

# DIRECTIONS

2019

## Cardiff and the Vale of Glamorgan

A guide to older people's mental health services,  
including younger people with dementia

Details correct at time of print



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# Understanding The Condition

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There is in fact a wide range of specialised services in the Cardiff and Vale of Glamorgan area providing support to older people with mental health problems and their carers in the community. This publication has been designed with the express aim of informing those caring for older people with mental health problems about the network of specialist services which exist in their locality to support them in their care-giving role. Perhaps more importantly, however, it aims to help them gain access to appropriate support services to meet their needs and the individual needs of the person being cared for.

Mental Health Services for Older People provide specialised services for:

- Older people (65 years and over) experiencing mental health difficulties such as anxiety or depression. These people are sometimes referred to by another term; Service Users.
- Adults of any age with dementia related illness - these people are also referred to as Service Users.
- Carers who support them - these people are the unpaid carers who are usually a partner, a relative or friend.

These two groups of mental health problems (dementia and other late life mental illness), which commonly affect older people, make up the definition 'Older People's Mental Health'; a term which is often used to describe the special needs of this group of vulnerable people in our society, and the services which are available to support them and their carers.

## What Is Dementia?

Dementia is a term used to describe the symptoms that occur when the brain is affected by a specific illness, such as Alzheimer's disease, vascular dementia and many other rarer conditions. Symptoms of dementia include loss of memory, confusion and problems with speech and understanding. The word 'Dementia' simply means a loss or impairment of mental functioning and comes from two Latin words meaning 'away'

and 'mind'. Alzheimer's disease is by far the most common form of dementia, accounting for approximately 55% of all cases, and Vascular Dementia is the second most common form, accounting for about 20% of cases. A further 20% of cases are a mix of Alzheimer's disease and Vascular Dementia and the remaining 10% are made up of the rarer dementias, including Dementia with Lewy Bodies, Fronto-temporal Dementia/Pick's Disease and Huntington's Disease. The main conditions are described in detail below.

**ALZHEIMER'S DISEASE** is a gradually worsening illness which increasingly affects the sufferer's brain and results in a gradual decline in their ability to remember, to learn, to think and to reason. The most usual early symptoms are a gradual loss of short-term memory; increasing confusion and forgetfulness; communication difficulties; and problems in performing everyday tasks, such as driving, managing money, cooking meals, or even washing and dressing. In the early stages of the illness the personality of the person with dementia may change and their behaviour may become unfamiliar or strange, sometimes being difficult for the carer to understand and manage.

Over a period of several years, as the person with dementia becomes more increasingly affected by the illness, their symptoms usually become more obvious and disabling and their confused and sometimes risky behaviour may become far more difficult for the carer to manage, especially if they are coping alone. At this stage behavioural problems, such as wandering, restlessness, or frustration and angry outbursts may be experienced, often during the night as well as in daylight hours. Similarly, physical problems may arise, such as difficulty with walking and postural problems; problems with eating or drinking and subsequent weight loss; or continence problems. Eventually the person with dementia may become so severely mentally impaired and physically frail that they are totally dependent on others to meet their needs.

In the later stages of the illness the multitude of care-giving problems may become so many that the lone carer simply cannot continue to care for the person at home alone and

specialist community support, or placement within a specialist residential or hospital care setting may be required. It is the duty of specialist services to help support people with dementia and their carers in such a way as to enable them to remain at home for as long as is possible and desirable and, if and when care-giving becomes too difficult, to facilitate a gradual and planned admission to the most appropriate continuing care setting.

The symptoms of **VASCULAR DEMENTIA** may be almost indistinguishable from those described above. However, unlike Alzheimer's disease, Vascular Dementia usually has a more abrupt onset and a person with dementia will have good and bad days, with a fluctuation in their level of confusion and self-care skills. Vascular Dementia is often caused by a series of 'mini strokes' (also known as infarcts), which destroy small areas of the brain, thereby producing the symptoms of dementia. As further damage occurs the level of confusion and memory loss in the person with dementia will increase, often suddenly and dramatically. Similarly, their level of self-care skills may deteriorate, sometimes overnight, and the carer has to adjust their coping and caring strategies to compensate for their changing needs. Slight improvements in the condition of the person with dementia may be apparent for a time, but sadly once the damage has taken place it is permanent and irreversible. Similarly, after each mini stroke the level of skills and abilities of the person with dementia, and the carer's roles and responsibilities, may level off and appear to reach a plateau for some time before the next infarct occurs. Eventually over several years, through this process of 'stepwise decline', the person with dementia will reach a level of moderate to severe dementia which is indistinguishable from advanced Alzheimer's disease.

## Young Onset Dementia

While dementia is generally regarded as an illness of old age it can affect younger people in their 40s and 50s and very rarely at an even younger age. Younger people are more likely to suffer from one of the rarer forms of dementia and Alzheimer's disease

is only diagnosed in one out of three cases of young onset dementia. Hence it is important that they and their families receive an accurate diagnosis of their condition.

While the younger person with dementia will have many of the same problems as an older person they and their families may also need specialist help and advice. Younger people are more likely to be in work at the time of diagnosis and may have heavy financial commitments. They may have a young family who are dependent on them. They will be physically stronger than an older person with dementia and may be more disturbed by their illness. It is particularly distressing for a younger person to receive a diagnosis of dementia and very difficult for them and their family to come to terms with the diagnosis.

## **INDIVIDUAL DIFFERENCES**

It should be noted that every person with dementia is an individual and will be affected in different ways. Some people with dementia may never experience all of the symptoms described above, whilst others may experience problems that have not been mentioned. Similarly, the pattern and course of the illness will vary from one person to the next, according to such factors as the type of dementing illness diagnosed, the age of onset of memory loss and confusion, and the physical health of the person with dementia. Even though conditions, such as Alzheimer's disease and Vascular Dementia cannot be 'cured', there is much that can be done to lessen the severity of symptoms and to improve the quality of life of those suffering from these illnesses. There is also much that can be done to improve the quality of life for carers and this publication is intended to help explain which specialist services exist to support the carer at a practical, social and emotional level.

## **Other Late Life Mental Illness**



In addition to dementia a number of mental health problems can occur in old age and people suffering from them may need support and treatment from specialist Mental Health Services for Older People.

These include:

**PARAPHRENIA** (or LATE ONSET PSYCHOSIS) - an illness occurring in old age which is characterised by fixed paranoid delusions, anxiety as a result of these beliefs and irrational or disruptive behaviour arising from the individual's response to them. For example a person may believe that their neighbours are listening to them through the walls and plotting against them. They may try to prevent this by putting tape round doors and windows and be extremely suspicious of visitors. It affects approximately 1% of older people and is more likely to affect women and those who live alone. It can be difficult to convince the person that they have an illness but it is possible to successfully treat this condition with medication and support e.g. from a community psychiatric nurse.

## DEPRESSION

Undoubtedly the kinds of things which we might expect to make us feel depressed do become more common as we grow older - having to stop work, probably less income, perhaps the start of arthritis or other physical problems. There are also the emotional losses - the death of a partner, or friends, or even of a dearly loved pet. Feeling low or sad is not the only sign of depression other common symptoms include:

- a feeling of sadness, depression or being 'down' which is worse than normal sadness
- a loss of interest in life - not being able to enjoy the things that usually give pleasure
- a sense of fatigue or tiredness which is there even when the person is not doing much - making even the simplest task a major effort
- a loss of appetite and weight or weight gain
- an inner feeling of restlessness, making it hard to rest or relax

properly

- a feeling of wanting to avoid other people. If people are around they may become snappy or irritable
- poor sleep. This may include waking early in the morning (at least an hour or two earlier than usual) and then being unable to get back to sleep again.
- loss of self confidence - feeling useless or a burden to others
- feelings of being bad or guilty - dwelling on things from the past and possibly getting things out of proportion, perhaps even wondering whether God is punishing them
- thoughts of suicide - most people with severe depression feel at some point like ending it all. These feelings should be taken seriously. They mean that help is definitely needed. Sometimes they become so strong that a person will work out ways of harming themselves, and even make preparations. This is a sign that help is urgently required.

Depression can make a person feel terribly worried and anxious. Some people have always worried more than others but, if this is unusual in person you live with or support, then it may be a sign of depression. In fact, worry and agitation may be so great that a person can feel and appear quite confused because they don't seem to be able to remember things. This itself can cause further anxiety because many older people worry about becoming 'senile'. Just occasionally, severe depression can be mistaken for dementia. Very depressed people are only too aware of not being able to remember things, whereas people with dementia usually are not. Dementia and depression are completely separate conditions, so don't put off seeking help. Having said this, people who do have dementia are quite likely to get depressed and treating this can be very helpful.

## ACUTE CONFUSIONAL STATES

The reason that these conditions are included is that in their most severe forms the symptoms of memory loss and confusion may mimic dementia and it can be very difficult to identify which illness the person is actually suffering from. Acute confusional states are characterised by severe confusion, disorientation

and a fluctuating level of awareness. This is usually caused by a medical condition, such as a chest infection, which has a sudden onset and an acute clinical presentation.

A significant number, perhaps one third of those admitted to hospital wards, suffer from an Acute Confusional State to some degree. This stresses the need for a comprehensive assessment of the individual's medical, psychological, emotional and social problems, which needs to take place in order to arrive at an accurate diagnosis.

People suffering from these conditions can be restored to independent functioning with an improved quality of life, and their confusion and memory loss can be reversed. If a person with dementia suddenly becomes much more confused it should not be assumed that this is merely a worsening of the dementia. It may be that they are suffering from an underlying condition such as a urine or chest infection. Once this is discovered and treated appropriately they can become much better.

## Notes

# Caring for a Person with Dementia

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Caring for someone with dementia can also be a very rewarding experience. For most carers the wish to care grows out of close ties of marriage and blood, as well as out of long established patterns of life reinforced by bonds of love and affection, or alternatively, out of a sense of duty or obligation. As the illness of the cared for person has persisted for many years rather than months, so the carer's skills in care-giving gradually develop and they make considerable changes in their lives. Despite the tremendous emotional, psychological, physical and social weight of caring, most carers derive a great deal of satisfaction from their role and express a wish to continue caring for their relative at home for as long as possible and up to their death. However, they cannot be expected to do so without appropriate forms of practical, social, emotional and psychological support. Indeed, without it the care-giving situation can break down and a crisis admission to permanent care result, with negative consequences for both the person with dementia and their carer.

Some carers do not recognise themselves as being a 'carer'; their caring role and their relative's illness having developed so gradually and insidiously. Many have not been identified by services that could provide them with practical help and support and some have received no specialist diagnosis for the illness from which their relative is suffering or a formal assessment of their needs. For these reasons dementia has been referred to as an 'iceberg condition', that is to say only the most severely affected families are known to services.

Caring relatives provide an extremely valuable service and as the responsibility of care giving usually falls upon one person's shoulders, most carers experience some form of personal, emotional and financial hardship. Yet the strain that carers are under and their invaluable contribution to care may not be fully acknowledged. Most carers cope with little or no support from statutory services and the burden of care-giving gradually builds up as their relative's condition progressively worsens over time. Carers realise that no matter how competent or committed they are, caring is likely to become increasingly more difficult. They worry for the future and how they will cope.

A great deal of support is needed to keep a person with dementia at home in the community. Many carers suffer from severe stress and strain as a result of caring 24 hours a day, 7 days a week over many months or even years. This endless caring has been referred to by carers themselves as 'The 36 Hour Day'; there never being enough hours in the day to do all the work that needs to be done and a feeling that one day melts into another. Many carers have to cope with problems which arise during the night, such as wandering, incontinence or severe insomnia, as well as having to provide constant care and supervision throughout the day. The physical and psychological health of carers may be adversely affected by such endurance, for example, a back injury may be sustained by lifting a heavy dependant into the bath, severe insomnia or gastric complaints may develop and depressive symptoms may result.

Carers have to make many psychological adjustments throughout their years of care giving, such as initially having to come to terms with the diagnosis and prognosis of the person's illness and what the future holds for them as individuals. They also have to come to terms with the constant adaptations which they have to make as new problems and situations arise, as well as the losses which are incurred as the condition gradually worsens, for example, when a husband or wife fails to recognise them for the first time or develops a continence problem.

Some carers continue to receive the support of family and friends, but for others caring can be an extremely socially isolating experience. Friends and relatives may stop calling due to embarrassment at the behaviour of the person with dementia, or carers might ask friends not to call or socially isolate themselves because they feel their situation too distressing to share with others. Some carers might simply become so restricted in their own home that it becomes impossible for them to continue with outside interests or social contacts. For others leaving their relative safely alone in the home is no longer an option, as they would be at risk of falling, wandering outside or even leaving gas cookers on unlit.

# Practical Guidelines For Caring For The Person With Dementia

A key to caring for someone with dementia is understanding that many or all of their problems arise from the illness from which they are suffering. Their loss of memory and skills and the behavioural problems they may experience are as a direct result of damage to their brain caused by the dementia. There is no control over the illness and therefore carers should be advised not to take difficult behaviour personally or apportion blame on the person with dementia because they feel they are 'not trying hard enough'.

The following practical guidelines may be of some value in helping carers better understand and cope with day-to-day problems in care-giving and in regaining some control over their situation.

## 1. Keep Things Normal

A diagnosis of dementia does not mean that you must suddenly start treating your relative like an invalid. In fact, you should try and make a point of keeping things as normal as possible for as long as possible. Carry on any pursuits which you have both found enjoyable, such as going to the pub, theatre or cinema, listening to music and singing or dancing, unless or until it stops being a pleasure. Introduce new activities if they seem appropriate - people with dementia often enjoy simple arts and crafts activities and derive great pleasure from the company of small children or animals.

## 2. Retain The Person's Independence

There are two major reasons for doing all you can to maintain your relative's independence and self-care skills for as long as possible. Firstly, it helps them to retain some sense of dignity and self-respect, and may avoid frustration being brought on by feeling helpless. Secondly, it makes less work for you - the more they can do for themselves, the less you have to do for them.

Encourage the person to carry on with things they can manage. When something becomes too difficult, don't give up on it completely - perhaps it could be achieved if it were broken down into smaller steps. But be sure to recognise when something is really beyond the capability of the person you care for. Try not to highlight their loss of competence and independence and avoid placing them in a situation where they will fail. Instead give them simpler tasks which you know they can complete successfully. Praise them (but not in a way that could be perceived as being patronising) when they complete a task successfully or for any help they can give you. In this way they will have a sense of achievement and their self-esteem will be maintained.

Cut down on what the person does independently slowly and reluctantly, because once self-care skills are not practised they are quickly lost. Brace yourself and start to gently take over when you see that their ability to achieve tasks has been lost and the loss of competence is distressing them.

### 3. Avoid Confrontation

There will be many occasions when you and the person you care for will have disagreements. You might think it's time he/ she changed his/her dirty clothes, and he/ she doesn't. He/she believes someone's stolen their money from their wallet/purse, you know they haven't. He/she insists it's perfectly all right to go out shopping dressed in their pyjamas, you'd rather not be with them when they did!

In fact, arguments won't usually get you very far. They generally lead only to frustration and upset for both of you. It's better to avoid confrontation whenever you can. Try not to contradict the person with dementia if they say strange or silly things. Instead, try to divert them from their confused behaviour onto something more interesting or constructive, like a favourite song or photograph. Talking about the past at times of upset can be reassuring when the present makes little sense to you. If this fails, go along with the person's behaviour until diversion is possible. For example, go out for a walk with them when they insist on wandering outside and while walking with them talk



about happier times or how nice a cup of tea would be after such a long walk! If all else fails and the person's behaviour is upsetting both of you then walk out of the room, having first ensured the person's safety, and have a break, a cup of tea, or even count to ten. This could help diffuse the situation and after a short time the person may well have forgotten what all the fuss was about.

#### 4. Avoid Crises

There will be occasions when the person you care for seems suddenly to get more confused, to behave particularly badly or to cry for no reason and they may be unable to explain why. This may be caused by what they perceive as a crisis in their life - an event or sudden change that seems normal enough to those unaffected by their illness, but alarming to someone who is confused.

A crisis for the person with dementia might be having to hurry to get somewhere on time; meeting too many people at once, even if they are people familiar to them; or going into new and unfamiliar surroundings.

Some of these crises may be avoidable. Try always to leave plenty of time to prepare for an outing, or to get a task done. Make sure that only one or two friends or relatives visit at once. Accompany the person to new places. If you take them away on holiday, try to go somewhere where both your problems and those of the person you care for will be understood. Above all else, try to stay calm yourself.

There will be times, though, when crises cannot be avoided, for example, when you are to have a break for the first time and an unknown sitter comes into the house, or when the person is to go to a new day-centre. On these occasions simply try to reduce the disorientation the person is likely to feel by introducing a new person in slow stages and with you present, or by using a family friend or neighbour as a sitter. The introduction to a day-centre or hospital should also be made gradually.

Don't avoid making any changes at all or stop your social life just

to avoid crises for the person you care for. Sometimes they are inevitable and may have a positive outcome for him/her - or you - in the long run.

## 5. Establish Routines

Routines are vital in caring for someone with dementia. Doing the same thing at the same time every day helps the person to remember and to feel safe and secure. If life is predictable and familiar, there is less chance of increasing their confusion. Maintaining a routine therefore helps you in the task of care-giving.

## 6. Make Things Simpler

A person who is already confused will find taking straightforward decisions, or carrying out relatively simple tasks, over-complicated and difficult. Taking a bath, for example, involves many separate actions, from putting in the plug to turning on the taps and obtaining the right temperature, getting undressed, and so on.

Try to simplify things: don't offer too many choices (two is probably enough); break tasks down into short, simple sections; if a task becomes too difficult ask them to do only part of it, doing the more difficult bits yourself; and try to consult the person and offer them choices, even if they don't fully understand. All these techniques can help preserve the person's self-esteem and feelings of self-worth which may be adversely affected if they feel they are losing control over their life.

Make things simple for yourself too. Don't fight lots of battles at once, but try and solve problems one at a time. That way you stand a better chance of success.

## 7. Maintain a Sense of Humour

Dementia is a tragic illness. There may nevertheless be times when you can see the lighter side of things, and it is important for your own mental health that you maintain the ability to laugh. The person you care for may still be able to enjoy a good joke or a funny situation and it will do you both good to laugh together.

Of course, laughing with someone is quite different from laughing at them, which should be avoided at all costs.

## 8. Make Things Safer

The risk of an accident increases in the home of a person with dementia and you should take great care to make the home as safe as possible.

Loss of physical co-ordination increases the likelihood of falls, so you should check the home for danger zones like a loose banister rail, slippery floor mats, awkwardly placed furniture, or carpets which have not been securely nailed down. You may need to have an extra stair rail fitted, along with hand rails near the bath and toilet.

Loss of memory and thinking ability can give rise to risks from a number of everyday activities. The person may turn on the gas fire but forget to light it; they may drop lighted matches into a wastepaper basket; they may scald themselves on a boiling kettle. Some of the solutions are obvious - switch off the gas at the mains when you go out, don't leave matches around, hide kettle flexes. The list is a long one, and largely a matter of common sense. You should review your home for all potential accidents and take action to avoid them.

## 9. Maintain General Fitness and Health

The general state of the person's health will affect their overall condition. If good general health is maintained it will help to preserve existing physical and mental abilities for as long as possible as well as encouraging independence and sustaining morale. The person needs someone, like their GP, to regularly check on their condition, that they are enjoying a balanced diet and taking appropriate physical exercise.

### Keeping a check on the condition

As the main carer you are the best person to monitor any changes in the cared for persons condition. A person with dementia will still suffer from the common colds, coughs and minor complaints that make everyone uncomfortable. They are

also more prone to certain ailments, such as chest infections, and more likely to suffer falls. A person who is unable to move easily and spends much time in one position may develop pressure sores or hypothermia in cold weather (especially if they live alone and are not closely supervised). All these things need to be carefully watched for as the person may not be able to explain to you what is wrong and may suffer pain or discomfort needlessly. Sometimes you may be able to give a remedy yourself, but do remember that even everyday medication such as aspirin may worsen their symptoms unless given in small doses. A check with your doctor is advisable if the symptoms are persistent, unusual, worsen suddenly, or if you are unsure what to do.

A district nurse, social worker, or community psychiatric nurse who makes regular home visits can also look out for any changes and reassess the person's needs. They can refer them to specialists or services for particular problems, such as falls. A doctor can prescribe medicines which may give relief from problems such as sleeplessness and wandering at night, or the sudden onset of incontinence which may result from a bladder infection.

## Diet

As the illness progresses there may be problems with the practical side of eating and tastes for food may alter. But it is important to try and include all the ingredients of a balanced diet especially as the symptoms of dementia can be worsened by an inadequate diet. Try to provide something the person with dementia likes eating from each of these food groups every day:

- meat, fish, eggs, pulses (lentils, beans, etc.);
- fruit and vegetables;
- cereals and bread;
- dairy produce, milk, cheese, etc.

Make sure the person drinks enough liquid to prevent them becoming dehydrated or constipated. If constipation becomes a problem an increase in high fibre foods, such as wholemeal

bread, cereals, fruit and vegetables, may help.

## Exercise

Physical activity can be pleasurable as well as helping to preserve existing abilities. The kind of exercise depends on the person's condition and what they like doing, such as walking, dancing, gardening, swimming or playing bowls - at least until these things become impractical. As the illness progresses a gentle stroll in a familiar street or the park may be more suitable and just as enjoyable.

### 10. Keep Channels of Communication Open

As the person's dementia progresses there will be increasing problems of communication between them and others. There will be difficulties for the person in expressing themselves and for carers explaining things and making themselves understood. This will affect daily activities and the expression of thoughts and feelings. Talking often becomes difficult for a person with dementia. They may use the wrong words, forget words completely, endlessly repeat words or phrases and lose the thread of the conversation. This can be distressing for both the person and carer.

There are several things which can be done to help keep channels of communication open. At a practical level it is extremely important to check that the person's senses are not additionally impaired by, for example, a hearing aid that does not work properly, dentures that are too loose, or glasses that are no longer of the correct prescription.

In conversation you should remember to speak clearly, simply and slowly, and to talk about only one topic at a time. Allow extra time for the person to reply. You may need to repeat things several times, find a simpler way of saying something, or guess the sense of what they are saying. If the person is confused, remind them of basic information gently, perhaps by using a picture or object. Try not to contradict or embarrass the person by correcting them bluntly.

And of course speech is not the only way of communicating

Body language - the way we look at a person, how close we move towards them, how we touch them - can be more important than words alone. In the later stages of dementia looking and touching may be the main way of expressing affection and care for the person, and the body language of the person with dementia gives you clues as to what they mean and how they are feeling as well.

## 11. Use of Memory Aids

In the early stages of dementia the person may be helped by using memory aids. These are things which may help to jog the memory, avoid confusion and disorientation, and keep things as normal as possible. Here are some things that carers have found useful:

- Regularly remind the person of the time, day and where they are
- Keep a clock with a large clear dial on view
- Keep a calendar that can be changed by the day, month and year
- Label the doors of rooms, such as the bedroom and toilet, with words, pictures and colours
- Keep photos of familiar people and the family on view
- Leave their personal possessions where they can easily find them
- Keep furniture in the same place
- Keep checklists of things to do that day, or lists of expected visitors etc., which can be ticked off
- Set things out in the order in which they have to be done
- Leave out things required, for example, one day's medication supply
- Leave a simple clear note with an address if you are going out

- Make a life story book together with details and pictures of the person's life to date, family etc. to use to help reminisce
- Don't forget textures, tastes and smells can also evoke memories

## Notes

# Dealing With Common Problems

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## 1. Dressing

People with dementia may not remember which clothes should be put on, in which order they should be put on, or how to actually put them on. They may end up wearing several skirts, and no underwear, or with things on back-to-front or done up incorrectly. They may also have difficulty doing up buckles, laces, bras and so on.

An additional problem is that the person you care for may not recognise the need to change their clothes, for example, when they are dirty or if they are going to bed. They may also choose to wear inappropriate clothing - going out in the daytime in their night-wear, for example.

### Possible solutions:

Try laying out clothes in the order they have to be put on. Avoid clothes with complicated openings and fastenings. Replace buttons with zips and Velcro, buckles and belts with elastic, lace-up shoes with slip-ons and men's 'Y' front pants with boxer shorts. Choose women's bras with a front opening.

You may need more persuasive tactics to overcome the last two problems. The person you care for may resent interference. Don't argue, try to encourage instead. Set out the clean clothes saying "These are the clothes you chose to put on", or "That dress really suits you". You may have to become tolerant of their preferences. One carer's father frequently wore four pairs of trousers at one time, another's mother liked to go to the day centre in her dressing gown. There was no harm done by either!

## 2. Washing and Bathing

People with dementia may forget to wash and no longer recognise the need. They may have forgotten what to do, or be unable to wash certain parts of their body because of physical impairment. Some will be unable to climb in or out of the bath safely or manipulate taps. They may be embarrassed by helpers seeing parts of their body usually kept private, and may refuse to wash at all. These problems are increased if they have continence problems and need to wash more frequently.

### Possible solutions:

Try to establish and maintain a routine for washing. You will need a good deal of tact. If the person is reluctant to wash you can emphasise the more pleasant aspects, the comfort of warm water, perfumed soaps and so on. You may have to tell them step-by-step what to do, wash with them, or clean your own teeth to demonstrate. You may have to help or supervise them because of physical difficulty and risk of accident or injury. There will be difficulties for the carer too if the person is large or heavy and you need to lift them. You may be able to get practical help from a Home Care Worker and aids such as rails and a bath seat or hoist which may alleviate some of these problems. Incontinence can be very difficult to manage, especially if embarrassment leads to concealment. And of course it's a problem for the carer who may be just as uncomfortable. A matter-of-fact approach might alleviate distress or embarrassment: "Your trousers are wet, and you'll get sore if you don't wash, please let me help you". However, telling them off or showing that you are upset won't help.

### 3. Going to the Toilet

People with dementia may forget to go to the toilet leading to inappropriate voiding and constipation. They may forget where the toilet is, even in their own home. There may be problems undoing their clothing in time. At night they may lose their way in the dark or mistake some other object, such as a waste-bin, for the toilet.

### Possible solutions:

At regular intervals, either remind the person you care for to go to the toilet or take them to it. Label the door, or paint it brightly. Make sure clothing can be easily removed. Take them before they go to bed. Leave on a lamp with a low wattage bulb or night light, or stick luminous tape on the wall as a guide.

A pot by the side of the bed may help.

## 4. Cooking

The problems are most severe if the person with dementia lives alone. The ability to cook even simple meals may be lost. Just buying food and keeping it fresh may be beyond their capacity. They may eat food that has gone off and not recognise it tastes bad. The gas cooker may be switched on and left unlit, pots may be left to burn. Poor physical co-ordination can lead to burns and scalds or cuts from utensils. The combination of these problems may lead to malnourishment in many people with dementia who live alone.

For the person with dementia living with others, the problems are diminished if the carer cooks for them - the problem in this situation may be for the carer who is unused to buying or cooking food, for example a husband carer who has to learn how to take over these responsibilities from his increasingly confused wife.

### Possible solutions:

There are safety devices which can be fitted to cookers to prevent some of these problems. Invest in an electric kettle. Remove sharp knives and other potentially dangerous utensils. Try to arrange for the meals-on-wheels service to call, but check to see that the person knows how to open the container. You may need to put the food out on a plate for them if they don't understand what the carton is for. Leave food that doesn't need to be cooked e.g. sandwiches, cold meat, biscuits in a place that the person will easily see. You may need to visit daily to help or supervise.

## 5. Eating

People with dementia may forget whether or not they have eaten. Some don't want to eat and claim they have just done so, others want to start on the next meal as soon as they have finished the previous one. They may develop strong dislikes of certain foods and cravings for others. Some don't know how to eat. They may forget how to use cutlery and be generally very messy. They may play with their food, not realising it is to go in

their mouth. They may be confused by different foods on one plate. Others have physical problems, they can't chew properly and have difficulty swallowing, which could lead to choking. Some forget to drink and may become dehydrated.

#### Possible solutions:

Have regular times for eating, and eat with the person you care for. If the person often wants to start another meal soon after the last one, keep some washing up in the sink to show the remains of the last meal. If they will eat only certain foods, you may have to ask your doctor about diet and vitamin supplements.

Don't worry about table manners - spoons are easier than knives and forks, and fingers came first of all! Use plastic table cloths and place mats so any mess can be easily cleaned up.

You may have to remind them how to eat by talking them through each stage, or show them by eating something yourself. Sometimes spoon-feeding may be necessary. Try to keep food simple. Cut it up small or keep it to one texture - soft, thick foods are easier to swallow. A mixture of liquid and solid at the same time may lead them to swallow instead of chewing and could result in choking. If choking occurs fluid thickeners may be required; your GP should refer the person with dementia to a speech and language therapist for assessment. Check that dentures fit properly and are kept clean.

Make sure that the person has several drinks a day (about a litre and a half a day is about right) and that the drinks are not too hot - he/she may have lost his/her judgement and could scald him/herself. If the person forgets to drink they could easily become dehydrated, which could lead to constipation, a bladder infection or a sudden worsening of their confusion.

## 6. Going Out Alone and Shopping

The most worrying problem for many carers is the safety of the person they care for. Traffic presents a threat on even the quietest roads and crowded, busy streets or shopping centres can confuse and alarm. The person with dementia may not

recognise even familiar places and become lost and frightened. Other people are not always helpful and may interpret confused behaviour as drunkenness. If they are shopping there are the additional problems of remembering what they went out to buy and handling money.

### Possible solutions:

Many carers are rightly reluctant to discourage the person with dementia from going out alone as it is often the last thing that they can do on their own. Encourage the person to walk in a park or other safe area away from traffic and crowds. If this is not possible you may have to accompany them - perhaps take them part of the way to a point where they cannot go wrong, or meet them on the return journey. One carer relied on a well-trained and trusted dog to help her husband cross the road and bring him home safely.

Persuade them to carry some form of identification - an identity bracelet or card explaining that they might become confused can be useful. Don't forget to put their name and a contact telephone number on it for additional reassurance. A more simple option might be to sew a name tape with this information on it into the pocket of their favourite coat.

If the person is shopping, give them a clear note and only the amount of money they will need. They will be able to buy only one or two straightforward items. If they need clothes you will have to go with them. Don't be embarrassed to explain the problem to shop assistants who are usually most helpful once they understand.

## 7. Driving

It can be dangerous for people with dementia to drive, even in the early stages of the illness. They become a hazard on the roads because their judgement is impaired and their reactions are slowed. Many road traffic accidents are caused by drivers who have dementia and many members of the public as well as the actual drivers and passengers are seriously hurt each year as a result.

## Possible solutions:

Once you feel that the person with dementia should stop driving, broach the subject with them gently. Some may be pleased to be rid of the responsibility driving brings. Others, who resent their loss of independence, may find giving up particularly hard. If gentle persuasion doesn't dissuade them from driving, you will have to take firmer action. In the first instance, offer to drive yourself (if you can), or suggest using a taxi or public transport. If needs be, hide the car keys or immobilise the car (go to a garage to discuss the easiest way to do this). In the longer term, it may be best to use an authority, such as your doctor, a solicitor, or police officer, to persuade the person you care for of the danger they put themselves and others in if they continue driving. Remember; many insurance companies require a medical certificate of fitness before insuring older drivers and a driver who has an accident who has not declared his/her illness will not be covered. Sometimes having their licence revoked by the DVLA is the only way that a person with dementia will be stopped from driving. Having a third party i.e. a professional make the decision to inform the DVLA takes the pressure off the carer and gives the dependant someone outside the care-giving situation to blame. An assessment of factors that affect a person's driving ability can be undertaken by the clinical psychologist based with the Community Mental Health Team for Older People or by the Driving Assessment Centre based at Rookwood Hospital, telephone 029 2055 5130. It can be difficult for the carer to accept that the person can no longer drive and to have to give up the convenience of having a car. However, this needs to be balanced against the terrible consequences that an accident could bring.

## 8. Alcohol and Cigarettes

If the person with dementia is in the habit of drinking alcohol in moderation, there is no reason why this should be stopped. Having a drink may be one of their remaining pleasures, and something you can enjoy together. You should take care, however, that alcohol is not left out where the person can help themselves. One carer admitted to having to replace the sherry with ginger ale to limit her husband's alcohol intake. If

they are on medication, remember to check with the doctor or pharmacist that the drugs mix safely with alcohol.

The use of cigarettes represents a greater danger. People with dementia are not safe with matches, and they may smoke in bed, leave lighted cigarettes on the edge of armchairs, or throw them away in wastepaper baskets.

#### Possible solutions:

If the person you care for really needs to smoke, it should only be under strict supervision. Far better is to dissuade them from smoking. If persuasion fails, choose a moment when they are otherwise occupied to remove their cigarettes. It may be reassuring to know that many people with dementia forget to smoke and so don't miss the habit once it is broken. Others do well with nicotine replacement therapy, which can be gradually reduced - talk to your GP if this seems like a good idea.

## 9. Wandering

Wandering is a common and difficult problem to deal with. People with dementia may wander aimlessly or anxiously around the home, or wander around the neighbourhood having slipped secretly out of the house. They may wander long distances to old haunts and get lost. You will be worried about their safety and their own bewilderment or fear, especially if they cannot find their way home or cross the road safely.

#### Possible solutions:

If you can work out a reason for the wandering you may find a solution. Sometimes wandering results from general restlessness and boredom and is a sign that the person needs more stimulation or physical activity. They may be searching for someone or things they think they have lost. Keeping photographs or personal possessions on view may help. Often the person feels insecure and may need both the emotional reassurance that you care and the concrete reassurance of things being kept in the same places and routines maintained. Wandering frequently starts after a visit to a strange place - after a holiday, for example - or after a change of habit, such

as starting at a day centre. In which case it may help if you go with them a few times until the change becomes more familiar. Moving home can be very distressing for a person with dementia and should be avoided if at all possible.

If you can find no apparent reason for the person's wandering behaviour, then you may have to prevent them wandering if you feel they will be at risk. You may be able to fix up an alarm that will alert you if the person goes beyond a certain point e.g. opens the back door or you may need to install a 'dead lock' on a street door which needs a key to open it from the inside.

An identity bracelet worn by the person giving details of how you can be contacted is an additional safety measure. If they do still manage to wander off, contact the police who will then keep a look out for him/her. Keep some recently taken photographs that can be used in case they do go missing.

## 10. Night Disturbance

Many people with dementia are restless at night and disturb the whole household by wandering and making a noise. This can be one of the most wearing problems for carers. Sometimes the person's sleep pattern is reversed and they are awake at night - thinking it is day - and asleep for long periods during the day.

### Possible solutions:

Again, if you can find a reason for this problem you might be able to alleviate it. Some of the more obvious reasons may be that the person:

- •Is looking for the toilet
- •Sleeps too much in the daytime
- •Goes to bed too early
- •Needs less sleep
- •Wakes up and is confused or frightened
- •Thinks it is daytime

Make sure that they have been to the toilet before going to bed. Try to discourage long sleeps during the day, perhaps by



increasing physical activity. Try to make them as comfortable as possible. A bedside lamp with a low-wattage bulb left on may help if the person wakes up frightened. Sometimes talking gently to the person will reassure them and send them back to sleep. If they think it's daytime or they think they need to get up for some reason you might have to go along with them as arguing could lead to upset. One carer spoke of her husband who regularly woke at night wanting to go to the shops. She always said, "All right then, let's go", walked him round the room and back to bed by which time he'd forgotten where he was going.

If nothing seems to work and the disruption to your own sleep makes you feel unable to cope, you will have to ask your doctor about night medication for a short time until a normal sleep pattern is re-established.

## 11. Repetitive Questioning and Actions

This problem can be extremely irritating for carers! Usually the person is unaware of what they are doing, although their behaviour may reflect underlying anxiety or insecurity. Repetition may also arise from frustration or boredom and can be a hard-to-break habit.

### Possible solutions:

Try to remember that this problem usually stems from the person's memory impairment - they are forgetting what was said or done a few minutes earlier - and is not usually a deliberate act. It could be that the person's needs have remained unmet in some way, for example they may still be hungry or need to go to the toilet. There's no point in getting angry or saying, "I've just told you ten times". If possible try to identify the person's underlying needs and meet them. If the trigger was removed, like giving them some money when they ask for it (their need being financial security), then the repetitive behaviour might stop. Alternatively, try to distract them by talking about something else or giving them a different activity, like listening to music or washing the dishes. Sometimes writing down the answer helps. Reassuring them of your concern may reduce

insecurity. If you find yourself getting very stressed take a short break from the situation in another room or the garden.

## 12. Clinging Behaviour:

Some people with dementia become reluctant to let their carer out of their sight and follow them from room to room. This can be very distressing for you, as it means you're allowed no privacy, sometimes even to go to the toilet.

The person probably behaves like this because they're feeling insecure in some way, and the care-giver represents security. Perhaps when they see you leave the room, they forget that you will come back and get frightened.

### Possible solutions:

While you're gone, give them some simple task to do or use the clock to point out when you'll return. Reassure them that you'll be back when the task is finished or when the clock reaches a certain time.

If this is a regular problem for you, it is important that you use sitters or find some other way of getting a break.

## 13. Losing Things and Accusation of Theft

Many people with dementia really do forget where they have put things, others deliberately hide things and then forget. In either case they may accuse you or someone else of stealing the missing items. The items lost may seem unimportant or trivial to you, but to the person with dementia they may hold some special value or meaning.

### Possible solutions:

Try not to take the accusations too seriously. Don't deny the charge and get into an argument - it won't be possible to reason with him/her and he/she will become more upset. Try to find out if they have a regular hiding place, such as under the mattress or in an old shoe. Keep replacements of essential items, such as keys or glasses. Put away or lock up valuables, money or dangerous things. Get into the habit of checking rubbish bins

before emptying them. Make sure that other people who help to care for the person are aware of the problem.

#### 14. Incontinence

Many people with dementia may be occasionally incontinent and wet the bed. Regular bladder incontinence and bowel incontinence is less usual. But even the occasional accident can be difficult to deal with. It is embarrassing and degrading for the person and distasteful for the carer who has to clean up after them.

If incontinence becomes frequent or develops suddenly, always check with your doctor as there could be an underlying medical reason.

There could be several reasons for incontinence:

- The person forgets to go
- They can't get to the toilet in time
- They can't undo their clothing easily
- They can't find their way at night
- They have an attack of diarrhoea
- They may be suffering from a bladder infection

#### Possible Solutions:

Take the person to the toilet regularly. If the toilet is upstairs or some distance from where they spend most of their time try to get a commode.

Clothing can be adapted by using Velcro instead of zips. Men's 'Y' front pants can be replaced by boxer shorts. Your district nurse can tell you about the special clothing that is available. If you're not already in touch with your district nurse ask your doctor to put you in touch with her.

Provide a bottle or pot for night-time use.

Use luminous tapes and plug in lights to mark the route to the

toilet.

Always take them to the toilet before they go to bed and if it prevents a wet bed take them during the night too.

Keep a check on their diet. If they are not eating enough roughage they may develop constipation which can lead to a blocked bowel and leaking diarrhoea. Increase vegetables, fruits and whole-grain cereals.

Try to reduce embarrassment by adopting a matter-of-fact approach, directing their attention to the task of cleaning and washing and avoiding any recriminations. To protect your furniture use washable covers or dustbin liners. Beds can be protected by using a plastic sheet between a draw sheet (a sheet folded in half and tucked in across the bed) or a plastic mattress cover (available from your district nurse/chemist)

Special pads and pants are available from chemist shops or through Health Trusts (ask your district nurse).

If the person experiences pain on passing water, or if their urine is foul smelling or cloudy take a sample to the doctor for testing to rule out a bladder infection. If treated with antibiotics it might reduce the frequency that the person needs to urinate and stop their incontinence.

If diarrhoea is present, ask your doctor to check for constipation as it might be overflow from an impacted bowel. Once this is cleared with an enema then the diarrhoea may stop and the urinary incontinence might also improve.

## 15. Delusions and Hallucinations

Delusions (fixed false beliefs not open to reason) are ideas that are imaginary, but that seem very real to the person experiencing them. Someone suffering from delusions may believe that there are some people who want to harm them, or that objects which are simply mislaid or hidden may have been stolen, even by members of the family.

Someone suffering hallucinations (abnormal senses with no

external stimulus) sees or hears things that aren't actually there. They may see strange people sitting in the room with them, or hear dead relatives talking to them.

#### Possible solutions:

Both delusions and hallucinations are imaginary and not real, but they are very real to the person experiencing them and can give rise to genuine feelings of anxiety or panic. They should therefore be taken seriously.

When the person is experiencing a delusion or hallucination don't argue with them or tell them they are mistaken. Remember they are outside the person's control so becoming angry or impatient with them will not help. If the delusion concerns a missing object, for example, try to find it, rather than deny it has been stolen. If the person is distressed by a hallucination, explain that you understand that they are seeing or hearing things and the feelings these cause, but also that other people cannot see or hear what frightens them. Try to comfort them, perhaps by putting an arm round them or holding their hand, and try to distract their attention onto something real nearby.

If the person you are caring for begins to suffer from delusions or hallucinations you should see your doctor. It could be that the side effects of medication are causing the problem, or the problem itself might respond to medication.

## 16. Sexual Relationships

The sexual relationship is very private and personal and not something that many carers can talk about easily. While dementia does not necessarily affect sexual relationships, the person's attitude to lovemaking may alter. They may not respond to affectionate gestures that you make or they may lose interest altogether. They may simply forget about it.

You might find that you lose interest yourself because of the stresses and tiredness brought on by caring for the person with dementia. You may also find it difficult to make love with a person whose personality has changed so much.

Occasionally, a person with dementia may become more sexually demanding. As the illness progresses, the person with dementia may no longer be able to consent to a sexual relationship.

#### Possible solutions:

There is no simple solution to such a complex and sensitive issue as this. If you find that your sexual relationship is becoming a problem, you should try and talk to an understanding person about it. There are counsellors trained to talk to people about such problems. Your doctor should be able to put you in touch with someone, or you could call the Solace service (see Nexus Carers Directory).

### 17. Inappropriate Sexual Behaviour.

In some cases a person suffering from dementia may exhibit inappropriate sexual behaviour, such as undressing in public, exposing themselves, or aimlessly fondling their genitals. In fact, such behaviour is unlikely to be sexual at all. Appearing naked in the sitting room may simply be the result of forgetting that they should get dressed, or of losing their way to the bathroom. A man found 'exposing' himself may only be trying to urinate in an unsuitable place. One carer's mother seen 'exposing' herself in the street had wandered out in the cold in her night-dress and pulled it up around her shoulders to try and keep warm.

#### Possible solutions:

Behaviours such as these can cause severe embarrassment to carers, but understanding the problem - and explaining it to others - should lessen your embarrassment. If the person touches their genitals in public, don't make a scene, but try to discourage them gently. If they appear naked, or start undressing themselves, remove them calmly to another room. It may be worth checking that clothing is not uncomfortably tight, or fastenings broken. In those rare cases where people complain and police become involved a truthful explanation usually receives a sympathetic response.

### 18. Verbal and Physical Aggression

Usually aggression in dementia is not planned or premeditated, it is the result of confusion and frustration, the response to which is poorly controlled because of the disinhibition that dementia brings.

A person who has never used bad language in his/her life before may start to swear, or a previously calm and gentle person might become short-tempered and hit out in anger. When it is directed at the carer it is especially distressing.

#### Possible solutions:

Say you are sorry for the person's upset and ask them to tell you what is troubling them. Gently encourage them to talk and if they are not too angry, hold their hand to comfort them. Do not raise your voice as this will heighten their aggressive feelings.

Whatever you do, do not respond to aggression with aggression. It will only make matters worse. Instead, stay calm yourself - count to 10 if need be - and try to distract their attention. Find out what brings on the reaction - frustration at a difficult task, a certain person's presence, rushing to be ready on time - and avoid it in the future. Don't forget that there may also be a simple explanation for such a change in behaviour, like discomfort from constipation or pain from arthritic joints.

If episodes of violence and aggression become frequent, you should talk to your doctor or case manager about medication which may help.

### 19. Failure to Recognise People

A person with dementia often fails to recognise familiar faces. They may recognise you as someone they know, but be unable to put a name to your face or remember your relationship to them. This is obviously distressing for a spouse carer who has been very close to his/her wife/husband. The problem here is that the person's long - term memory is being affected by the dementia and they are 'living in their past'. Perhaps if you asked them how old they were they would think of themselves as a young person - so it is not surprising they don't recognise you or mistake you for a dead relative (especially if you are a son or

daughter carer who resembles their parent!).

### Possible solutions:

Keeping out large photographs of family occasions through the years, so that the person with dementia sees that he/she has also grown older has helped some families. Understanding what is happening can relieve the distress carers feel in such a situation. If it is not possible to re-orientate the person to the present - who you are and how old they are, etc., then talk about important people from the past (their present and about the special endearing relationships which they have had. They may talk about you as if you were a much younger person and by sharing photographs or mementoes you can be brought closer together.

### LOOK AFTER YOURSELF!

Finally, it is important that you have support with your care-giving, both from formal services and from relatives and friends. Even if you think you don't need help now, find out what is available and how long it takes to arrange, as in some cases it may be weeks or even months. Find out about having a Carer's Assessment (see section). Then, when the time comes when you do require help, you can start the process in good time. Don't be afraid to ask for help, as some people might think you want to cope single-handedly.

You need to take your own needs seriously. Over-doing things could result in physical illness or injury, for example high blood pressure as a result of stress or a hernia from helping the person you care for up from bed. Such physical problems could jeopardise your future caring role. If you feel you are beginning to have problems in coping ask for help from services in your area that are listed in this publication. Make sure you have regular breaks from caring - either from a home sitter or by way of day care or respite care for longer periods.

Consider your emotional needs too. Caring is a very stressful experience. Talk about your feelings with others who understand what you are going through and don't keep things bottled up



inside. Find out if there is a Carers' Support Group (see section) in your area and go along and meet others who have similar problems. A great deal of mutual support can come from these meetings and provide a tremendous release of tensions which have built up. Alternatively contact any of the support services listed in the Nexus Carers Directory or have a chat with volunteers and past carers who have a great understanding and empathy for your situation.

## Notes

# Caring for a Person with Late-Life Mental Illness

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This section gives some information on caring for an older person with a mental health need other than a dementia.

## Depression in Later Life

It's often a relative or a friend who notices depression coming on in an older person. Gently encourage them to accept help. Explain that depression is quite common and that, with help, it gets better in the great majority of people. Be clear yourself that it's not a form of 'madness', or that seeing a psychiatrist or a psychologist is a slur on the family.

## What to Do

Firstly, you should encourage the person to speak to their GP. They are quite used to helping people with depression and almost all of them have had training in how to deal with it.

The time to get help is when feelings of depression in the person you care for are worse than you would expect, when it has gone on for several weeks, when it is interfering with their and your life, when they can't face being with other people or when they get to the point when life hardly seems worth living. Mild to moderate depression is usually treated first with a 'talking therapy' with a counsellor. If problems persist or the depression is severe the GP may prescribe anti-depressant medication.

## Psychological treatments

These involve the person experiencing depression talking to someone about the way they feel, about problems in their life and about ways of helping them to feel better. They can help both in mild and moderate depression, but also in severe depressions when medication has started to work. It does not necessarily involve 'baring your soul', which many people find off-putting, but is usually very practical. It can involve looking at ways of thinking, about yourself and the world, and which thoughts tend to make you depressed - and changing them. It can help in getting out of the trap of negative thinking that is often part of a depressive illness.

Anxiety or worry is very common and there are very effective ways of helping a person to feel relaxed and worry less. These range from relaxing CDs to special techniques that can be taught. Sometimes, just talking over problems with a doctor, psychologist or nurse can make a person feel better. Sometimes depression may have been triggered by a bereavement or problems in a marriage. Bereavement counselling or marriage therapy can be very helpful.

### Treatment with Medication

If the person you care for is so depressed that they have physical symptoms (such as poor sleep, poor appetite and loss of weight), your doctor may think first of prescribing an anti-depressant drug. There are several different types now available, so there should be no difficulty in finding one to suit. But it is worth remembering that all tablets may cause side effects - your doctor will warn you of the common ones. Most side effects are merely a nuisance and tend to get weaker or disappear completely after a few days - so it's worth persevering with them. It's also worth knowing that these drugs will usually not start to lift a person's mood for a couple of weeks, although they may improve sleep quite quickly. You may find that it takes at least 4-6 weeks for the person to start to get back to normal.

### Social treatments

These involve help with practical aspects of daily living. Depression might develop because a person is living in poor housing or a dangerous neighbourhood. If so, a social worker may be able to help the person to move. But a word of warning - it is important not to make decisions about moving when a person is still depressed because they may regret it when they are feeling better. Social workers and mental health workers can also help with finding ways to occupy people with depression and help them spend time with other people. This can be very important because many people become quite isolated when they are depressed and find it quite hard to get back into the swing of things. There may be lunch clubs, day centres and support groups where the person may go.

## Not getting better

Although most people get better at home with these treatments, some people do not. If this happens, the GP may ask a psychiatrist to see them for some expert advice or refer them to the Community Mental Health Team for Older People. The GP may need a second opinion or advice about the best treatment in a particular case.

The person may be seen in an out-patient clinic or may be visited at home either by a psychiatrist or a community team member.

The first interview with a specialist psychiatrist or community team member usually takes about an hour. The depressed person may find it difficult to remember some of the details of how it all began. So, the psychiatrist may ask if a friend, neighbour or close relative can attend with them. It will help the psychiatrist to get a complete picture of the situation. The outcome may be a change in medication and a community psychiatric nurse may visit to monitor this. A referral to a clinical psychologist may also be made and the person may be asked to attend day hospital.

## Coming into hospital

A small number of people need to have their depression treated in hospital. This may be because they cannot look after themselves properly at home, or occasionally because they want to harm themselves. Sometimes it may be because they need a specialist treatment that is usually only given in hospital.

## Staying well

Getting over a bout of depression is usually straightforward. But doctors are also interested in keeping people well and stopping it happening again. For this reason it is important not to stop any tablets for depression until the doctor advises. Even if the person is feeling back to normal, there's a chance of depression returning if they stop their tablets too quickly. Don't worry - unlike some tranquillisers, tablets for depression are not habit-forming or addictive.

If the person's general health is good and there has been an obvious upset leading to their depression, they will probably need to stay on the tablets for only 6 to 12 months. If they have already had a number of periods of depression, the GP or psychiatrist may recommend that they stay on an anti-depressant drug for much longer. Psychological treatment also helps the person recognise the warning signs that they are becoming depressed and teaches them strategies to help manage these in the future.

Remember that older people with depression get tired easily. It's often enough to show your concern by being there - or particularly by doing something practical to help, like the shopping or cleaning. It's important to make sure they eat properly and this may mean you preparing the food for them as they may 'not be bothered' to prepare food for themselves.

Don't force them to talk. Don't bully them into doing things. Although getting out and getting some gentle exercise helps, it may not help if you find yourself having to nag them to do it. In fact, people will often dig their heels in if they feel they are being put under too much pressure.

Be patient. Older depressed people may constantly ask for reassurance or become convinced that they've got something physically wrong with them. It's often because they are frightened or don't understand what is happening to them. Reassure as much as you can and be a good listener. Especially reassure them that they are not going to end up 'going mad'.

Don't be embarrassed to ask whether they have felt suicidal. It's a myth that talking about it makes it more likely that someone will attempt suicide. Suicidal thoughts are a sure sign that help is needed, and most people who feel like this are relieved when someone asks about it.

Finally, don't make decisions about housing or accommodation when someone you know is depressed. They may put pressure on you and say that it's all to do with where they live. But things are not usually that simple. Many older people who move when they are depressed wish, once they have got better, that they

had stayed put.

### Looking after yourself

Caring for someone with depression can be exhausting and you may find yourself also becoming depressed! If you are getting worn out by everything, do ask for help. Community Mental Health Team workers can help you by arranging for your relative to go to a day centre or day hospital to give you a break. They can also help by being there for you to talk to.

## Notes

# **Practical Guidelines For Caring For The Person With Paraphrenia (Late Onset Psychosis)**

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People with late onset psychosis often develop strange ideas and delusions. For example, the person may believe that their neighbours are persecuting them and that they can hear the neighbours talking about them through the walls. The ideas can be quite bizarre e.g. an elderly lady may believe that there are people living in her loft and that they are sending messages down her telephone line.

The symptoms of late onset psychosis can be particularly distressing for both the older person and the carer. It is important to first of all check out whether there is any truth in what the person is saying. Very often it will be very obvious that what they think is happening could not possibly be occurring. However, it may be that they are misinterpreting something or in fact the situation is true. It is not unknown for an older person to live in a flat with very thin walls where they can hear music being played by neighbours at all hours of the day and night! Reassure the person that they are not going mad and that you do believe them. However, try not to get caught up in their beliefs and do not collude with them.

Encourage them to visit their GP and if possible go along with them to explain the situation. If they have no insight into their illness and refuse to visit the GP it may be necessary to arrange a home visit. People with this condition are usually referred to the Community Mental Health Team for Older People. They will probably be prescribed medication and a Community Psychiatric Nurse will visit to monitor this and to support the person and yourself.

The person may not believe that they are ill and may refuse to take the medication. If possible try and persuade them to try the medication. However, if they adamantly refuse do not get into a battle with them.

They may be quite socially isolated. It can help to encourage them to go out with you e.g. for a cup of coffee in a local café and they may benefit from attending day hospital or day care.

People with this type of illness may believe that their problems will go away if they move, especially if their delusions relate to

their neighbours. This rarely works and very often the problems transfer with them.

If the person is very distressed by their delusions they may put themselves at risk at home by trying to do something to make the delusions go away e.g. refusing to have the heating on in the depth of winter. If this happens it may be necessary for the person to be admitted to hospital to receive treatment and careful monitoring. The person may be very relieved at the suggestion of a hospital admission. However, in some cases it is necessary for them to be admitted to hospital under a Section of the Mental Health Act for their own safety.

This condition can be successfully treated with medication. However, what sometimes happens is that the person begins to feel well and so stops taking their medication and then the symptoms reoccur. It is very helpful if carers can keep an eye on whether medication is being taken as prescribed and encourage the person to keep taking their medication.

## Keeping yourself well

Seeing the person so distressed by their delusions can be very stressful for the carer. It can also be very difficult for the carer when the person who is clearly very unwell refuses to accept that there is anything wrong with them and instead accuses the carer of turning against them. It is important to have a break from caring and you should talk with the community team member who visits to discuss what support there is available e.g. it may be possible for some care in the home or for the person to attend day-care. You may also find it helpful to attend a carers' group or have one to one support either face to face or over the phone.

# Notes



# **Carers Assessment & Carers Allowance**

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In order to obtain help from your local social services department, you and the person you care for may be offered an assessment of need. The person you care for may have an assessment called an Integrated Assessment. As a carer, you are entitled to have your needs considered and this is called a Carer's Assessment.

Social Services have a duty (now enshrined in law in the 'Social Services and Wellbeing (Wales) Act 2014'), to assess if carers need any support. An assessment gives you a chance to talk to someone about what support might make caring easier.

As a Carer you need to recognise your own needs for help and support, and you have a right to expect others, such as professionals in health and social care, to recognise those rights and direct you towards support which is appropriate for your individual situation.

You have a right to request a Carer's Assessment if you provide or intend to provide unpaid care for an adult or disabled child. The assessment looks at your support needs as a carer. When carrying out the assessment the local council must:

- seek to identify how caring affects your life and what outcomes you wish to achieve to look after your own well-being
- assess whether the provision of support, preventative services, information, advice or assistance could contribute to help you achieve those well-being outcomes.
- consider what well-being outcomes you wish to achieve and work with you to produce solutions

The carer's assessment will look at support, preventative services, whether a carer works or wishes to do so and if a carer wants to participate in education, training or any leisure activity.

It is the level of 'support', if identified, which determines what help can be provided by social services. A social worker or a carers support officer will visit you to talk about what help would be useful to you and the person you care for. Some of the things you will talk about are:

# Notes





*carers & service users involved in older people's mental health*



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**For more copies please contact:**

[nexus@cavamh.org.uk](mailto:nexus@cavamh.org.uk) | 029 2022 2000

84 Glebe St, Penarth CF64 1EF

[www.cavamh.org.uk](http://www.cavamh.org.uk)