

Northumbria Pilot Site Parkinson's Disease Training Pack

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Script

Hello, this is [*your name*] and I am calling on behalf of Northumbria Parkinson's disease service following your recent request for information. Is this a good time to speak? [*If not, agree a time in which to phone back*]

Recently you requested some information about Parkinson's disease from Northumbria Parkinson's disease service, I am calling to get a better idea of what information you require.

Can I just confirm your name and date of birth?

You wanted information about [*information category or additional information details*]? *Explore in detail the user's information request.*

Confirm what information they have requested so far and ask if there is any other information they would like.

Most of the available information is in leaflet format, but some information is available in other formats, such as large print or audio, would you prefer the information to be in a different format?

Yes – Unfortunately, not all of the information leaflets are available in [XXXX] but I will check what is available and send you the information in this different format if possible. If the information is not available in [XXXX], I can forward your query to the Parkinson's Disease Society and one of their trained advisors will be able to talk through the information with you on the phone. Do I have your permission to forward your name and telephone number to the Parkinson's Disease Society helpline who will call you back regarding the information you require? Someone will contact you within the next X days. When would be the best time to phone?

Confirm method of delivery and postal/email address.

Someone will contact you within the next two weeks to check that you are happy with the information, see if you have any questions or would like further information. When would be the best time to phone?

How to use the directory/ what information to select

Navigating around PD directory

You can search for a particular word in the directory by using the 'Find' function in Excel. To access this function:

1. Press Ctrl + F
2. Click on 'Options >>'
3. Under 'Within', change 'Sheet' to 'Workbook'
4. Type the word or phrase in 'Find What'

Information categories in the directory

Benefits and financial – Information about what benefits and financial support patients and carers are entitled to. There is a link to the PDS rights & benefits information sheets with a general information sheet on rights and benefits ('Welfare Benefit General Information') or information on specific benefits and financial support if needed (e.g. Carer's allowance). It would be a good idea to provide the contact details for Disability North so that they can also speak to someone about benefits etc if they need to.

Carer/Family information – Information for the carers and relatives (e.g. children, grandchildren, teenagers) of those with Parkinson's disease. It also includes information and advice on sex, relationships, end of life matters, respite care and how to talk to your children about Parkinson's. Local support groups and the PDS helpline are also good resources for carers and relatives.

Overview of information resources – If service users would like to know about the range of information that is available, you can send the PDS Catalogue and Order form, which lists all the available resources (see PDF attached).

Planning for future – Information and advice on palliative care and end of life issues (e.g. making a will). In the directory this category is accessible in the more advanced stages of the condition, however, access to this information is not restricted for users in earlier stages (if they request it).

Practical advice – Information and advice on getting around (e.g. driving, transport) and everyday activities and issues (e.g. equipment and disability aids, employment). A good resource is the contact details for Disability North which allows them to speak to somebody about equipment, house adaptations and disability aids if they need to.

Self management – Information on how patients can help themselves to better manage their condition (e.g. with diet and exercise). The Keeping Moving video is a good resource – it is an exercise video for those with Parkinson's.

Branches and support groups – Information about what support the PDS can offer and local PDS support groups. A copy of the PDS's helpline leaflet

should be sent as standard with **every information request**. To search for a local support group:

- Use the link in the directory (or go directly) to http://www.parkinsons.org.uk/local_to_you.aspx.
- Click on '**Find a local branch**'
- You can either search by *postcode* or *region* (this will always be North East) and *County* (Should be either Northumberland or Tyne and Wear). The region and county function limits the search more than the postcode function.
- This will suggest a number of local PDS support groups so you may need to confirm with the service user which is the most convenient group for them.
- Read brief details to the patient (e.g. where they meet) and print and send the relevant web page.

Treatment & Care – This is a large category that includes information on a number of treatments, Parkinson's related symptoms, how Parkinson's is diagnosed, professionals involved in care and palliative care. The Drug Treatment and Parkinson's is a very popular leaflet which includes information about all Parkinson's related drugs, what they do, their side effects and general advice about medication.

Accessing local services

If users wish to access local services such as physiotherapists, dieticians, speech and language therapists, occupational therapists, psychiatrists, they will need to go through their local Parkinson's disease nurse specialist (email Kate Greenwell). If they need access to social services they can do so in two ways: (1) they can be referred through their local Parkinson's service (the procedure for this is provided in the directory) or; (2) self refer by phoning their local social services (telephone numbers provided in directory).

Selecting the right information

To avoid bombarding the service user with too much information, their specific information needs will have to be assessed over the phone. For example, if the IP form specifies that the user would like information on treatment and care, rather than sending the user every information resource from that category whether it is relevant or not, during the call you will need to find out what they would like to know about treatment and care (e.g. falls, hallucinations, palliative care). There will not, however, be a limit on the amount of information that a user can request or that you can send them.

Information in the directory is organised into stages of the condition in order to make searching for and recommending information resources easier. Access to information in other stages, however, is not restricted and is available to all if requested.

Within the directory of information there are a number of key materials, which are the most commonly requested items from the PDS. These are listed below.

Parkinson's and You: an introduction to Parkinson's disease

This booklet provides a good overview about the condition, its treatment and how it may affect their working lives and relationships for people who may have been recently diagnosed, and their family members, friends etc

Being There DVD

This DVD provides a good overview about living with Parkinson's, again for those who have been recently diagnosed, and their family and friends.

Moving On... for people who have had Parkinson's for some time

This booklet provides useful advice about all aspects of living with Parkinson's, for individuals who have been living with the condition for some time – ie people in maintenance through to complex stages - and their loved ones. This booklet has just recently been updated and become available.

The Drug Treatment of Parkinson's Disease

Booklet about different medications used in the treatment of Parkinson's disease

Planning for the end of life for people living with Parkinson's disease

Booklet for people with advanced Parkinson's and their loved ones, or people wanting to think through end of life care options

PDS Catalogue & Order form

The catalogue provides an overview of all PDS materials with pictures of their front covers (apart from information sheets and rights and benefits information sheets). This can be sent, with an order form which is separate, to anybody wanting an overview of what material is available. It will also be useful for NHS Direct staff to use to familiarise themselves with PDS publications. These have just gone to the printers and hard copies should be available by the end of this week, which I will put in the post.

Dealing with complex enquiries

Problem	Solution	Instructions	Contact Details
<ol style="list-style-type: none"> 1. User requests information that is not available in the directory 2. Information is not available in requested format 	Refer to PDS helpline	<ol style="list-style-type: none"> 1. Email the PDS helpline 2. Include the caller's name, contact details, the nature of the query, preferred time to call and what information (if any) you have sent to the patient. 3. Inform the user that the relevant team member will call the individual back within 2 working days. 	PDS helpline enquiries@parkinsons.org.uk
<ol style="list-style-type: none"> 1. Advice on their medication 2. Accessing local services (e.g. physiotherapy) 	Refer to Kate Greenwell	<ol style="list-style-type: none"> 1. Email Kate Greenwell who will refer to local PD nurse specialist 2. Include the caller's name, contact details, the nature of the query and what information (if any) you have sent to the patient. 3. Inform the user that you have referred their query to their PD nurse specialist who will contact them soon 	Kate Greenwell Email: Kate.Greenwell@northumbria-healthcare.nhs.uk Telephone: 08448118111 Ext: 2817
NHSD needs advice on what information to send to patient		<ol style="list-style-type: none"> 1. Use PDS catalogue of publications and products, which provides overview of all available materials and formats at a glance. 2. Look at PDS website which categorises information into themes 3. Call Kate Greenwell or PDS helpline for advice on what information to send. 	See PDF of catalogue attached http://www.parkinsons.org.uk/advice/publications.aspx Kate Greenwell Email: Kate.Greenwell@northumbria-healthcare.nhs.uk Telephone: 08448118111 Ext: 2817 PDS helpline 0808 800 03 03
Advice for callers who 'want to talk to someone'	Direct to local PDS branches/support groups, or helpline.	<ol style="list-style-type: none"> 1. If the caller wants someone to talk to about their Parkinson's, inform them about their local PDS branch or support group where they can share their experiences with other people with the condition/carers/family members. 2. Pass on details of the PDS helpline to the caller 	Find the local PDS branch http://www.parkinsons.org.uk/local_to_you.aspx PDS helpline 0808 800 03 03
Any other queries		Contact IP Project Manager	Kate Greenwell Email: Kate.Greenwell@northumbria-healthcare.nhs.uk Telephone: 08448118111 Ext: 2817

Communicating with people with Parkinson's via telephone

Communication challenges

People with Parkinson's can have a very quiet voice with poor articulation. They may require more time to form sentences and answer questions.

Communication difficulties can create a misleading and incorrect impression of the person being difficult, deaf, intoxicated or unintelligent. Misunderstandings arise due to a lack of awareness of these difficulties and many people with Parkinson's feel very socially isolated as a consequence.

About half of all people with Parkinson's have associated speech problems at the onset of their condition. As Parkinson's progresses, so do their communication difficulties. Often, but not always, the severity of their speech difficulties relates to the extent of their physical difficulties.

Speech can be:

- slurred
- monotonous with a lack of variation and expression in the voice
- hoarse and tremulous
- lacking or fading in volume
- disordered in rate and rhythm
- hesitant or difficult to start
- progressively faster
- unintelligible with very slow response

It is also recognised that people with Parkinson's have extreme difficulty with the following in a conversation:

- taking turns talking
- following a multiple topic conversation
- interjecting

As a result some people use minimal responses. This can heightens the incorrect perception of people with Parkinson's as unable to understand conversations or disinterested.

Tips for communication via telephone

The following do's and don'ts have been put together for health and social care professionals who may come into contact with people with Parkinson's, and not specifically for the NHS Direct staff involved in the project who will be trained to a high level in communicating with people with a range of health conditions. However these are tips worth considering when talking to people with Parkinson's over the telephone.

DO:

- keep all sentences short and precise
- encourage new ways of saying the message
- give them time

- make time to talk with them and give them extra time to respond
- try vocal techniques, such as suggesting the person with Parkinson's imagines that they are speaking in a bigger room than they are in
- ask them to repeat it in another way
- give them the opportunity to talk and encourage them
- talk normally
- listen carefully
- use short sentences and stress key words
- make sure they can see and hear you
- have patience and don't interrupt

DON'T:

- talk for them unless absolutely necessary
- repeat exactly what was said again and again
- interrupt when they are trying to speak
- insist that the person pronounces each word perfectly
- become irritated when the person cannot communicate
- encourage the person with Parkinson's all the time as it can be tiring for them
- isolate the person with Parkinson's
- pretend to understand if you have not
- finish the sentence for them
- speak above noise
- shout
- ask complex questions.
- ask their carer to speak for them, unless they wish this to be the case

In some instances carers will have an agreed strategy where they do all the talking to assist the person they live with. This can be misinterpreted as interference. Always try to find out from the person with Parkinson's if this is an acceptable coping strategy for them.

Examples of information requests

Example 1

"I have been recently diagnosed with PD, I have received no information at all, what do you recommend?"

Parkinson's Disease and You (P002)

Talking to your Doctor

PDS website – finding local PDS support group

Other suggestions: Being There DVD is a good resource for newly diagnosed patients

Example 2

"Does Sinemet have side effects?" "Information about incontinence" "Local support group" "Can I drive with Parkinson's"

Parkinson's Disease and Driving (B47)

PDS website – finding a local PDS branch or support group

Looking after your bladder and bowels

Drug Treatment of Parkinson's Disease

Example 3

"I need advice on equipment that will help my mother get around the house?" "How do I contact my local social services?" "What benefits are myself (as a carer) and my mother entitled to?" "What shall I do about work now I am caring for my mother?"

Signpost Patients to Local PDS – referral to Social Services

If they need access to social services they can do so in two ways: (1) self refer by phoning their local social services (Tel numbers provided in directory) or; (2) they can be referred through their local Parkinson's service (the contact details of the local PD nurse specialist are provided in the directory).

Disability North

Rights and Benefits Fact Sheets

The Carers Guide

Other suggestions: Equipment and disability aids sheet. If this query related to getting around outside of the home, you could send the Help with Getting Around sheet which covers wheelchair, driving and transport issues.

Example 4

"I am visually impaired, I would like information about the symptoms of PD, how it is diagnosed, drug treatment advice, how massage can help Parkinson's and how do I plan for the future"

Introduction to Parkinson's Disease - Parkinson's and You (audiotape)

Diagnosis and Scans Information

Complementary Therapy Drug Therapy in Parkinson's Disease (material in large print)

Other suggestions: This is a complex enquiry as not all information is available in large print or audio format. You could send the Being there DVD, Parkinson's and you in audiotape format (this covers symptoms and how PD is diagnosed) and the drug therapy leaflet in large print. The queries regarding complementary therapy and planning for the future should be referred to the PDS helpline. If the patient was not visually impaired, for planning for the future, you could recommend - planning for end of life/Choices: A guide to health and social care services (B079)/making a will, depending on what type of information they need.

Example 5

"I am Welsh-speaking, I have been referred to Northumbria Healthcare from my GP as I have suspected Parkinson's, what is Parkinson's and how do the doctors find out whether I have it or not?"

Introduction to Parkinson's Disease in Welsh

Other suggestions: This is a complex enquiry. Normally you would recommend Parkinson's and You and the Diagnosis and Scans information sheet, however, as these are not available in Welsh, you can send the Intro to PD leaflet in Welsh (as you have suggested). As this leaflet is not very detailed, it would also be a good idea to also refer this query to the PDS email helpline service (complex enquiry) and the relevant member of PDS staff will be able to deal with this. You will need to explain to the PDS what information you have already sent to the patient.

Example 6

"I am at the Advanced stages of Parkinson's, how can I help myself with diet and exercise? My wife is getting frustrated with me because she can't understand what I'm saying, what information can you suggest?"

PDS Support Groups - this would be helpful resource to provide support for any relationship problems they may be having as a result of the communication difficulties

Speech and Language Therapy – it would also be useful to provide contact details for a speech and language therapist (details provided in directory)

Communication

How can I help myself with diet and exercise information factsheets

Example 7

"I am at the Complex stages of Parkinson's, I don't know what information I want because I don't know what is out there"

I think this call would need further clarification, has he received anything so far, then you could look at all the options, there is a variety of information for the complex stage – reading out the information categories to the patient would be helpful for this

Other suggestions: Another suggestion is to send out an overview of the information resources available at that stage (General literature order form).