

**Report of the stakeholder event held at Choppington Welfare Centre  
on 13<sup>th</sup> April 2007 from 12 noon to 5pm**

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## **Executive Summary**

A stakeholder event held to launch the development of an information prescription (IP) for Parkinson's disease was attended by people with Parkinson's disease (PWP), carers, representatives of voluntary organisations, information managers, health and social care professionals.

### **Aims:**

- Examine the current status of information provision
- Identify key topics and the most appropriate stage of PD to provide information about these
- To consider how IPs should be issued and by whom
- To explore the format of an IP
- Enlist the help of stakeholders

### **General themes:**

1. Information provision could not be classified by stage of disease
2. Information was needed for a pre-diagnostic stage
3. People need to talk to a person when given information
4. Information was needed on how to use and access NHS services
5. Information needs to be generalisable to areas where the local service is different
6. There should be links to generic information on management of long term conditions

### **Task 1 – The current status of information**

Stakeholders identified a need for a choice of format. They accessed a variety of resources in different formats from different providers. Information could not be provided by NHS Direct until patients had a diagnosis or by health and social care professionals until they were referred to them. Different strategies were employed to quality assure information.

### **Task 2 – Timing of information**

Information requirements were mapped onto the stages of Parkinson's disease. Stages were not clearly delineated as the natural history of the condition differs between individuals. Categories of information often applied to every stage of disease progression, but with altered emphasis.

Information for relatives and carers was important to enable families to understand and cope with the condition.

### **Task 3 – Format, structure and issue of IPs**

A wide variety of formats and media were considered.

Stakeholders identified who should issue IPs, with suggestions for their structure, and how they could be quality assured and maintained. One suggestion was to accredit and quality assure organisations rather than separate sources of information.

Individual differences in learning style and cultural differences in health seeking behaviour flagged the importance of personalising information provision.

### **Task 4 - What will an information prescription look like**

The IP may provide a signpost to a directory or log a patient's information journey, like a passport maintained by a patient or carer.

Stakeholders were confused about the difference between an IP and actual information.

The IP might also be used to flag an information vacuum where more work is needed to develop new resources.

### **Stakeholder support**

Stakeholders were asked to evaluate the event and to indicate if they would be happy to work with the project team to develop an IP for Parkinson's disease. Many were happy to be involved but were unsure of their role.

All stakeholders were asked to comment on the report of the event. There was one omission on help for symptoms from speech and language therapists and a carer commented that duplication of information at different stages would deter people seeking information.

## **Key recommendations**

1. Similar types of information need to be accessed at different stages of the disease progression
2. An additional category of information should be made available for patients prior to confirmation of a diagnosis of Parkinson's disease
3. Patients and carers should be able to talk through the information they receive with a health or social care professional, or trained support worker.
4. Information should be designed to enable patients and carers to understand how services or the system works in order to enable them to participate fully in organising their health and social care.
5. Information prescriptions should include information on local as well as national services
6. Information should be generalisable to areas where the services differ
7. There should be links to generic information and related non Parkinson's specific services and voluntary organisations

## **Introduction**

This is a report of a stakeholder event held to launch the development of an information prescription (IP) for people with Parkinson's disease (PWP). The aims were to gather information about suitable topics and format of an IP, and to enlist the help of stakeholders for the duration of the project (Finishing date 31<sup>st</sup> January 2008). The programme is shown in Appendix 1.

## **Who attended**

The event was attended by 39 people including people with Parkinson's, carers, members of the Parkinsons Disease Society (PDS), a representative of the carers society, hospital doctors and GPs, specialist nurses (Parkinsons and continence), allied health professionals (Occupational Therapist, Physiotherapist, Speech and Language therapist, Pharmacist), a health psychologist, social workers, a member of NHS direct, a librarian and the PDS information manager and 20 completed an evaluation form before leaving the event.

## **Stakeholder evaluations**

The evaluations of the event were generally positive with only one person feeling that the organisers were unable to answer questions about the project sufficiently well and one feeling that the meeting was not at the right level. Delegates appreciated the opportunity to network and to engage in open discussion. Useful suggestions to improve a second event were made (eg. Use a PA) and to improve the project such as the inclusion of other stakeholders or organisations (eg. Disability North, Age Concern) and some key tenets were emphasised such as being able to generalise the Information Prescriptions to other localities. Concerns were expressed about the timescale and people generally feeling rushed both on the day and for the duration of the project.

Many people offered help, but some were unsure of the role they could fulfil.

## **Four tasks**

The event aimed to complete four key tasks:

- Examine the current status of information
- Identify key topics and the most appropriate stage of PD to provide information about these
- To consider how IPs should be issued and by whom
- To explore the format of an IP

The feedback from the event was recorded by rapporteurs sitting at each table and on flip charts during whole feedback sessions. This is reported below by task.

### **Task 1 – The current status of information**

- **For health and social care professionals: What information do you give to people with Parkinson's at each stage in their condition?**
- **For people with Parkinsons and their relatives or carers: What information were you given at each stage in the condition?**

### **General comments**

1. It was not always useful to think of personalising information by using stages, as stages were not clearly separated and issues relevant at one stage were often important in the next, people's information needs vary depending on personal circumstances, and some people like to have all available information from the outset, whilst others prefer not to know much at all and just deal with issues as they arise. One problem is that people may expect to experience all the symptoms of PD at some stage in the course of their illness which may not be the case and this would require them knowing irrelevant facts. There is a case for only providing information relevant to problems as they arise.

2. Another stage should be added for the period before diagnosis of Parkinson's. The process is often long drawn out, confusing, with no indicative tests readily available, and this is marked by feelings of uncertainty and anxiety. There is a problem with providing information when no diagnosis is attached (especially for NHS Direct), but it was suggested that an IP should be made available for people with suspected PD or Essential Tremor.

3. Patients and carers reported having little or no information at diagnosis, certainly nothing written down, and being left to look it up for themselves. They felt as though they were 'in limbo'. One person reported that even on referral for a CT scan the diagnosis was given in 30 seconds and they were just told to let the consultant know when they needed to know something. People are reluctant to contact hospital physicians for information even when the offer is made. In this case they looked up information on a mental health website. An information pack is now given at diagnosis.

However, information alone is not enough; there is a need to have someone available to newly diagnosed patients especially if they access information which is upsetting (One person reported seeing a distressing TV programme about people in the end stage of Parkinson's). They recommended having printed information available on diagnosis about the condition with details of who to contact with questions.

4. The group also emphasised the need to have people available to talk to throughout their condition and not just to be given information without support

5. A recurring theme was needing to know how to access specialist services and social care.

6. PWP reported receiving better information once they had been referred to a dedicated service, however, information will need to be applicable where there is no specialist service in the area and some work needs to be done to consider how GPs access their own information.

7. Information may be PD specific, but we should draw upon information from other services such as continence and palliative care, or more generic information about benefits and social care or managing long term conditions.

## **Key themes**

### **Choice**

The group wanted a choice to have information to take home to read at leisure and, importantly, an opportunity to talk this through with a professional.

### **How is information given?**

Information is currently given in a range of different ways:

- Verbally – discussion
- PD Northumbria care guide
- User guide about support groups
- PDS leaflets and resources
- Relevant leaflets which may include non PD specific information such as information about continence
- Booklet
- NHS Direct
- Copies of letters between clinicians made people feel more informed.
- Telephone

Families and carers were given information verbally but felt poorly informed and they were often the people who researched the condition most. They wanted different information; they were not given information to allow them to understand and cope with symptoms often leading to misunderstandings.

### **What do people currently get information about?**

- Information about driving was given early on
- Medical
- Dyskinesia
- Falls
- Access to services
- Information about the PDS
- Drug information
- Benefit entitlement
- Living with PD
- Living with uncertainty
- Uncertainty of diagnosis process is not fully explained

### **Who gives information?**

- GPs during the referral process
- Info support workers
- Info support services
- Internet - WEB
- PDS both the national and local service
- PD service
- Specialist nurse
- NHS Direct
- Library
- Doctors
- Expert Patients
- Pharmacists
- Disability North
- Radio and TV
- Drugs companies – the leaflets that come with medication

Professionals reported giving information on contact and many patients felt they had to ask for information and needed to be self-directed learners. This was difficult as PWP were not sure what they should know in order to ask the right questions.

There are conditions limiting information giving. NHS Direct and GPs were unable to give information before a diagnosis is available. Allied health professionals (Physiotherapists and Occupational therapists) were often not involved in the care pathway until the later stages even though people would benefit from some preventative advice early on. The exception to this was where

someone had been referred for another long term condition in which case they may also be given advice on managing Parkinson's Disease.

### **How do you quality assure information?**

- EMS approved information for GPs
- Looking for consistency of information across websites
- NHS Direct need to check copyright information before this can be used
- Noting when the information was last updated
- Quality assuring agencies such as the PDS who carefully research and validate information they issue
- Community legal services check originating agencies and documentation
- Evidence base
- In approved guidelines for best practice
- Noting who wrote the information
- Trusting professionals

### **Accessibility issues**

Ethnic minorities – translation into other languages should be available and content needs to be checked as people have different health seeking behaviours.

Disability – Media and style need to be considered to accommodate physical or sensory impairments and learning difficulties (Braille, audiotape, DVD).

### **What information did you want?**

- How to access services
- How to get in touch with the local branch of the PDS
- Drug related information, although PWP were confident about the currency of drugs information.
- They would have liked a pack of information at diagnosis
- They wanted a variety of formats as they sometimes had problems reading leaflets.

## **Task 2 – Timing of information**

- **What are the top five things in each stage you would like information about/give information about**
- **When/where would you want to get/give this information**

Participants were asked to write the most important five things they wanted to know on post it notes and stick these onto a chart, with the four stages of PD marked on, to indicate when the information would be most appropriate. These topics have been thematically analysed and categorised by stage in the chart attached to this report.

## **Task 3 - Format, structure and issue of IPs**

- **In an ideal world how would you like to give/be given information about Parkinson's Disease?**

Participants in the workshop initially considered the medium used to deliver IPs.

## **Media for Information Prescriptions**

### **Electronic**

DVD

CD

Web site useful for PD society – offered not mandatory

Internet

Videos

Tapes

Computer – e-mail – website

### **Telecommunications**

Telephone

NHS DIRECT

Telephone contact – listening service

### **Written**

Info pack at diagnosis – then other triggers

Printed info available on diagnosis about the condition and who to contact with questions PDNS.

Need and opportunity to read at leisure then ask questions

Booklets

Leaflets

Info leaflet (locality based)

## **Verbal**

Support services

Word of mouth

Contact person – not necessarily PDNA/Professionals

Contact list

Appropriate contacts – expert patient or carer takes phone calls

Word of mouth – PDNS – Verbally

Support groups

PD Pathway – user prof guide

IPs should be extra not replacing verbal info.

Preference verbally always, but with backup of written to reinforce...

always need verbal.

## **Personalising**

1. Information prescriptions may be used by professionals (eg. for evidence-based information) or organisations (eg. for employment purposes), carers or patients. The issue of an IP may need to take account of who the user will be and their needs. Patients and carers in particular may need different information and they may prefer this to be presented in different formats, using different media. Access to and style of IPs should be adapted according to 'who wants the information'.

2. Individual differences in learning style suggest different structures to the material.

- *Structure from basic facts to more advanced*
- *Should we give all the information now or as each stage requires?*
- *Knowing a lot or a little*
- *As client appropriate – learning ability needs to be taken into account*

A suggestion was that the PD Nurse Specialist could co-ordinate information giving and tailor what is needed by asking patients and carers what they know and what they want.

3. Self management was not appropriate for all patients, some finding it easier to follow instructions rather than being proactive in the management of their condition.

4. People attending support groups or joining the PDS may differ in their self management style to those who do not (*'doesn't float everyone's boat'*). There was a concern that people who do not like groups would be missed out especially if they did not want to bother health professionals with questions. A way of giving permission to people to ask questions and facilitate their learning was needed.

5. Personalising requires materials be adapted to allow for ethnicity and disability.

### **Structure and Management of IPs**

Suggestions for the structure of IPs included:

- Developing an information Template
- Providing site addresses
- Signposting to topics – both PD specific and generic
- Having information ‘slots’ to accommodate locally relevant materials
- Ensuring local access, possibly at the outpatient clinic (‘a one stop shop’)
- Individualising and contextualising to tailor information as well as providing general information.

An information manager would be needed to maintain the currency and quality of information and to support individuals trying to access information.

- IPs would need to be started by referrers into a service, and thereafter provided by the person best equipped in the multidisciplinary team to provide information elements.
- Information given should be recorded in notes to ensure all members of the team knew what had been issued.
- The concern is that this would become a medically led process and steps need to be taken to ensure that patients have ownership of their own learning needs.
- To empower patients and carers they would need support to know what is available and to be supported in their learning by health professionals. This would require training of staff as the effectiveness of IPs may be dependent on the communication abilities of the person is at delivering them.

### **Where should this information come from?**

Information prescriptions could be issued at clinic visits, by a doctor, specialist PD nurse, or allied health professional, or by any appropriate health or social care professional in contact with the PWP. Where no specialist service exists, a GP, community matron or practice nurse may prescribe information.

The national PDS or a local branch could issue information prescriptions through their information support service.

## Quality Assurance

It was agreed that the person who has the correct information for the PD patient or carer should be able to issue an IP. But this raises the question about the credentials of the person issuing an IP.

Two suggestions were sign posting to accredited professionals or sources of IPs, or to have a kind of 'ringmaster' or information manager to co-ordinate and accredit issuers.

IPs should be dated and the issuer identified, and details of the way accuracy has been assured issued with the IP.

The procedure of issuing IPs should be monitored and reviewed, perhaps by carrying out a satisfaction survey.

Information should be dated and reviewed at regular intervals with review dates recorded as well.

Certain agencies could be accredited to dispense information rather than information itself being quality assured.

## Task Four - What an information prescription will look like.

- **What do you think an information prescription should look like?**

### Directory

Information prescriptions were conceptualised in one way as a directory in a quick look-up format with signposts to information, or prompts to help people identify information they might not know is available, or hadn't thought to ask.

*Where you can access information – signposted eg. About the Disease or support – different agencies in each area*

*Basic info pack – index by symptoms, or medication (eg.- description of medication by performance and date of production)*

*Mapping of all potential information*

*PD 'at your fingertips'*

*Something on the web – prompt of wants*

Information would need to be mapped to include condition specific information, relevant generic information, nationally applicable information and locally available information (to allow for variations in locally available services). This

could be categorised by stage of condition progression or by topic, or a staged access to each topic.

## **Passport**

Another format was conceptualised as a sort of information passport which was carried by the patient and information added to inform their journey through the care pathways.

## **Conceptual confusion**

It was unclear what was meant by an information prescription and there was some confusion between a prescription, passport, or actual information. Some form of definition was needed.

It was also important to identify who would initiate the information prescription. Would this be the health and social care professional or the patient or carer? This fits with different models of learning – a didactic, a problem solving model, or a self directed learning model where a portfolio of information is developed and new learning needs are identified by the PWP. These models may be useful, but there is a need to devise ways they would fit together and to consider the impact of their use on training health and social care professionals in the way IPs are used.

## **Format**

Personal contact was still regarded as essential, but an IP may help to locate a person who is expert in a specific area.

The internet is a useful tool, but there were concerns about its reliability and that this form of IP may not be readily available to all PWP.

It was important to provide choice of formats to be as inclusive as possible.

New technologies could be explored such as text messages or using mobile phones.

We should look at other services to see if they have models of information giving that would be of use – eg Look at stroke information pack

### **Impact on service development**

The PDS have provided a card to indicate services which may be important to PWP. This will have the effect of flagging up services that are not available to some people and which could be developed by the local service eg Clinical Health Psychology.

### **Member check**

This report was circulated to all stakeholders who were invited to comment. Two replies were received and commented that it represented views accurately and one carer commented that he did not agree that the meeting was 'not at the right level'. Other comments below were:

1. We were asked to include in the thematic analysis of task 2 that speech and language therapy helps with speech and voice problems.
2. The duplication of information for different stages of disease progression in task 2 may deter people from accessing information

## Appendix 1 - Programme

Information Prescriptions for people with Parkinson's disease and their carers

A stakeholder Event at  
Choppington Welfare Centre  
on  
13<sup>th</sup> April 2007 from 12 noon to 5pm

*NOTE: There are four tasks that we will be asking you to participate in over the course of the afternoon, it would be very helpful if you could look at these prior to the event and come with some ideas and thoughts on each of them. Thank you.*

### Programme

12.00	Registration and Lunch	SC & AH
12.45	Round table introductions	
12.55	Introduction to Information Prescriptions and the project	AH
1.10	<p>Task 1 –</p> <p>People with Parkinson's/ carers What information were you given when you were first diagnosed a year or two after diagnosis as your symptoms became more complicated (please outline when this was) How did you get hold of it? Who gave it to you? What format was it in? (eg a leaflet, website, other) How did you check if it was accurate and up to date?</p> <p>Professionals What information do you give to people with Parkinson's at what stage in their condition? How do you obtain this information? In what situation do you give it? What format was it in? (eg a leaflet, website, other) How did you check if it was accurate and up to date?</p>	
1.45	Feedback	SC & AH
2.00	Introduction to the four stage paradigm	AH

2.05	<p>Task 2</p> <ul style="list-style-type: none"> <li>• What are the top five things in each stage you would like information about/give information about</li> <li>• When/where would you want to get/give this information</li> </ul>	
2.40	<p>Feedback</p> <ul style="list-style-type: none"> <li>• Developing an information timeline</li> </ul>	SC & AH
2.45	Hand out evaluation forms - Tea	
3.05	<p>Task three</p> <ul style="list-style-type: none"> <li>• In an ideal world how would you like to give/be given information about Parkinson's Disease and other</li> <li>• Where should this information come from</li> </ul>	
3.25	Feedback	SC & AH
3.40	What might an information prescription look like?	HK Parkinson's Disease Society
3.50	<p>Task Four</p> <ul style="list-style-type: none"> <li>• What do you think an information prescription should look like?</li> </ul>	
4.15	Feedback	SC & AH
4.30	Next steps – what will be happening	SC
4.40	Feedback	SC & AH
4.50	<p>Plenary</p> <ul style="list-style-type: none"> <li>• Thoughts the project team can take home</li> </ul>	SC & AH
5.00	<p>Evaluation forms</p> <p>Close and Thanks</p>	AH