

Bookmarks: Parkinson's disease

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Web information on the disease, suffered by over 120,000 patients in the UK.

Parkinson's disease is a subject that I am getting more and more requests about. The disease seems extremely common as many of us will have experience of a friend or relative as a sufferer. According to the BBC health page,¹ there are over 120,000 patients in the UK suffering from the disease. Parkinson's disease is a progressive, degenerative, neurological condition for which there is currently no cure. The symptoms are depressingly familiar – tremors, facial tics, difficulty in moving arms and legs, and a third of patients develop senile dementia. I found the BBC site to be excellent, identifying the prevalence of the disease, symptoms, causes and treatments, both conventional and experimental.

In terms of associations and societies, the Parkinson's Disease Society (PDS)² is well worth a view. The Society exists as a charity to support patients and their families, friends and carers. Well-organised and patient-focused, the site is an excellent example of a resource that informs without being patronising. I liked the summary of current research areas which explained the issues around controversial stem-cell research. At the time of writing, the Society was preparing for Parkinson's Awareness Week in April and was providing support and advice to local groups on publicity.

The American Parkinson's Disease Association³ is a similar resource, but nowhere near as user-friendly as its UK

counterpart. For instance, the site gives no background on the disease and assumes that all website users will be aware of the disease and its implications. Indeed, the home page merely talks about what it has achieved in terms of support, research and education. The other pages do give some information on publications, getting involved and current events, but I felt that it was uninspired and needed to review what it was there for.

The European Parkinson's Disease Association (EPDA)⁴ was a little better, but again seemed to be concerned with its own importance rather than the reason for its existence. I suspect that there is much overlap with the PDS, as many of the issues raised on the EPDA site were similar to those on the PDS site. The drop-down lists on the site were difficult to use as they often disappeared before you were able to 'drill down' to the information that you needed. However, the patient information section was excellent and well explained.

The excellent Brain and Spine Foundation site⁵ has, in my opinion, the best approach of all the association websites in that it is in a question-and-answer format looking at what Parkinson's disease is, who gets it, how a diagnosis is made, signs and symptoms and so on. This simplistic approach was very accessible and well written.

In terms of support for clinicians, there are a number of useful resources. For instance, the Clinical Knowledge

Summary (CKS)⁶ is interesting, if a little frustrating. For those who have not used CKS, there are excellent summaries of evidence-based resources from the National Library for Health. The problem is that the resource is very menu driven, so the front page says very little, while the related pages, such as patient information and in-depth coverage, say a lot more. My first impression was that there was nothing worth bothering about until I decided to click on the links from the menu.

Other useful resources are the collected resources page from the *BMJ*.⁷ These are excellent as current awareness tools and the Parkinson's disease page included much research from the past year. I also like the MedlinePlus pages⁸ as they give a detailed summary of the issues related to the disease – it explains the symptoms and the fact that it is more common in men than women, an issue that none of the other sites had discussed. I liked the straightforward approach to the topic and the links to research, patient information and interactive patient information. I also like the way that MedlinePlus organises itself into six categories relating to each disease – basics, learning materials, multimedia, research, reference materials and patient information.

Finally, speaking of research, I must draw your attention to Bandolier's⁹ attempt to look at the disease. They summarise information relating to the incidence of the disease, the benefits or otherwise of NSAIDs and treatment of the disease. What I found very interesting was their summary of recent research related to coffee drinking and smoking which infers that these vices appear to reduce the incidence of Parkinson's disease. Although the figures are compelling, it then goes on to challenge the research on the basis that Parkinson's disease is rare whereas the side effects of coffee and cigarettes are not!

Websites

1. <http://news.bbc.co.uk/1/hi/health/medical_notes/199709.stm>.
2. <www.parkinsons.org.uk>.
3. <www.apdaparkinson.org/user/index.asp>.
4. <www.epda.eu.com>.
5. <www.brainandspine.org.uk/information/publications/brain_and_spine_booklets/parkinsons_disease_and_parkinsonism/index.html>.
6. <www.cks.library.nhs.uk/parkinsons_disease>.
7. <www.bmj.com/cgi/collection/parkinsons_disease>.
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9. <www.jr2.ox.ac.uk/bandolier/booth/booths/neurol.html>.