What are hallucinations?
When a person hallucinates they may see, hear, feel, smell or taste something that, in reality, does not exist.

While most people with Parkinson’s disease do not get hallucinations, some people may experience hallucinations and these are usually visual. While the hallucinations may comprise quite complex scenes, they typically involve the person seeing small animals, insects or other people in the room with them. These images do not usually speak or make sounds and they can either disappear quickly or last for some time. Occasionally, the hallucinations are auditory (where the person hears a voice or sound without seeing anything), or tactile (the person feels something touching them), but for people with Parkinson’s, these are less common than visual hallucinations.

Sometimes, people with Parkinson’s experience delusions of presence; when they feel that an animal or object is present just next to them but they do not actually see it.

Most people with Parkinson’s find that the hallucinations they experience are not threatening or distressing. In many cases, the person with Parkinson’s is actually aware that the images or sounds are not real, and are able to cope with them. In fact, some people even look upon the person or object that they see as a companion. In other instances, the hallucinations can be very frightening, particularly if the person with Parkinson’s believes that the image they see or sound they hear is real and do not realise that they are, in fact, hallucinating. In such cases, coping with hallucinations can be difficult.

What causes hallucinations?
The hallucinations associated with Parkinson’s can affect both younger and older people, but they are more common in the older age group, and particularly in those who have had Parkinson’s for a long time.

Medication
It seems that the hallucinations are caused partly by Parkinson’s itself and partly by the medication that is prescribed to treat it. While just about any of the drugs can be to blame, hallucinations are more likely to affect people who take dopamine agonist and anticholinergic drugs, particularly if they are in the older age group. Further information about these drugs is available in the Parkinson’s Disease Society (PDS) booklet The Drug Treatment of Parkinson’s Disease.

Sometimes, hallucinations occur when an adjustment has been made to the dose of a particular anti-Parkinson’s drug or when a new drug is added to a combination that the person is already taking. On other occasions, it seems that the hallucinations occur spontaneously, without any immediate cause.

It is important to remember that most people who have Parkinson’s take their medication successfully, without experiencing hallucinations. You should not, therefore, be put off taking the drugs that are prescribed for you. If you are worried or have questions about the medication you are taking, you should discuss these with your GP, specialist doctor or Parkinson’s Disease Nurse Specialist. You can also call the Society’s freephone Helpline (0808 800 0303) to talk to a nurse adviser.
Other illness
Sometimes, hallucinations are not simply due to Parkinson’s or its drug treatment, but are precipitated by some other cause. For example, an acute illness such as a bladder or chest infection can cause people to hallucinate, as can some medications that are prescribed to treat other conditions. Hallucinations can also be a feature of dementia.

Eyesight
Occasionally, visual hallucinations may be due to severely impaired vision. See the PDS information sheet Parkinson’s and Eyes for more information.

How are hallucinations treated?
If you are experiencing hallucinations, it is important that you visit your doctor so that the cause can be identified and any appropriate treatment given.

Treat any underlying illness
If there is some other underlying cause, such as a bladder infection, the doctor will treat this and the hallucinations should then disappear.

Adjustment of anti-Parkinson's medication
If the hallucinations are associated with Parkinson’s but are not troublesome, the doctor may decide to delay giving treatment and just monitor the situation. If, however, the hallucinations are causing distress to the person with Parkinson’s, the doctor may suggest that some treatment is necessary.

The first line of treatment is usually to adjust the anti-Parkinson’s medication. This will involve a reduction in the dose, or the gradual withdrawal, of particular drugs. The doctor will usually withdraw anticholinergic drugs, particularly in older people, and other drugs may also be reduced. Such measures can often eliminate or reduce the hallucinations, and any improvement is usually noticed within a few weeks, or sometimes even within a few days.

Unfortunately, making adjustments to the anti-Parkinson’s drugs does not always eliminate the hallucinations. In addition, you may find that a reduction in the dose, or the withdrawal, of some drugs can mean that the symptoms of Parkinson’s are not as well controlled as they were before. In these cases, the doctor will usually try to achieve a balance by reducing the hallucinations to an acceptable level while, at the same time, trying to maintain a good level of control over the Parkinson’s symptoms. This compromise is usually acceptable if the hallucinations are not distressing and the Parkinson’s symptom control is relatively good. If a satisfactory balance between hallucinations and symptoms cannot be achieved, the doctor may consider prescribing a special drug to help overcome the problem.

Treatment with special drugs
The type of drug that is often prescribed to treat hallucinations is called a neuroleptic or antipsychotic drug. Unfortunately, most of these drugs can make the symptoms of Parkinson’s worse. There are two types – the older, conventional ones and newer, atypical drugs.

Older, more conventional neuroleptics, such as haloperidol (trade name Haldol) and chlorpromazine (Largactil), always markedly worsen parkinsonism. Thioridazine (Melleril) and sulpiride (Dolmatil) cause moderate worsening. The newer, atypical neuroleptics are so called because they are less likely to cause side effects than standard antipsychotic drugs.
However, 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), because of an increased risk of stroke and other cerebrovascular problems. It is unclear whether there is an increased risk of stroke with quetiapine (Seroquel) and clozapine (Clozaril). Quetiapine (Seroquel) seems much less prone to worsen Parkinson’s symptoms and is often used to treat hallucinations, especially when they are accompanied by troublesome delusions. Clozapine (Clozaril) also usually does not worsen Parkinson’s symptoms, but can be associated with serious bone marrow toxicity. It is, therefore, only used in special circumstances, and with close monitoring through regular blood tests.

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

Cognitive impairment and Parkinson’s
Hallucinations may arise, either on or off anti-Parkinson’s drug treatment, in people with Parkinson’s who already have some degree of cognitive impairment (for example, poor recent memory), often associated with fluctuating alertness and arousal (sometimes falling asleep after taking their tablets). In this situation, drugs called cholinesterase inhibitors such as donepezil hydrochloride (Aricept), rivastigmine (Exelon) and galantamine (Reminyl) may improve both cognitive and behavioural problems and often also hallucinations. These drugs can sometimes worsen Parkinson’s tremor. Increasingly, Parkinson’s specialists are more likely to consider rivastigmine as the drug of choice for treating hallucinations, especially if there is co-existent dementia.

Caring for someone who experiences hallucinations
Hallucinations can be very difficult for a carer to cope with. It is not always easy to know how to react and what to say to someone who is hallucinating.

While the hallucinations can be quite distressing for the carer, it is important to try to stay calm. Do not agree that there is something in the room when there is not and try not to let an argument develop about whether the image or sound is real. Instead, offer reassurance, particularly if the hallucinations are causing distress to the person.

It is sometimes helpful to explain that you cannot see what they are seeing or hear what they are hearing, but you understand that the images and sounds are very real to them. It can also be effective to distract the person in order to take their mind off what they are seeing. The image may then disappear. Of course, it is important to encourage the person with Parkinson’s to discuss the hallucinations with their doctor because it is likely that something can be done to help.

Where can I obtain further information?
If you or the person you are caring for is experiencing hallucinations, the best person to advise you is your GP or consultant. It is important that you visit the doctor so that the cause of the hallucinations can be identified and any appropriate treatment given.
If you have access to a Parkinson’s Disease Nurse Specialist, it is likely that they will be able to provide you with further advice about coping with hallucinations. The PDS is also here to help you. If you have any questions or require further information, please contact us. Our Helpline number is 0808 800 0303, available Monday–Friday, 9.30am–9pm, Saturday, 9.30am–5.30pm (except bank holidays).

Thanks
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