

INFORMATION PRESCRIPTIONS PILOT PROPOSAL APPLICATION FORM

Proposed pilot site	Northumbria Healthcare NHS Foundation Trust working collaboratively with the Parkinson's Disease Society of the United Kingdom
Contact information: Job title, name, address, telephone number and e-mail	<p>Dr Richard Walker, Consultant Physician Department of Medicine North Tyneside General Hospital Rake Lane North Shields Tyne & Wear NE29 8NH Phone: 0191 2932709 e-mail: Richard.Walker@nhct.nhs.uk</p> <p>Helen Kirrane Health Policy & Campaigns Officer Parkinson's Disease Society 215 Vauxhall Bridge Road London SW1V 1EJ Phone: 020 7932 1325 e-mail: hkirrane@parkinsons.org.uk</p> <p>Other members of project team</p> <p>Allan Erwood (Head of Information, Support and Education, PDS) Daiga Heisters (National Education Adviser, PDS) Clare Moonan (Health Policy and Campaigns Manager, PDS) Annette Hand (PD Nurse Consultant) Brian Wood (Consultant Physician)</p>
Please outline proposals for introducing information prescriptions and areas that you are proposing to cover (see section 7 of criteria document)	<p>An NHS/voluntary sector partnership to develop information prescriptions for people with Parkinson's and their carers in Northumbria, to provide:</p> <ul style="list-style-type: none">• Relevant information about symptoms and treatment options at all stages throughout the progression of the Parkinson's, from diagnosis to advanced stages, including end of life care• Information about how to access local NHS and social services• Signposting to local benefits services and support• Signposting to local and national sources of information and support, including the Parkinson's Disease Society (PDS) and local PDS branches/support groups. <p>The unique partnership combines the expertise of a nationally recognised Pd service – the service was mentioned three times as an example of good practice in the NSF for long-term neurological conditions – and a national patient organisation dedicated to supporting all</p>

people with Parkinson's, their families, friends and carers.

The project will have wider relevance for the development of information prescriptions beyond the Pd population to:

- people with long-term neurological conditions
- people with communication problems
- people with cognitive impairments.

Conditions/ care needs

Parkinson's disease (Pd) is a progressive, neurological disorder, affecting one in 500 of the general population, with prevalence increasing with age. It can affect all activities of daily living including communication, walking, and swallowing.

Due to the wide range of care and therapy options, people with Pd in particular require high quality information relevant to the stage of their condition to support self-management, and choice between therapy options and care packages.

Although the progression of the condition is highly individual to each person, in time people with Pd will require more intensive care and support, with many people eventually requiring admission to residential or nursing homes.

About 50 per cent of people with Pd develop problems with their speech and communication. In addition, people with Pd often experience difficulties with facial expressions, which may further hinder communication between them and health/social care professionals.

At least 40 per cent of people with Pd will develop dementia in the course of their condition, with more experiencing milder cognitive impairments.

Settings

We propose to develop a system for issuing the information prescriptions to people with Pd and their carers in primary, secondary and social care settings.

Processes to develop content

Content will be identified by external project worker overseen by a steering group composed of Northumbria Pd service and PDS staff, drawing upon and adding to existing information held by both organisations, as well as input by local voluntary Pd groups regarding benefits information and support.

The Northumbria Pd service has all the info/contact details of relevant health and social care services. In

addition local PDS staff and branches/support groups can add help with signposting to local services and other information of relevance to people with Parkinson's such as benefits services.

The PDS has a large range of publications and information sheets for people with Parkinson's in existence, from which relevant information can be drawn from. The PDS also operates a national free-phone helpline service and has a network of Community Support Workers across the UK delivering face-to-face information and support to people with Parkinson's.

The PDS will facilitate consultation with people with Parkinson's and their carers on a local and national level on content and format.

The Northumbria Pd team has experience of producing information support for people with Parkinson's and has developed a detailed Care Guide. The Guide comes in two separate editions: one for service users and one for professionals working with people with Parkinson's (GPs, doctors, nurses, therapists and social workers working in hospital and the community.) The Service User Guide contains information about the range of symptoms that people with Parkinson's will experience throughout the duration of their condition with references to more detailed information sources interspersed throughout and signposting at relevant points of members of the local Pd service.

Processes for issuing IPs

A wide variety of health and social care professionals are involved in the care of people with Pd at various points in the patient care pathway.

We envisage professionals including Parkinson's disease nurse specialists (PDNSs), GPs, physiotherapists, speech and language therapists, occupational therapists, neurologists, elderly care physicians, community matrons, social services professionals providing needs assessments, and so on would have the appropriate knowledge and skills to issue information prescriptions to people with Pd. Our pilot will explore the practicalities of involving these professionals in the issuing of information prescriptions in the course of their regular consultations/ patient contact.

We will explore through consultation with these professionals, people with Pd and their carers what form a template information prescription will take, taking into account:

- Providing information that is relevant to the individual, taking into consideration their symptoms

and stage of Pd

- The care settings in which Pd patients/care users are seen
- Patient/ care users' preferred format
- Both the professionals' and patient's access to technology
- Working with people with communication difficulties and or cognitive impairments
- Support for carers, especially for patients with cognitive impairments.

The project will seek to identify flexible formats in which to provide information prescriptions to suit individuals with widely differing information requirements, IT literacy level and communication needs.

Cost of delivering IPs

We do not envisage that delivery of information prescriptions will incur significant additional staff costs or time as they will be given in the course of existing patient consultations.

Printing/ IT costs need to be investigated, pending consultation with patients and professionals (above).

Impact on service users/carers/professionals

Information prescriptions will greatly help people with Pd and their carers to get accurate, relevant and integrated information about their condition, local services and support and empower people to make decisions about treatment options and care packages. This high quality and relevant information and signposting will help support self-care and the independence of service users.

Information prescriptions will support the educative role of health and social care professionals working with people with Pd by pulling together information relevant to the patient into one template. Prescriptions will also facilitate professionals to signpost patients to other relevant members of the multi-disciplinary team and social services.

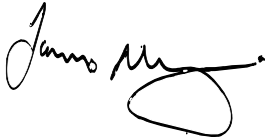
Support for people to use IPs

The project will help identify how information prescriptions can be adapted for people with widely differing symptom severity, communication needs and levels of comprehension.

The PDS has extensive experience of providing information and support to a wide variety of hard to reach groups including:

- Reaching isolated patients (both rural and individuals living on their own) through befriending schemes involving volunteers and partnerships (with local

	<p>community service volunteers)</p> <ul style="list-style-type: none"> • Black and Asian communities through work with local BME community and faith groups • Carers - through cares newsletters/ local groups within PDS branches • Care homes (it is a planned priority for the PDS in 2007 and beyond to focus on educating of care home workers through training sessions; DVD and distance learning.) <p>The PDS has a national network of approximately 70 Community Service Workers (CSWs) delivering face-to-face information and support to people with Parkinson's and their carers in their own homes. CSWs play a vital role in supporting people from hard to reach groups, such as people not able to leave their home without assistance and people in care homes.</p> <p>We propose collating and comparing existing practices of local PDS teams to identify the most successful approaches for a range of hard to reach groups.</p>
<p>Please give an overview of the project governance arrangements. Include clear identification of project management arrangements.</p>	<p>The project will be managed by the project team composed of PDS staff and professionals from the Northumbria Pd service (as named in box 1) who will appoint an independent and external project manager. The project team will act as a steering group, overseeing the work of the project manager.</p> <p>The project worker will follow the principles of project management tool, for example Prince2.</p>
<p>Please indicate proposals for providing data to the national evaluation organisation (including ethical clearance)</p>	<p>The project worker will develop a reporting mechanism on a monthly basis and at key milestones, including the results of consultation exercises. Northumbria Pd service will seek guidance from the Trust's workforce analyst to see if data can be sent to the DH using existing framework for data collection.</p> <p>Northumbria PD service will approach the local ethics committee for ethical clearance for the qualitative research.</p>
<p>Please provide a description of your proposals to:</p> <p>Work with stakeholders and partners</p>	<p>PDS and Northumbria Pd service colleagues will form a steering group, as outlined above to oversee the development of the project.</p> <p>The PDS can facilitate consultation with local PD Support Groups and with patients and carers nationally through its membership base. Consultation will include surveys and focus groups.</p>

<p>Develop a system for delivering information prescriptions in your area</p> <p>Identify the content for information prescriptions</p>	<p>The Northumbria Pd team will facilitate communication between the project worker and local health and social care professionals working in primary care and social services.</p> <p>The Northumbria Pd team consisting of:</p> <ul style="list-style-type: none"> • 3 consultant physicians, running a total of 7 different PD clinics (at Berwick, Alnwick, Morpeth, Wansbeck, Blyth, Hexham and North Tyneside) • 1 nurse consultant in specialising in Parkinson's, working Trust-wide • 3 Parkinson's disease nurse specialists (PDNSs) based at two different centres in the Trust <p>will initially deliver information prescriptions through outpatient appointments, nurse-led clinics and home visits.</p> <p>The project will expand to involve professionals working in primary and social care in the delivery of information prescriptions to people with Pd.</p> <p>Information prescriptions for people with Pd will include:</p> <ul style="list-style-type: none"> • Relevant information about symptoms and treatment options at all stages throughout the progression of the Parkinson's, from diagnosis to advanced stages, including end of life care • Information about how to access local NHS and social services • Information and signposting to relevant bodies to support self-management • Signposting to local benefits services and support • Signposting to local and national sources of information and support
<p>When do you anticipate that work will start?</p>	<p>The project team will advertise immediately for a project worker to start as soon as appointed. We envisage work will commence in March 2007.</p>
<p>Signatures:</p>  <p>Chief Executive Northumbria Healthcare NHS Foundation Trust</p>	

A handwritten signature in cursive script, appearing to read "Peter Lord".

Chief Executive
Parkinson's Disease Society