



Parkinson's
Disease Society

Dementia and Parkinson's

What is dementia?

The term 'dementia' describes a group of symptoms caused by the impact of disease on the brain, resulting in a global impairment of intellectual function sufficient to interfere with normal social functioning. While each person is unique and will experience dementia in their own way, symptoms typically include problems with planning, memory, speech and perception.

Short-term memory is usually affected. This may mean, for example, that the person with dementia forgets the names of family or friends or how to perform simple everyday tasks. Usually, however, a person with dementia will retain their long-term memory and clearly remember events from the past.

A person with dementia might have problems finding the right words or may have difficulties understanding what is being said to them.

As verbal communication diminishes, someone with Parkinson's and dementia is doubly disadvantaged as they may also be unable to communicate feelings, needs and preferences through facial expression and body language.

Perception is also usually affected as the person with dementia tries to interpret and make sense of the world about them. This may make their behaviour and speech appear different to those of other people. Dementia in Parkinson's is often associated with difficulty in problem solving and planning activities (this is often referred to as dysexecutive syndrome, which may be remembered by the acronym SOAP = strategy, organisation, abstraction, planning).

Alzheimer's disease is the most common cause of dementia, but there are many other causes.

How common is dementia in Parkinson's and what causes it?

Parkinson's can affect the intellect, but in many cases the effects are insufficient to cause dementia. For instance, Parkinson's can be associated with slowness of thinking and reacting, but the memory

remains intact, and not all people with Parkinson's experience dementia.

Dementia does, however, occur in 15–30% of cases. A study by Foltynie et al (2005)¹ suggests if you look hard enough, one-third have evidence of frontal dysexecutive syndrome within two years of diagnosis. Aarsland (2004)² has shown that more than 80% have cognitive impairment after ten years with Parkinson's. However, how dementia occurs in Parkinson's disease is not yet clearly understood.

It is possible that Lewy bodies (the microscopic deposits that occur in nerve cells in the brain stem of people with Parkinson's) have a role to play in the development of dementia in people with Parkinson's. There is also another condition called dementia with Lewy bodies, which has some similarities with Parkinson's. Some people initially diagnosed with Parkinson's may later be re-diagnosed as having dementia with Lewy bodies. See the PDS information sheet *Dementia with Lewy Bodies* for more information on this condition.

The drugs used to treat Parkinson's do not cause dementia but may exacerbate or bring to light the symptoms of dementia, such as hallucinations, confusion or aggressive behaviour.

In the first instance of deterioration in memory or behavioural disturbance, a search for reversible/treatable conditions, for example side effects of drugs (not just those for Parkinson's) or other medical problems such as urinary infections should be investigated.

Sometimes, particularly in older people, dementia may be due to a co-existing but unrelated cause, such as Alzheimer's disease, or multiple small strokes.

1. Foltynie T et al 'The cognitive ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study' *Brain* (2004) Mar;127(Pt 3):550–60 Epub 2003 Dec 22

2. Aarsland D et al 'The rate of cognitive decline in Parkinson disease' *Archives of Neurology* 2004 Dec;61(12):1906–11



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What kind of symptoms of dementia do people with Parkinson's experience?

Symptoms of dementia in Parkinson's vary and often fluctuate, so the person may seem better or worse at different times of the day. This relates, in particular, to levels of alertness. Parkinson's dementia is marked by forgetfulness, slowness of thought processes, lethargy and loss of 'executive functions', such as decision making, planning, reasoning and coping with novelty. There may be loss of emotional control with sudden outbursts of anger or distress, although these features are uncommon. Visual hallucinations may also occur and can be associated with delusions³. See the PDS information sheet *Hallucinations and Parkinson's*.

How are psychiatric behavioural and dementia symptoms in Parkinson's treated?

This is a specialist area and requires the involvement of a team with expertise in treating both Parkinson's and dementia. Psychotic symptoms in Parkinson's dementia can be exacerbated by side effects of the anti-Parkinson's medication so, sometimes, reducing the drug dose or withdrawing a drug may help particularly with problems such as hallucinations.

A reduction in dose or the withdrawal of some drugs can mean that the symptoms of Parkinson's are not as well controlled as they were before. This is sometimes referred to as the 'motion-emotion conundrum'.

Hallucinations are often more worrisome to the carers than to the person with Parkinson's and so do not always warrant intervention.

The type of drug that is often prescribed to treat symptoms such as disruptive behaviour in a person with dementia and other psychiatric conditions is called a neuroleptic or antipsychotic drug. Unfortunately, most of these drugs make the symptoms of Parkinson's worse. There are two types – the older, conventional ones and

newer, so-called 'atypical' drugs. Older neuroleptics such as haloperidol (trade name Haldol) and chlorpromazine (Largactil) always worsen Parkinson's. Sulpiride (Dolmatil) causes moderate worsening. They should therefore be avoided.

The newer, atypical neuroleptics are so called because they are less likely to cause side effects, such as parkinsonism. None of these drugs are licensed to treat behavioural problems in Parkinson's dementia. At least two of these drugs, risperidone (Risperdal) and olanzapine (Zyprexa) should be used with caution to treat dementia in people at risk of stroke (the risk increases with age, hypertension, diabetes, atrial fibrillation, smoking and high cholesterol). It is unclear whether there is an increased risk of stroke with quetiapine (Seroquel) and clozapine (Clozaril). Quetiapine is less prone to cause worsening of Parkinson's symptoms and is often used to treat dementia in people with Parkinson's, although the evidence for benefit is weak. Another atypical neuroleptic, clozapine (Clozaril), usually does not worsen Parkinson's but can be associated with serious bone marrow toxicity and, therefore, is only used in special circumstances and with close monitoring through regular blood tests. All these drugs can worsen memory problems in older people.

The potential risks of any drug treatment will need to be balanced against the difficulties that might ensue if nothing is done.

The anti-dementia drugs donepezil hydrochloride (Aricept), rivastigmine (Exelon) and galantamine (Reminyl) seem to benefit people with dementia with Lewy bodies as well as those with Alzheimer's. There is reasonable evidence that rivastigmine helps reduce hallucinations and behavioural disturbance in Parkinson's dementia.

Care of people with dementia

This is a complex subject and anyone caring for someone with dementia needs expert advice. Several organisations, such as the Alzheimer's Society and

3. Alzheimer's Disease Society, *Rarer Causes of Dementia* information sheet, available from their website: www.alzheimers.org.uk



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Alzheimer Scotland – Action on Dementia, provide support and information for anyone affected by dementia. The contact details are listed at the end of this sheet. It is vital that anyone caring for someone with dementia makes sure they also receive support, including respite care.

Communication problems in Parkinson's dementia

Communication problems are likely to be more severe in people with Parkinson's who have dementia as communication is affected in both conditions.

It is important to remember that if people with Parkinson's have communication problems, it can present a very misleading picture. To a person not familiar with the symptoms of Parkinson's, someone with the condition can appear to be unresponsive because their communication problems make it difficult for them to respond quickly. A lack of facial expression and body language can add to this misconception. Communication problems in someone with Parkinson's do not mean that they have or are developing dementia. Even when they do have dementia, the poor communication skills may make the dementia appear worse than it actually is. Conversely, the loss of communication skills may mask the dementia.

Some people with Parkinson's also experience something called bradyphrenia or slowness of thought. This term is used to describe a certain slowness of response, for example, in reply to a question. You may have to wait longer but the answer will be perfectly sensible when it comes. For example, you may ask, 'What time is it?' and get no response. Then some time later, the person you asked will reply 'it was 2.25pm when you asked me the time.' This is quite different to dementia. A similar kind of slowness can also be seen in people who are depressed. As depression is common in Parkinson's, affecting about one in three people⁴, it is important that depression be

4. Jahanshahi M and Marsden CD (1998) *Parkinson's Disease: A Self-help Guide for Patients and their Carers*, Chapter 5, page 138, Souvenir Press (E&A) Ltd

excluded as a cause of symptoms that could be related to the onset of dementia.

The 'on/off' syndrome, which is a side effect of long-term levodopa therapy, can also cause confusion. This can cause the person to change from being 'on' and mobile to being 'off' and virtually immobile, sometimes all within a very brief period of time. As a result, when the person is 'off' they can appear slow and unresponsive, both physically and mentally, and mistakenly be thought to have cognitive impairment. When they switch 'on' again, they will appear less slow and more responsive. This too can cause misunderstanding with the person being labelled difficult when they are not.

Swallowing difficulties are relatively common in Parkinson's, particularly in the later stages, but are very common and challenging in dementia. A speech and language therapist can advise on any problems that a person has with communication, language or swallowing. (See PDS information sheets *Speech and Language Therapy* and *Eating, Swallowing and Saliva Control* for more information.)

It is also possible, of course, that a problem with communication is caused by a hearing problem. If you suspect this, the person should be encouraged to discuss this with their GP.

How to communicate

It is important to remember that like Parkinson's itself, dementia affects each person in an individual way. Having both conditions will complicate the picture and you need to give people a lot of time. Remember to speak clearly when talking to them and give them plenty of reassurance.

The following guidance on communication with people with dementia has been produced by Alzheimer Scotland – Action on Dementia (available on their website: www.alzscot.org) and is used with their permission.



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Introduction

Communication is a very complex process and it is not surprising that many communication skills are lost when someone has dementia. The way we speak, the words, articulation, volume, tone and understanding are all affected. Some skills of expression are well preserved while other aspects are considerably impaired. Although individual people who have dementia will differ in how their language and communication skills are affected, there are often similarities in their losses.

How communication is affected

The ability to think of the right word may be noticeably worse in the early stages. Later only everyday words may be used and other words lost completely.

Pronouncing letters and words is not affected until the very late stages. Putting sentences together is not affected much in the early and middle stages, but may get worse later.

Knowing when to reply is not affected at first, but the person will tend to say things that relate to him or herself rather than respond to what has been said. This makes the person appear uninterested in what others are saying.

A person with dementia may fail to pick up humour or sarcasm or subtle messages. What the person has to say is most affected. In the early stage, topics are fewer and the person does not try to explain original thoughts or insights. They may speak less and conversation tends to be dull. Later, the person with dementia cannot keep to the topic and becomes vague and rambling. They may speak more but make less sense. Messages are repeated. Less and less is communicated.

In the late stages, the person may say almost nothing or keep repeating only one or two phrases or sounds that may appear to make no sense. Although it makes no sense to us, it may well have a true sense for them.

Generally, it is the automatic language skills, for example responses such as 'hello', which are said without thinking, which are retained for the longest

time. It is often these short automatic phrases that are constantly repeated. This can be very tiring for those caring for the person. Aspects of communication that require careful thought are lost soonest.

Remember, all these features may occur in addition to the speech and communication problems that arise in Parkinson's.

How you can help

When we speak to someone with dementia, we must try to send messages that he or she will understand. This can be difficult because problems with understanding are harder to spot than problems with expression. The response of the person to what you say can indicate if he or she has understood. The person's ability to communicate can give you a good idea of the level at which to pitch a conversation. However, this is not always the case. Short, friendly speech is easy to fake and visitors have to be aware that the person with Parkinson's and dementia may understand very little, but just appear to understand because social speech is still intact.

Make sure that the person is paying attention to you. Looking directly at the person and eye contact are important. Gently touching and calling the person's name can draw his or her attention. However, remember that, for some people, eye contact and touching may be inappropriate. When communicating proceed very quietly and slowly and never scare them with touch or movement.

Speak clearly. Don't talk too fast or give too many messages at once. Make one point at a time. Keep sentences short and simple. Stick to simple, familiar ideas rather than complicated new concepts. Make statements and not logical arguments. Allow plenty of time. If they don't understand something, try saying it again in a different way.

Say exactly what you mean. Avoid suggested or implied messages. Don't say (with a sigh) 'Monday and it's raining again!' Say: 'It's Monday. It's raining. I can't put the washing out to dry.'



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Use real names, not pronouns (he, she). This reminds the person of who you are talking to or about.

Do not ask questions which need a complicated answer. Questions that can be answered with a word or two are best. Examples include: Are you feeling well? Does it hurt? Show me where it hurts.

Information is not easily taken in. It helps to repeat the important parts of a message. Also remember that, if they experience bradyphrenia (discussed at the beginning of this information sheet), they may take longer to reply so you always need to give them plenty of time to respond. Try not to fill in the silences. Use the pauses to allow them time to take in the messages.

Gestures, body language, touch and tone of voice are often understood right through to the late stages of the illness. Sit in a position where the person can easily see you. Never appear rushed or angry as this can be upsetting as people with dementia and Parkinson's are particularly sensitive to body language and tone. If you are rushed and abrupt they will be more confused and upset. The topic of the conversation needs to be one that both parties can grasp. For people with dementia, this tends to be the old and familiar things in life.

Sometimes, people think that if a person with dementia does not understand then it is all right to talk about them in their presence or believe that, even if the person does grasp something of what is being said, he or she will forget it in five minutes. Both ideas are wrong.

Never use baby talk to someone with dementia. Never talk about them in front of them or signal to someone else in their presence that you want to talk about them. The best rule of thumb is treat them as you would want 'you or yours' treated. Body language and gesture are likely to be understood and so the person with dementia will be aware of being talked about, even if he or she cannot grasp the meaning. This can be upsetting. It is also possible that he or she will continue to feel anger or upset long after forgetting the original reason.

In company, conversation becomes much more difficult to follow. People talk quickly or talk at the same time and the person with dementia is soon lost and feeling isolated. Generally, it is best to avoid large groups, but encourage visits from old friends and members of the family. If they are in a large group, try to sit with them and perhaps hold their hand or reassure them. This will make them feel included and lessen their fear.

In terms of general environment, never change surroundings by moving the furniture. Even moving small items that are familiar to them can be distressing. If you have to move something to make space, talk to the person as you do it. Tell them why you are doing it. Show them where you put it. To move things quickly without explanation is upsetting and disturbing for the person with dementia.

Be patient when communicating with someone with dementia. Try to put yourself in their shoes. If you were the one with dementia, how would you feel in their situation? Embarrassed? Annoyed? Wanting help? Frightened?

Offer to help them, but don't assume that the person wants to be helped.

People who have dementia and Parkinson's can have difficulty finding the right words, they can find it difficult to repeat something if you ask them to and they may misunderstand what you say. If the person you are communicating with is having trouble finding a word, suggest one, but don't interrupt them.

Handling money can be difficult for people with dementia. If you need to help, count out the money slowly in front of them then, repeat what you have used.

Ensure that anyone with dementia carries a contact number in a pocket or bag. Do not put their full address somewhere for all to see as this makes them very vulnerable to those who are less well meaning! Some people find wearing a piece of Medic Alert or SOS Talisman jewellery (for example a pendant, bracelet or watch attachment) can be helpful. These are items



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of jewellery that provide contact details and medical information if someone is involved in an accident or if they have dementia and either get lost, wander off or can't remember where they live.

More information on these is available from:

Medic Alert

1 Bridge Wharf
156 Caledonian Road
London N1 9UU
Freephone: 0800 581420
Email: info@medicalert.org.uk
Website: www.medicalert.org.uk

Talisman Ltd (SOS Talisman)

21 Grays Corner
Ley Street
Ilford
Essex
IG2 7RQ
Tel: 0141 639 7090
Email: sostalisman@btinternet.com
Website: www.talismanhouse.com

Further information and advice

The Alzheimer's Society

Devon House
58 St Katherine's Way,
London E1W 1JX

Tel: 020 7423 3500
Helpline: 0845 300 0336 (8.30am-6.30pm, Mondays to Fridays)
Email: enquiries@alzheimers.org.uk
Website: www.alzheimers.org.uk

Alzheimer Scotland – Action on Dementia

If you need information or emotional support on any issue to do with dementia, you can call the Scottish 24 Dementia Helpline:
0808 808 3000.

Alzheimer Scotland – Action on Dementia

22 Drumsheugh Gardens
Edinburgh EH3 7RN
Email: alzheimer@alzscot.org
Website: www.alzscot.org

The book *Parkinson's Disease: A Self-Help Guide for Patients and Carers* by Marjan Jahanshani and CD Marsden (1998, Souvenir Press Ltd ISBN: 0 285 63317 1) has a useful chapter on Parkinson's and dementia, which includes information on coping with dementia-associated issues.

Thanks

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