

**Report of the Parkinson's Disease Society (PDS) Conference held at Durham Cricket Club on 18<sup>th</sup> July 2007**

**Introduction**

A conference was held by the Parkinson's Disease Society (PDS) and was attended by people with Parkinson's disease (PD), carers, representatives from the PDS and representatives from the information prescriptions project team. Kate Greenwell (Information Prescriptions Manager) and Sally Corbett (Senior Researcher) from Northumbria Healthcare NHS Trust presented an update on the information prescriptions project. The aim of this presentation was to inform the local PDS members about the project and obtain information that would aid the development of the project.

**What information would you find useful?**

It was emphasised that information should be reliable, up-to-date and easily accessible (e.g. Libraries, GPs, Citizen's Advice Bureau, Dentists, Chiropodists).

***What information would be useful to patients?***

Attendees identified a number of key points at which information would be beneficial.

*1. Pre-diagnosis*

What information would be useful pre-diagnosis?

- Information regarding the signs and symptoms of PD, the tests involved in diagnosis, the speed of results and the accuracy of diagnosis.

*2. Diagnosis*

Diagnosis was highlighted as an important point of access. It was suggested that a basic information pack should be issued following diagnosis that includes links to further information.

What information would be useful at diagnosis?

- Information on treatment options, progression of PD, PDS, local advice centres (financial advice etc), available services (e.g. physiotherapy, speech therapy, occupational therapy), support groups, local contacts and transport provision.
- Advice regarding insurance, mortgage, driving, foreign travel, travel agents, adaptations to property, employment (e.g. how to deal with employer, given with a gentle approach)
- Contact path (procedures)

- PD information days attended by health professionals and representatives from the PDS are very useful

### *3. Starting drug treatment*

What information would be useful when starting drug treatment?

- Information on how the medication works (or not), ups and downs associated with medication, benefits and side effects of medication, long-term implications, how PD progresses
- Attendees emphasised the importance of the doctor's support and reassurance during this time

#### ***What information would be useful to carers?***

- Information regarding PD (e.g. how patient may go up and down), helplines, contact details, support carers centres, carers own rights, respite care, financial rights, employment, child care, driving, marital counselling, social activities
- Information should be confidential and personal to the carer

#### ***In what format would you like to receive the information?***

Attendees identified that verbal information is the most important, however, as verbal information is easily forgotten, it will need to be backed up with more tangible material such as leaflets. DVDs and videos are a good idea, however, they are less likely to be used as some people may not have the appropriate knowledge or facilities to take advantage of them. The suggestion was made that consultations could be videotaped and given to the patient to be viewed at a later date.

#### **How would you like to receive the information?**

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- Hand-delivered on a one-to-one basis
- Posted - as long as this is followed up by a face to face discussion
- Email
- Drop-in centre ran on a monthly basis.
- Information prescriptions could be collected at pharmacies along with their medication.

##### ***Who would you like to deliver the information?***

- Someone you know/trust
- Someone knowledgeable about PD
- Someone who can gauge how much information you want
- Not an external source

- Home visits are ideal
- Dedicated staff to provide support at point of diagnosis

### **What support would you need after you have received the information?**

Attendees agreed that the follow-up process is a vital element of the information prescriptions process.

#### ***What would you need from a follow-up?***

- It is less important how the information is accessed as long as it is preceded by an expert follow-up
- Contact details should be given with the information so that patients and carers can talk to someone regarding further information or clarification

#### ***Who would you prefer to conduct the follow-up?***

- On a one-to-one basis, preferably by a Parkinson's disease nurse specialist or a community support worker from the PDS

### **Personalising information**

As people with PD are a diverse group, it was emphasised that information must be personalised. Attendees raised the concern that too much information early on can be upsetting and detrimental, therefore, it is crucial that information is given by someone who is able to assess how much or how little information is required.

### **Discussion points**

The point was made that the PDS already provide an excellent information service, via the telephone helpline service and community support workers. Additional provision by the NHS seemed superfluous to requirement. Our response to this was the need to offer various modes of accessing information as some modes will suit some people better than others, also people may prefer to access certain types of information from specific sources. It seemed inappropriate on the day to mention that not all patients join the voluntary organisation. These points are well made though and we need to be clear about the specific service we are able to offer and how it differs from others.

Concerns were raised that providing a non-expert service through NHS Direct may suggest there is no need for specific expertise on Parkinson's disease. This would run counter to the case the PDS are making for the development of specialist services.