working as hard as they can to be "normal" and telling them that they are wrong or that they have forgotten something will leave the person feeling vulnerable. They may become cross as a consequence of your 'helpful' behaviour.
- Maintain social etiquette and manners.
- Learn to work with all of the feelings that the person with dementia expresses especially fear and anger. Learn to acknowledge and validate the feeling. Do not avoid it and don't take it personally.

- Generally, for people in stage 1, whoever is nearest 'gets it' ... it's meant for the whole world – not you. Control your own feelings. Do not argue, or leave the angry person with dementia all alone. This can increase their isolation and mistrust of others. Eye contact, a calm presence and 'interest in the immediate situation' (good questions asked in a respectful, interested tone of voice) will often calm a person quickly.

- When communicating with a person in stage 1, ask 'who', 'what', 'where', and 'when' type questions. Try not to ask 'WHY' type questions directly as these can feel confrontational to the person with dementia. Also this may force the person to lie about something, confabulate or become defensive.

- If you do not know the person with dementia very well, do not expect to explore feelings immediately with people in stage 1. Wait until you have their trust or are given signs or hints for you to pick up on.

- Keep your normal social distance (usually about 1 metre) and use formal manners until you receive

an indication that you may move closer (these "signals" may be verbal or non-verbal. Remember to watch their body language and your own!)

- Until familiar and trusted, people in stage 1 often prefer to be addressed by their surname, rather than first name.
- Anger, fear and attempts to minimize the losses the person with dementia may experience, can be expressed in indirect ways and through symbols. Make sure important objects are present if they provide a sense of security (e.g. by carrying a handbag, wallet, newspaper, or a cane). These can still make the person FEEL safe and normal, even if the bag or wallet is empty. If the person has a community nurse or social worker, these types of interventions should be placed in their care plan.

- Routine is important. Individuals at stage 1 may like to sit in same place ('their' chair), and be neatly dressed (for example by wearing jewellery, make-up, and their best clothes, if this is how they have always dressed).



lead them to some ‘bizarre’ conclusions). However, they are trying to make the best sense out of a situation, when they do not have all the information).

- Most people in stage 1 will benefit from being reminded where they are, the day of the week, time of the day etc. This is called reality orientation.

- People with dementia will benefit from being with other people their own age and staff (if they are admitted to hospital or a care facility). They will feel frightened and less comfortable being around people in stages 2 and 3.

- People in stage 1 can still participate in simple games (with only a few rules) and should be encouraged to continue previously enjoyed activities, although they may require gentle prompts during these.

- It is important to help people in stage 1 maintain social contacts by phone, correspondence and visits with family and friends. However, it is important to recognise that too many people or an unfamiliar environment may lead the person in stage 1 to feel stressed.

- There is no point in arguing ‘facts’ with a person in stage 1. In stage 1 of dementia a person’s ability to reason deteriorates (which may

Stage Two: Time Confusion

The person with dementia at stage 2 will make obvious, frequent mistakes about the year, time of day and regarding their location. Facts are no longer important to people in stage 2. Instead the person will try and make sense of their surroundings using their emotional reaction to the place or the person. For example, “Where does this place feel like?” or “Who does this person feel like?”

The person at stage 2 cannot lie anymore. They become disinhibited (have less control over their behaviour) and are no longer able to disguise some of their emotional responses, sometimes at the expense of politeness, sensitivity, or social appropriateness. If the person starts displaying behaviour that is different, e.g. swearing or touching someone, it may be that this has always been in their internal world, but they are no longer able to hold it in. Using the example of the traffic light system referred to in stage 1, people with dementia at stage 2 onwards no longer have an amber light (or time to stop and consider whether they should say something, if they have thought it, they say it) and therefore they go straight from red to green.

The person at stage 2 experiences obvious noun finding difficulties (the name of a person, place, thing, or idea) and will often lose the thread of a conversation.

The person in stage 2 is 'lost'. When the person feels safe, they may think they are at home or at work, or that they are looking after their children. When a person in stage 2 asks

to go home or suggests that his or her parents will be expecting them, this may indicate that he or she does not feel safe or secure. Home is not a literal place; instead look for the meaning behind the words, as facts are no longer important. The emotions behind the words are very important. This is a different kind of fear because everywhere is lost.

Reality orientation is useless in stage 2 onwards, unless during a lucid moment, when the person shows a sudden clear understanding of something. These moments do not last very long.

The person in stage 2 will not recognise family members due to certain types of visual damage. As their ability to reason has been damaged, they may refer to you or other family members by the name of their spouse, parent or sibling. Females with short hair may be referred to as males as the person tries to make sense of who they are communicating with. Carers or strangers may also be identified by their personal attributes (e.g. weight, height, skin colour) sometimes at the expense of politeness or sensitivity.

When speaking to someone in stage 2 about the past, use the past tense with them, although they will answer using the present tense. When they are talking, they may lose the thread of the sentence. Even with prompting, this will not come back. They are very good at offering you their opinion. Ask their advice, but be careful how to phrase the question.

The person at stage 2 onwards cannot watch television. They often cannot detect what carers are doing and can't read a book. Damage to the dorsal system means that the person cannot detect movement and that images are not formed properly.

The person at stage 2 will no longer know where their own handbag is, but may take another person's. It is the

symbol that is important. For men, if they always had a wallet in their back pocket and keys in their front pocket, replicate this.

Genuine incontinence starts at the end of stage 2. If incontinence occurs before this, it may be because the person cannot find the toilet.

Helpful 'tips' to improve communication for people at stage 2:

- Encourage conversation, whatever they want to talk about. Simple questions people in stage 2 could answer:
 - What are you doing?
 - What plans have you got for today?
 - Do you miss your own home? What do you miss about home?
 - How could we make this place more like home/better?
 - What is it like to become old?
 - What do you think about most?
 - What was your husband/ wife, father/mother ... like?



- Are you sometimes (fill in the feeling) lonely / frightened/ sad/ happy?
- Are the people here friendly?
- What are the most difficult (and best) things about living?
- Resist the urge to change the subject if the person at stage 2's conversation isn't 'happy'.
- Acknowledge the person's feelings and life experience.
- Communication should be at an emotional level, not factual.
- Resist the urge to correct mistaken facts.
- Give the person at stage 2 a chance to share their wisdom. For example, ask questions like "What advice would you give ... to parents about disciplining children?"; "... to people wanting to get married?" etc.
- Use non-verbal forms of communication, e.g. touch, eye contact, music, singing and movement.
- The person at stage 2 will need frequent, close contact with others.
- If the person is in day care or in a residential home setting, find them a 'buddy' in the same stage. 'Buddies' refers to a friendship between people who are both permanently disoriented or lost in time. They may think they are and behave like best mates, companions, spouses or family members. It is a case of mutual mistaken identities. They are devoted to each other and content and hence do not try to leave to go home or to work; call out for their parents; go to their own or others' bedrooms trying to pack; or request the frequent attention of staff.
- Try and figure out where the person at stage 2 thinks they are or the time of their life that they think they are in.
- Learn how to respond to the person at stage 2's feelings of being lost, frightened, missing people and things from the past. 'Wanting to go home' is often a code for feeling lost and unsafe. You can ask questions "What's so good about home?"; "Who are you thinking of there?"; "What's not so good about this place?"; "What makes a place feel like home?"; "What would make things better here?"



Stage 3: Repetitive Motion

During stage 3 the person's speech deteriorates. The person will repeat the same word, sound or phrase over and over again just because it sounds nice. Don't be alarmed if this is a swear word. They will also often have very limited speech and may echo what you are saying.

The person during stage 3 requires different forms of stimulation. If the person is not getting enough stimulation from the world around them they will use self-stimulation, in the form of body movements or repeated speech.

The person at stage 3 will have very poor vision, slow eye movements and very poor eye contact.

The person at stage 3 will be immobile due to visual problems. Due to their peripheral vision problems, in order to communicate well with the person with dementia, you must get very close to the person. Sit in front of them and if their posture makes it difficult for them to sit up or lift their head, sit on the floor in front of them (if they are on a chair) and look up at them. At this stage of

- The person at stage 2 will like to have contact and closeness with you or another person so that they can feel safe.

- The person at stage 2 likes to help with familiar household-type tasks. For example give the person a duster and an apron, towels to fold, a block of wood and some sandpaper etc.

their dementia, their vision is at its best within approximately a small 18 inch triangle.

When speaking to the person in stage 3, wait until you are within their visual field and keep your movements slow, as they will find it difficult to follow you with their eyes. Use sensory stimulation before you start to talk, for example a hand massage, in order to give the person the best opportunity to realise you are there, and to understand what you are trying to say.

The person at stage 3 may often display rocking movements when they are upset. By picking up on this kind of communication, you will be able to try and work with them to make them feel better.

Helpful ‘tips’ to improve communication for people at stage 3:

- Place yourself and important things in the person’s visual field. This may now be reduced to a small triangle of approximately 18 inches.

- Encourage the person with dementia to use their speech, even if this is only swear words.

- ‘Mirror’ or copy their movements and ‘echo’ their sounds.

- Use touch, music, singing and movements to replace more verbal types of communication.

- The person at stage 3 will need extra time to respond. Wait until you have eye contact, body contact, and until they are aware that you are present before starting to talk. Wear a bright red scarf or red lipstick to allow them to focus on your face.

- Use very simple (often vague) questions. For example, “You’re making everything all tidy”? “You’re working hard”? “You’re happy”?

- Intensive one to one forms of communication occurs best in a quiet environment. Make sure the television or radio is turned off and all other noises are reduced or stopped before this communication starts.

- Try using a combination of eye contact, touch, a nurturing tone of voice, music or rhythmical movement and positive sensory stimulation. However, avoid over stimulating the person. By checking how the person responds to each of these forms of communication, you may be able to use the ones that they find most beneficial. This allows your approach to be tailored to best meet their needs.
- For group activities cosy circular seating arrangements help people in stage 3 to be most aware of the presence of other people in the room due to their limited visual field. 'Winged' backed chairs reduce the amount that

people at stage 3 can see people on either side of them because of their peripheral visual problems.

- Make up a special apron or tabard (with large pockets and Velcro strips to attach objects to). This can be a good way to keep important objects within the person's view. Ideas for objects to attach to the tabard may include curlers, coloured pieces of paper or material, a change purse, handkerchiefs, keys, tea towels, or doilies. Use objects with different textiles or sounds.

- For men at stage 3, give them pieces of wood and sandpaper, or thin strips of wood with holes drilled in them to put very large nuts and bolts onto. They may also be interested in large playing cards, or dominoes. You might have other similar ideas for activities given your knowledge of the person's likes and dislikes.

- Use sensory stimulation. This may be explained as the use of stimulation to make the most of each of the six senses:



1. Vision.

For example, you could arouse the visual sense by projecting unpatterned images. Particular attention should be made to the use of bright, contrasting colours (e.g. reds, oranges, yellows and pinks), which are easier to identify for individuals in the latter stages of dementia.

2. Olfactory. (i.e. smell).

You could stimulate the olfactory sense through the use of different aromas.

3. Auditory.

For example, you could arouse the auditory (hearing) sense by playing a varied selection of different kinds of music. You could record a selection of music (10 or so songs or pieces of music). Play a sample of each track and encourage the person with dementia to express their likes or dislikes (verbally, or by thumbs up or thumbs down, head shaking etc).

4. Tactile.

You can stimulate the tactile (touch) sense by handling objects with different textures. Try using a box of beads for



this task. These can be secured on a string, or may be loose as long as you are with the person and are supervising what they are doing. Tactile stimulation can also be introduced by the use of hand massage (a pleasant smelling hand cream will also stimulate olfactory stimulation). A gentle shoulder or arm massage may also be used as long as you have checked if your relative or friend can tolerate it.

5. Taste.

You can stimulate the taste sense through detection of different tastes by the tongue and the mouth. Remember that our sense of taste reduces

as we get older. Therefore remember to choose items with a strong taste, for example lemon sherbet sweets, or pieces of orange, melon or grapefruit etc.

6. Kinaesthetic.

You can stimulate the Kinaesthetic sense through the use of movement and rhythm.

- Sensory objects or “triggers” often activate more than one sense (e.g. vision and touch when holding a piece of fabric), at the same time.

Stage 4: End Stage Withdrawal

At this stage the person looks like going in and out of periods of inactivity. The person will appear to have withdrawn from all that is going on around him or her.

At stage 4 the person’s eyes are often closed as if sleeping. There is very little movement or sound (noises, words) made by the person.

At stage 4 the person still responds to positive stimulation i.e. touch, nurturing voice tones, music.

At this stage the person may stare intensely at things that catch their attention (usually visual things).

At stage 4 the person may still laugh at slapstick-type humorous events that they see.

Helpful ‘tips’ to improve communication for people at stage 4:

- Like those with stage 3, it is important to make good use of sensory stimulation with people in stage 4. Use touch, nurturing voice tones, tapping rhythmically to music whilst holding the person’s hand, and hand massage. Use examples documented in stage 3 ‘helpful tips’.
- Communicate with and stimulate the person through their senses as much as possible. For example let your relative or friend with dementia smell her favourite perfume by spraying this on a handkerchief and placing this into her hand, feed him favourite flavours of yogurt, give her a hand massage, play familiar and favourite music CDs, sing to him, reading him well known

poems and prayers, bring her flowers, and always wear bright clothes so that the person can see you.

- Sometimes people who are **under-stimulated** in stage 3 may appear to be in stage 4. The quality of their eye movement, (i.e. whether attempts are made to follow the movement of people around), can be useful in determining whether the person is at stage 3 or 4.

- Use both the person's first name and surname when talking to them, or trying to get their attention. For women use their Maiden rather than their married name.

And finally **Split Staging** occurs when the person does not exactly fit into the behaviour stage model completely.

Look at the stage of each of their abilities e.g. physical, emotional and verbal, in order to work out the best method for communication.

Finally... Look after Yourself

When caring for a family member who is experiencing dementia it can become easy for you as a carer to lose sight of yourself and the things you enjoy doing. It is important that you take time for yourself too as attitudes (positive or negative) are contagious.

- Share your problems

It can become overwhelming if we keep a problem/concern to ourselves. Always be sure to seek help from someone you know and trust. Sometimes a fresh eye on a stressful situation can work wonders. Each and every one of us needs help from time to time, never be afraid to ask for it.

- Schedule some time

Schedule some time out (when possible) to look after yourself. Do something you enjoy doing to help you relax such as going for a walk, reading or a massage. Pace yourself, you can't do everything.

- Sleep

Good sleep is essential to effective functioning but it is often the first thing that goes wrong when we are stressed. Even though we might not realise it consciously we often become irritable and anxious when not having slept adequately the night before.

Before you go to sleep establish a bedtime routine where you relax by reading or simply lying down and listening to some music. Don't keep a TV or computer in the room where you sleep and try to avoid naps during the day. Exercise can work wonders on how we sleep at night, it tires us out physically and when we go to bed we are ready then to sleep. Remember we can all cope better with any difficult situation when we have had a good night's sleep. We can tolerate a lot more too.

Avoid alcohol and heavy meals 2-3 hours prior to going to bed and also cut down caffeine. It is a known fact that when we are stressed about something these concerns often disrupt our sleep at night. In order to eliminate this happening think about what is stressing you, then what you think you might do about it and

write it down, by doing so you have created a plan and are putting it out of your head for the time being. If your friend or family member is having difficulty sleeping at night some of these strategies may also be beneficial to them.

Write out a daily or weekly to-do list (if you are worried about forgetting something that is important to you at the time). You can then refer to this the next day and throughout the week. Record ideas and thoughts as they occur to you. It is impossible to hold too many thoughts in your head at the same time – even trying to may make you more stressed. It can even feel therapeutic to keep a journal or diary of thoughts or events that have occurred. A pencil and paper make excellent concentration tools. A written goal can bring clarity and focus. It is also a powerful reminder that you can use to keep yourself on the right track when you are feeling stressed which may lead to making hasty decisions. Feeling calmer and more relaxed not only improves your mental and physical health but also makes life easier.

Some Simple Tips

- Focus on what the person with dementia can do.
- Be a good listener; be patient, accept and support them.
- Keep a diary – it keeps everything together like appointments and events.
- Keep important things in the same place (with labels if necessary) e.g. - keys, money and glasses.
- Have a calendar and clock visible.
- Do things together, ensure that the person with dementia feels valued and of worth. It adds structure to the day and also promotes a sense of achievement.
- Begin to cherish moments.
- Try to understand how your friend or family member feels; let them talk and be there for them.
- Remember – Their reality is different from yours, they will view things differently from you and this can often explain their actions.



Always remember that you can ask for help and that it is readily available from a variety of sources, some of which are mentioned already in this booklet; as well as your family and friends. Everyone needs someone to talk to. Hopefully it has been of use and benefit to those reading it and has answered some of your questions. Don't forget to **Thank Yourself!** You are managing a lot of things and you are there for someone who needs you. You are finding strengths you didn't know you had and your efforts are very much appreciated by all around you. Remember you are only human.

Helpful Information Sources and Organisations for Carers

Below is the link to the Dementia services page on the Western Trust website. This provides information on dementia and the local services available.

<http://www.westeritrust.hscni.net/3583.htm>

NI Direct (Government Services) has a comprehensive dementia information and resource section with links to support and information in each Health & Social Care Trust area in Northern Ireland.

<https://www.nidirect.gov.uk/conditions/dementia>

Alzheimer's Society has produced a wide range of publications designed to support and inform anyone affected by dementia. They include information on the different types of dementia, living with and caring for someone with dementia.

<https://www.alzheimers.org.uk/get-support/publications-factsheets-full-list>

TIDE "Together in dementia everyday" is a UK wide involvement network of carers, former carers and health and social care professionals. They produced a booklet for carers focusing on the complex feelings of grief carers experience when they care for a person with dementia.

<https://www.tide.uk.net/resources/>

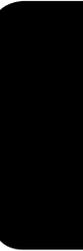
Explaining dementia to a child or younger person within the family, the following links are useful

<https://kids.alzheimersresearchuk.org/>

<https://www.alzheimers.org.uk/get-support/daily-living/explaining-dementia-children-and-young-people>



Older Adult Mental Health Services







Dementia

A Carer's Guide

February 2020

This booklet has been developed for use with carers of people with dementia within the WHSC Trust area. This booklet was written by Dr Gillian Mullan, Consultant Clinical Psychologist for Older People, based on the Psychology Services' ongoing work with carers. Contributions are also acknowledged from Ms Kathy Cooke, Nursing Student, University of Ulster and Dr Kim Sharp, Clinical Psychology Trainee, Queens University, Belfast.