

Living with Parkinson's

The debilitating effects of Parkinson's disease are upsetting and disturbing for both patient and carer alike. Making substantial life changes and sticking to a careful diet, however, can help you manage the illness

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Sadly, Parkinson's disease has been at the forefront of my mind twice in the past few months: Michael J Fox recently announced that he is giving up work to devote more time to fighting the disease and, closer to home, the sister of a treasured friend has just discovered that it is responsible for her muscle weakness and tremor.

Parkinson's affects approximately one per cent of people over the age of 50 and can also hit people in their twenties and thirties. We still don't know what exactly causes this disease, but it's a chronic, progressive disorder of the nervous system, resulting from the degeneration of certain brain cells. These brain cells produce a substance called dopamine, which is a neurotransmitter; in other words it helps the nerves communicate messages to one another. Without dopamine the nervous system falters.

Parkinson's commonly starts with a tremor in one arm that occurs when the arm is at rest. As the disease progresses, movements gradually become more rigid, walking and balancing become difficult, the face can become frozen (speech and swallowing can become problematical), and there is progressive difficulty in performing simple tasks we take for granted, such as dressing ourselves - which can become impossible. The time that elapses between the first symptoms (typically a tremor or weakness) and when the more debilitating scenarios kick in varies greatly, but the degenerative path this disease follows means that Parkinson's affects not only the individual but also everyone around them - as time goes by, the sufferer frequently has to rely heavily on others for help. In Britain, there are only about two people with Parkinson's under each GP; many practitioners don't know the best ways of dealing with the disease, so it's essential to find a neurologist who has an interest in it.

No one can deny that Parkinson's disease is a distressing condition, but since the discovery of drugs such as Levodopa, the prognosis has changed dramatically. Levodopa restores the deficiency of dopamine within the brain by providing the brain with the amino acid L-Dopa (L dihydroxy-phenylalanine) from which the dopamine is derived. Levodopa remains the 'gold standard' of Parkinson's therapy as it's the most potent anti-Parkinson's drug available (although a few people fail to respond to this therapy). Long-term use of Levodopa often leads to complications later in this disease, most importantly dyskinesia, (uncontrolled movements) and in the short term, side effects such as depression and extreme tiredness (which usually occur when you first start taking the drug), both of which can make this medication route far from ideal. Thus many specialists now like to consider the use of other drugs, and the trend in treatment is toward combination therapy - the substitution or addition of other drugs at different times in the disease's progression. Some specialists may also consider surgery - either the removal or electronic stimulation of certain cells in the brain which control tremor and balance, or more recently and controversially, scientists are looking at the implantation of (pig) foetal tissue to restore the brain's ability to produce dopamine. Currently, surgery remains a less common option - for the majority of people, drugs provide the core of their conventional therapy.

But it's not just the drugs that need attention, food has a major role to play; it not only helps the body remain as fit and healthy as possible, which is vital in this degenerative disease, but more specifically what we eat has a relationship with L-Dopa. Before exploring this specific drug-food relationship, there are a couple of other wider issues. First, the importance of having a well-balanced, antioxidant-rich diet (fruits, vegetables, etc), since there is some evidence to suggest that free radical damage can be involved in the progression of Parkinson's - and boosting antioxidants counteracts this damage. Your diet also needs to include plenty of calcium and vitamin D-rich foods (dairy products, oily fish, etc) to ensure the bones remain as sturdy as possible. You may become unbalanced and/or weak, as the disease progresses - if you fall over, brittle bones are more likely to fracture. If you suspect that your intake of calcium and vitamin D is low, discuss taking supplements with your specialist. Constipation can also be a significant problem, not only because it causes discomfort, but because it interferes with the absorption of Levodopa - so try to keep your intake of fibre (wholegrain breads, pulses, cereals, fruits and vegetables, etc) and water high.

The major food issue to address, however, is what to eat when you're taking Levodopa. This drug is taken orally and is absorbed most effectively through the upper part of the small intestine, the part encountered by food as it leaves the stomach. It's best taken on an empty stomach, as there are nutritional factors which in some people can interfere with the metabolism and ultimately the efficacy of the drug. In some individuals, certain amino acids (molecules within protein) interfere with the metabolism of L-Dopa; if these protein-sensitive people eat protein foods and take the drug at the same

time, L-Dopa will not be able to work efficiently in the body.

You might think that the simplest thing to do would be to cut out protein, but this would lead to other malnutrition problems. Protein is essential in maintaining a healthy muscle system and is also needed to keep the immune system feisty. In fact, all you need to do is separate concentrated sources of protein from the drug doses, so that your body can glean the protein and respond well to the treatment. Your specialist will be able to advise you as to the time you should leave between taking your medication and eating protein-rich foods (meat, poultry, fish and eggs - the slower absorption of protein from pulses such as dried beans, peas and lentils makes them less of a problem). However, leaving an hour before you eat seems to be commonly advised. I cannot give an exact time, because everyone's metabolism is different.

Other foods such as cereal-based carbohydrates (pasta, rice, bread, potatoes, etc) and dairy products also contain protein, but in a less concentrated form, so these, and of course vegetables and fruits, will not interfere with the actions of the drug. So if you take Levodopa and want something to eat before your curfew time, these are the foods to choose. Base breakfast and lunch on carbohydrates (porridge, honey on toast with banana, cereals, etc, for breakfast; risotto, pasta or a simple non-protein sandwich - jam or peanut butter etc, for lunch) and save the protein (roast chicken, fish casseroles, meat, eggs, etc) until the evening meal, eating it an hour after you have taken your last dose of medication. It's important to stick to this sort of structure, in meal quantity, quality and timing - if you vary things too much, the action of the drugs may be compromised.

As the disease progresses, a vicious circle can develop: the disease can weaken and depress you, and it can be so physically difficult to prepare and eat meals that the desire to eat can disappear. Lack of nutrients leads to more depression, chronic fatigue, weight loss and reduced physical strength, all of which compound the problems of dealing with Parkinson's. The best way to tackle these problems is to eat small meals often. Simple meals such as egg on toast or a rich soup are generally better managed than a whole roast lunch. Fruit fools, egg custard, soufflés and omelettes slip down easily, if swallowing is difficult. Keep ahead of the game, by having simple-to-prepare foods such as cheese, sliced meats, individual portions of home-made soups and vegetable flans in stock. Having cake tins stocked with nutritious bakes such as fruity maltloaf, flapjacks or biscuits can help you satisfy hungry moments and keep on top of the disease.

You can contact the Parkinson's Society on 020 7931 8080; or call the national freephone helpline on 0808 800 0303

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