Hallucinations and Parkinson’s

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 in fact, are, 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.

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 therefore, should not 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.

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.

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.

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). Drugs are available which may improve both cognitive and behavioural problems and often also hallucinations. However, these drugs can sometimes worsen Parkinson’s tremor so consultation with a Parkinson’s specialists is essential 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.

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Relevant Leaflets
NM11: Dementia and PD

DISCLAIMER – The information on these pages is not intended to be taken as advice. No changes to your treatment should be made without prior consultation with your doctor or allied health professional.

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