

Evaluation of Current Information Provision

Introduction

In order to evaluate current information provision and inform future development of the project, questionnaire data was obtained from health and social care professionals, patients with Parkinson's disease (PD) and their relatives and carers. This questionnaire data enabled us to assess the accuracy, accessibility and suitability of the information currently available and identify any information gaps or problems that exist in the current information provision service.

Methodology

Health and social care professionals questionnaires were distributed to health and social care professionals working throughout the Trust including GPs, PD Hospital Doctors, PD Specialist Nurses (PDNS), Social Workers, Physiotherapists, Speech and Language Therapists and Occupational Therapists. Patient and carer questionnaires were also distributed to patients with Parkinson's disease (PD) and their carers who are either members of the North East branch of the Parkinson's Disease Society (PDS) or patients at Northumbria Healthcare NHS Foundation Trust who attended outpatients in June 2007.

Main Findings: Health and Social Care Professionals

Health and social care professionals returned 18 questionnaires.

What information do you provide?

- Only a minority of respondents accessed information for patients or carers on a regular basis (11%).
- The majority of respondents provided information to people with Parkinson's disease verbally (94%) and in leaflet format (78%).
- Information was also provided in patient letters regarding what was discussed during their clinic appointment.
- Respondents access information from the PDS, other organisations relevant to their specific disciplines (e.g. speech therapy) and via EMIS.
- Most respondents were familiar with the PDS, regularly used the service to look up information and recommended the organisation to service users.
- 78% of respondents rated the information provided by patient organisations as high quality with no respondents rating that the appropriate information was unavailable or of insufficient quality.

- This suggests that health and social care professionals feel confident about the quality of the services provided by voluntary organisations, in particular the PDS.

Barriers to information provision

1. Responsibility of information provision

- Most respondents felt that it is the PDNSs main responsibility to provide information to service users, whereas some believed that 'everyone in the team has the responsibility to provide information to patients and carers'.
- Many respondents, especially the allied health and social care professionals, explained that they often did not provide information as they believed that may have already been provided by the PDNS:

'I would ask the patient to contact their PDNS or I would take their contact number/details myself and ask the nurse to make contact with them'
(Specialist Nurse Continence Service)

'I see client's generally when the PD team is involved so presume that all of the information side of things is being dealt with' (Community Occupational Therapist)

'I usually ask the patient if they have the info they want and signpost in the direction of the PDS or the PDNS as the leaflets are kept in their office. I rarely give any leaflets out' (Doctor)

- Many were uncertain about who's responsibility is it to restock the information resources and ensure they are up-to-date.

2. Limited time during consultations

- 50% of respondents believed that the main barrier to providing information was limited time during consultations.

3. Information provision is not a routine part of care

- For some respondents information provision was not a routine part of care and 67% believed that health and social care professionals only provide information if they are asked to do so by a patient or carer .

'It's a case of thinking about [information]' (GP)

'Only if the client raises [information] to me do I then look as to how best meet their queries' (Community Occupational Therapist)

- Those from non-specialist services, such as GPs or occupational therapists reported that they are rarely asked for information related to Parkinson's disease.

4. *Knowledge and skills regarding information giving*

- Some respondents expressed concerns over 'bombarding' patients with information, providing inappropriate or inaccurate information and reported a lack of awareness of what information is available and whether patients would find it useful.
- There were some information requests that respondents found difficult to deal with, such as welfare benefits, complementary therapies and issues of uncertainty (e.g. prognosis, cause).
- 72% of the professionals would find a training course on information provision useful.

5. *Accessibility of information resources*

- Accessibility of information resources was also a barrier to information provision.
- Only 33% reported that they would be able to provide the contact details of an organisation that can give them further information and support if requested.
- Only 44% reported that a stock of PD information resources was kept in their clinics/department.
- Respondents from non-specialist services reported that, as they are rarely asked for information about PD they do not stock related information resources.

The following barriers to accessing information resources were reported:

- Lack of storage space in clinics/departments
- Difficult to ensure information is up-to-date
- Stock often unavailable from publisher's distribution house
- Funding issues
- Many professionals are often working in the community or away from 'base' where the leaflets are kept (due to Northumbria's geography)
- For some professionals, stocking PD leaflets is not worthwhile as they rarely get asked for PD information

Summary of the results from the Health and Social Care Professionals questionnaire can be found in Appendix A.

Main Findings: Patients and Carers

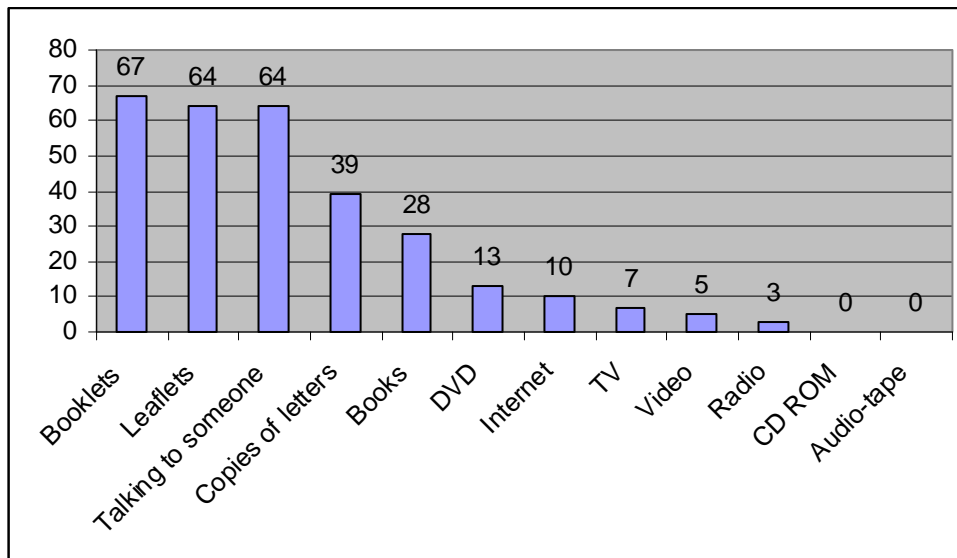
Patients and carers returned 39 questionnaires, with 3 returns from patients attending another service.

- In general, patients and carers were satisfied with the current status of information provision, however, there was some regional variability with patients and carers from other services reporting lower quality informational care.
- Several informational gaps were identified that the pilot must address.

Source of information

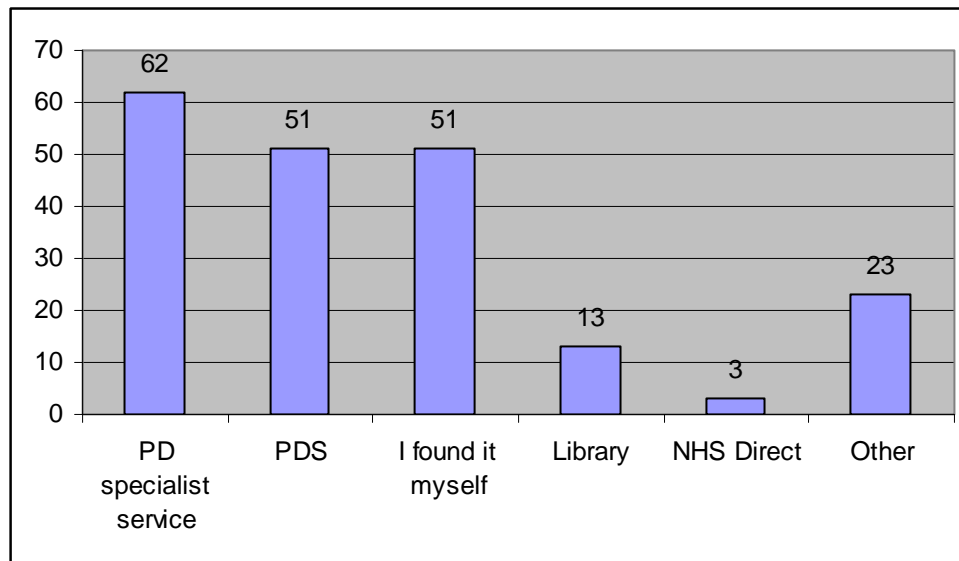
- The main source of information for patients and carers is by talking to someone (64%), leaflets (64%), booklets (67%) and copies of the clinician letters (39%) and rarely access information in alternative formats or via the Internet (10%). Figure 1 illustrates the main sources of information used by patients and carers in the past.

Figure 1. How have you been given information in the past (%)?



- Patients and carers mostly received information from the PD specialist service (62%) and the PDS (51%). 51% of respondents accessed information themselves. Figure 2 illustrates the how patients and carers accessed information in the past.

Figure 2. Where did you find or who gave you the information (%)?



A summary of the patient and carer questionnaire results can be found in Appendix B.

Conclusion

As Northumbria PD Service is a well established specialist service that provides patients with high quality information, it is unlikely that this project will improve the informational care of patients attending this service. However, by developing resources and exploring modes of information provision this project will help to reduce the variability in provision throughout the UK, especially where no specialist service exists.

Key recommendations:

1. Information provision needs to be a routine part of care with IPs being integrated into the everyday care of service users for all health and social care professionals.
2. IPs should offer a service that ensures that information is accessible to professionals, reliable and up-to-date.
3. IPs need to be recorded so that all professionals are aware of the information the patient has received and to avoid duplication.
4. Training on information provision would be useful for health and social care professionals.
5. Information prescriptions should be quick and easy to issue during consultations.

6. Information should be offered in a variety of formats including hard copy materials (e.g. leaflets), verbal information (e.g. health and social care professionals, helplines) and electronic information resources (e.g. Internet).

Appendix A – Health and Social Care Professionals Questionnaire

1. How do you provide information to people with Parkinson's disease? Please tick all those that apply.

Verbally 94% (17) Leaflet 78% (14) Tape/DVD/Video 11% (2) Website address 33% (6)

Contact details of a patient organisation 33% (6) Recommended reading 17% (3)

Other 22% (4)

Please specify

- Telling them about PDS and the PD team
- PDS leaflets/print offs from website
- Via PD nurse specialist, copy of clinic letter, referral

Any comments?

- By copying their GP letter to them
- Specific Speech and Language Therapy info – generally designed for the patient individually
- Recommend the PDS at diagnosis
- Use the mentor website
- This is what I would do but have never done this
- Usually at the time of diagnosis our patients get lots of information from their consultant/NS
- Referral neurologist

2. (a) Do you regularly provide patients with Parkinson's disease details of voluntary organisations and other support (for instance the Parkinson's disease Society)? Please tick the relevant box.

Very frequently 28% (5) Sometimes 50% (9) Rarely or never 22% (4)

2. (b) How do you find out about the patient organisations and their relevant contact details? Please tick all those that apply

Parkinson's Disease Society website/literature 83% (15)

Long Term Medical Conditions Alliance website/literature 11% (2)

Internet 33% (6)

Other 17% (3)

Any comments?

- Assume that this is mainly provided by the PDNSs
- Information held within our service
- I would ask the patient to contact their PDNS or I would take their contact number/details myself and ask the nurse to make contact with them
- PDNS
- Social services/local councils
- I rarely do this

3. If a patient or carer asks you for the contact details of an organisation who can give them further information and support, are you able to provide this information? Please tick the relevant box.

All of the time 33% (6) Some of the time 61% (11) Rarely or never 0%

Any comments?

- I would refer them to their PDNS
- If the patient is able to use the Internet I can always provide them with websites but sometimes have to give them phone numbers/addresses later when back at base.
- Via PDNS
- Usually suggest PDS as first port of call, but sometimes ask the patient to approach their PDNS/ask the PDSNS when in clinic about things such as insurance
- PDS main contact – also has helpline
- Never had to do this but would try the Internet
- Depends on information required

4. Overall, how do you perceive the quality of patient information provided by patient organisations? Please tick the relevant box.

Excellent 17% (3) Very good 61% (11) Acceptable 17% (3) Poor 0% Very poor 0%

Any comments?

- Varies between patients
- Have not really looked into it

5. (a) Do you keep a stock of information leaflets and other resources about Parkinson's disease in your surgery or department? Please tick the relevant box.

Yes 44% (8) No 39% (7) Sometimes 17% (3)

Other - please specify

- There are information leaflets in the PD office at NTGH

5. (b) Are there problems preventing you or making it difficult for you to keep a stock of patient information? Please comment.

- Difficulty to keep in clinic room as used for many other clinics
- At times information/leaflets run out – a lot of staff in our office accessing. Need to keep stock replenished, which is also up to date.
- A general department so not always appropriate to have
- Sometimes difficult to keep them up to date as this involves time to keep checking and changing the stock
- We are just starting a service (palliative care) and the numbers are small. Also there are problems with where we are doing OP – in the process of moving
- Northumberland's geography
- Space! Unable to stock all info as not enough space. Availability – obtain most info leaflets from PDS – not always stock available
- Is a case of thinking about it. In general practice only limited storage. Should be thinking about which LTC we should be holding information on in leaflet form as opposed to printing it out at the time.
- No, but its rare anyone asks for info
- We have electronic access to patient info leaflets, many of which have further useful addresses etc
- Can access info on Internet but often funding related issues regarding further patient info/leaflets
- Storage space

6. Do you hand out to patient and carers the leaflets listed below. Please tick the relevant boxes.

‘Parkinson’s and you: An introduction to Parkinson’s disease’

Very frequently 6% (1) Sometimes 22% (4) Rarely or never 33% (6) I was not aware of the leaflet 33% (6)

‘Join us: become a member of the Parkinson’s disease Society’

Very frequently 6% (1) Sometimes 17% (3) Rarely or never 44% (8) I was not aware of the 28% (5)

‘Resources for People with Parkinson’s, their families and carers’

Very frequently 0% Sometimes 22% (4) Rarely or never 33% (6) I was not aware of the leaflet 39% (7)

Any comments?

- Assume done by PDNS
- In most instances the patients have already been seen by the PD service and received the information
- Not really my role as I am not a specific PD therapist
- I usually ask the patient if they have the info they want and signpost in the direction of the PDS or the PDNS as the leaflets are kept in their office. I very rarely give any leaflets out.

7. Do you access information (about conditions, treatments, sources of help) for patients/ carers (for instance by downloading from websites or making a telephone call to request information)? Please tick the relevant box.

Very frequently 11% (2) Sometimes 44% (8) Rarely or never 44% (8)

Any comments?

- Often download leaflets from PDS website as easier and I know it would be up to date version
- Will go to a website whilst patient present
- Depends on patient’s desires for further information
- Download usually just from PD website for patients with no internet access

**8. What are the information requests from patients/ carers that you find difficult to deal with?
Please tick all those that apply.**

Prognosis 22% (4)

Treatment options 39% (7)

Welfare benefits 44% (8)

Sexual problems 17% (3)

Cause/ aetiology 28% (5)

Complementary/ alternative therapies 56% (10)

Other 22% (4)

- Advanced care planning
- A patient once asked me for information about co-enzyme Q10 as she had looked it up on the internet and wanted to take it
- Insurance/holiday advice about medication timings etc

Any comments?

- Information regarding the above is not necessarily difficult, it is addressed by the health professionals involved i.e. GP, PD service. In relation to sexual problems, the difficulty can be accessing the appropriate support they can assist.
- Some of the above are not asked to me directly – I would tend to get questions specific to my area of expertise – SLT
- These are often hard to address as often unknown (prognosis, treatment options, cause/aetiology)

**9. What do you think are some of the reasons why health and social care professionals sometimes do not give people information about their condition or where they can go for further help?
Please tick all those that apply.**

There is not enough time in the consultation 50% (9)

People can access information through the Internet/ NHS Direct 11% (2)

They do, but only if asked by patient or carer 67% (12)

The information currently available is not of sufficient quality 0%

Generally, there isn't any appropriate information available 0%

Other 28% (5) Please specify.....

Any comments?

- Information not readily available in clinic
- Not wanting to give inappropriate/inaccurate information
- Possibly do not want to bombard them with information – needs to be timely. Or because they think it is not their role to do so. I see client's generally when the PD team is involved so presume that all of the information side of things is being dealt with – only if the client raises it to me do I then look as to how best meet their queries.
- There isn't always up to date information available at their fingertips and having time to update it
- I think it's a timing issue, therefore when the consultation is busy only patients and families who highlight the issue are likely to get information they need. People generally may not know they need (or want) to know.
- Lack of awareness of what is available on the part of the Healthcare professional
- Is lack of awareness of what is good and helpful
- Usually provided by the hospital
- Need to increase awareness of local groups especially

10. What would be most useful to include in a web based toolkit to support you in providing information to people with Parkinson's disease? Please tick a box to indicate how useful each item would be.

	Very useful	Quite Useful	Not useful
List of helpline numbers	83% (15)	11% (2)	0%
Guidelines on breaking bad news	6% (1)	33% (6)	56% (10)
Signpost to latest research findings	33% (6)	56% (10)	6% (1)
Model policy for the organisation of information provision	17% (3)	56% (10)	28% (5)
List of training courses about providing information	28% (5)	44% (8)	22% (4)
Guidelines on communication with people who have speech and language difficulties	39% (7)	61% (11)	0%
Guidelines on communication with people who have cognitive impairments	56% (10)	44% (8)	0%

Any comments?

- Also about roles of other professionals and how to refer and when etc.
- Referral forms for other disciplines e.g. PCT, OT, dietician, SLT, SW, health psychology/counselling etc and the procedures for referral.
- Guidelines about benefits which may be available, advice about planning ahead
- Information on latest research findings probably only relevant to a minority of patients who would be interested in reading about this, but important as often the only source of info they have had up to then is the newspapers/TV which are not terribly reliable

11. Is there someone in the multidisciplinary team who has the main responsibility for providing information to patients and carers?

Yes 33% (6) No 22% (4) Don't know 44% (8)

If yes, what is there job title?

- PDNS
- We all have a responsibility but in terms of diagnosis, prognosis and treatment options – the Consultant and Parkinson's Disease Nurse Specialist
- I find that PD nurses tend to have provided a lot of info before I would have any involvement with the patient

Any comments?

- (PDNSs) Have initial, and subsequently more contact with patient
- Think anyone should if they feel it is necessary or the client asks. I think generally it is the medical team (the PD team) as they are often the first port of call and the ones who are seen as the ‘experts’
- I think everyone in the team has the responsibility to provide information to pts and carers, and if they can’t give it themselves they should know who to ask for it
- It is really the responsibility of all team members to provide information to carers, but if I had to point to one member, then I would say the PDNS as they are the main point of contact for the patient/carer and provide continuity for the patient
- Everyone has a responsibility to provide info

12. Is there someone in the multidisciplinary team who has the main responsibility for ensuring information resources are available and up to date. Please tick the relevant box.

Yes 22% (4) No 17% (3) Don’t know 61% (11)

If yes, what is there job title?

- PD Nurse Consultant
- Suspect it is administrative support and the PD nurse specialist who are doing this
- PD nurses and PD team
- PD nurses

Any comments?

- Think this should perhaps be a more research department or PR department for providing the up to date information but we should each be responsible for what we hand out etc.
- Anyone who finds information that is not up to date or is not available should take it upon themselves to locate an up to date version or ask for new supplies
- PD nurses, PD secretaries – they will print out leaflets etc/order info as instructed by the PD nurses
- Difficult to keep up to date over 100’s of different areas, especially if information in leaflet form – soon go out of date
- When we “run out” we order more or download info frequently from PD website

13. Approximately, how often is the provision of patient/ carer information discussed at the team/ multidisciplinary team meeting? Please tick the relevant box.

Once a month 0% Every six months 17% (3) Once a year 11% (2) Rarely or Never 22% (4)

Any comments?

- Do not know – do not attend regular multidisciplinary team meetings
- I don't attend multidisciplinary team meetings
- Work in the community so do not have these meetings
- Difficult to answer as not often at team meetings
- I don't know. I am on the edge of the PD MDT.
- I am not sure
- Discussed when we do pt surveys and at clinical meetings

14. Is there a discrete budget in your department for the provision of information to patients/ carers? Please tick the relevant box.

Yes 6% (1) No 28% (5) Don't know 61% (11)

Are there any other comments you wish to make?

- I work for a continence service providing clinic or home visits to PD patients referred by the PDNS or medical team
- There could be good ideas to learn from the stroke service as they have already established systems for giving information to patients and an information officer
- I think we need to think about a generic training programme for giving information and who gives what but at least a basic information giving programme for all so that whatever stage/health care professional is there – the same level of good info can be given. I think there is a presumption that GPs and nurses know what they are doing and know where to go for info. I'm, not sure this is the case!

Appendix B – Patient and Carer Questionnaire

Information about Parkinson's disease?	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
What is Parkinson's disease?	21% (8)	36% (14)	44% (17)	10% (4)	39% (15)	41%(16)	3% (1)
What are the signs and symptoms of Parkinson's disease?	15% (6)	62% (24)	23%(9)	8% (3)	56%(22)	26%(10)	3% (1)
How is Parkinson's disease diagnosed?	21% (8)	62% (24)	13% (5)	13% (5)	46%(18)	21% (8)	3% (1)
Which parts of the body and their functions are affected by Parkinson's disease?	26% (10)	56% (22)	18(7)	18%(7)	46%(18)	23%(9)	0%
Understanding problems with movement and mobility	26% (10)	41%(16)	31%(12)	10%(4)	49%(19)	13%(5)	0%
Understanding other problems not related to movement	33%(13)	49%(19)	13%(5)	21%(8)	49%(19)	10%(4)	0%
Information to help me choose the service I want to be referred into	54%(21)	33%(13)	10%(4)	28%(11)	23%(9)	15%(6)	0%
How do I access a specialist service?	39%(15)	31%(12)	23%(9)	23%(9)	15%(6)	28%(11)	0%

Information about how Parkinson's disease affects everyday activities?	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
Information about being able to work	46%(18)	18%(7)	5%(2)	18%(7)	10%(4)	3%(1)	33%(13)
Information about being able to carry out other activities eg housework, DIY, leisure	41% (16)	46%(18)	8%(3)	21%(8)	41%(16)	8%(3)	3%(1)
Information about driving	49%(19)	28%(11)	8%(3)	21%(8)	21%(8)	13%(5)	18%(7)

Is information available for:	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
People with Parkinson's disease at different stages of their illness	49%(19)	39%(15)	10%(4)	26%(10)	31%(12)	13%(5)	0%
The family	51%(20)	21%(8)	8%(3)	23%(9)	15%(6)	8%(3)	5%(2)
Young children	56%(22)	15%(6)	0%	18%(7)	13%(5)	0%	26%(10)
Carers	41%(16)	18%(7)	13%(5)	21%(8)	13%(5)	10%(4)	15%(6)

Who are the people and professionals who can help?	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
What are the roles of the health and social care professionals?	28%(11)	51%(20)	15%(6)	18%(7)	46%(18)	15%(6)	0%
Information about the Parkinson's disease society	21%(8)	41%(16)	33%(13)	10%(4)	39%(15)	28%(11)	3%(1)
Are there voluntary services that can help?	56%(22)	26%(10)	8%(3)	26%(10)	23%(9)	8%(3)	5%(2)
How can NHS Direct help?	74%(29)	18%(7)	0%	26%(10)	21%(8)	3%(1)	5%(2)
What a physiotherapist can do for me?	36%(14)	23%(9)	33%(13)	15%(6)	18%(7)	33%(13)	3%(1)
What can an occupational therapist do for me?	54%(21)	21%(8)	21%(8)	21%(8)	23%(9)	18%(7)	0%
What can a speech and language therapist do for me?	67%(26)	15%(6)	13%(5)	31%(12)	15%(6)	13%(5)	3%(1)
What can a dietician do for me?	77%(30)	10%(4)	5%(2)	39%(15)	8%(3)	8%(3)	5%(2)
What can a psychiatrist or psychologist do for me?	74%(29)	10%(4)	7%(3)	36%(14)	7%(3)	10%(4)	8%(3)

Information about taking care of myself	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
How can I help myself with diet and exercise?	33%(13)	44%(17)	18%(7)	21%(8)	31%(12)	23%(9)	0%
What can I do to reduce problems later on?	56%(22)	28%(11)	10%(4)	28%(11)	23%(9)	13%(5)	0%
How to recognise problems?	59%(23)	28%(11)	8%(3)	31%(12)	18%(7)	13%(5)	0%
What help can I get to help me adapt to my changing illness?	49%(19)	31%(12)	15%(6)	26%(10)	28%(11)	15%(6)	0%
How do I get the most out of a clinic appointment?	51%(20)	33%(13)	13%(5)	21%(8)	33%(13)	15%(6)	0%

Information about money	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
Where can I get help and advice about benefits?	64% (25)	21%(8)	3%(1)	23%(9)	18%(7)	7%(3)	13%(5)
Where can I get advice about financial issues and insurance?	72%(28)	10%(4)	0%	26%(10)	13%(5)	0%	18%(7)

Information about drug treatment	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
What types of medications are available?	18%(7)	49%(19)	31%(12)	15%(6)	36%(14)	36%(14)	0%
When should I start treatment?	23%(9)	46%(18)	23%(9)	15%(6)	36%(14)	31%(12)	0%
How do I monitor my own treatment?	44%(17)	41%(16)	10%(4)	21%(8)	39%(15)	13%(5)	0%
What are the side effects?	44%(17)	33%(13)	21%(8)	28%(11)	26%(10)	26%(10)	0%
How will I know if my treatment needs to change?	56% (22)	31%(12)	8%(3)	26%(10)	26%(10)	13%(5)	0%

Practical help and respite care	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
What kind of social care help is available for me to stay independent and living at home?	62%(24)	15%(6)	8%(3)	26%(10)	8%(3)	13%(5)	18%(7)
What are the reasons I might need to go into respite care?	72%(28)	13%(5)	3%(1)	31%(12)	10%(4)	3%(1)	15%(6)
How do I arrange respite care?	74%(29)	5%(2)	5%(2)	33%(13)	3%(1)	5%(2)	21%(8)

Information about planning for the future	I was given no information	I was given some information	I was given a lot of information	Information was not at all useful	Information was somewhat useful	Information was very useful	I did not want this information
How do I get support to come to terms with my changing role and relationships	74%(29)	13%(5)	3%(1)	28%(11)	8%(3)	5%(2)	13%(5)
How do you produce a living will or advanced directive?	77%(30)	3%(1)	0%	31%(12)	5%(2)	0%	21%(8)

Please **circle the words in the box below** that best describe **how** you have been given information – you can circle as many of the items listed as you require.

Leaflets 64%(25)	Booklets 67%(26)	Books 28%(11)
Copies of letters sent to you by health professionals 39%(15)		
DVD 13%(5)	CD ROM 0%	Video 5%(2)
		audio-tape 0%
TV 7%(3)	Radio 3%(1)	Internet or Websites 10%(4)
		Talking to someone 64%(25)

Please **circle the words in the box below** that best describe **where you found or who gave you** the information – you can circle as many of the items listed as you require.

Parkinson's Disease Society 51%(20)	NHS Direct 3%(1)	Library 13%(5)
Specialist service/PD nurse 62%(24)	I found it myself 51%(20)	other 23%(9)
Other - Newsletter, Questionnaires, All the information I have is from reading and talking to other PD sufferers		

Extra comments

- How do you produce a living will or an advanced directive – I would like to know this
- I based this information on when I was first diagnosed at a different hospital. Since transferring to North Tyneside I can't praise enough the amount of help and information I've received.
- I have had Parkinson's for 2+ years and during that time have gleaned information from family and friends, apart from the hospital staff and have noticed changes in my condition as the disease progressed. If I have needed any more information, I have asked for it. I have been encouraged to talk to professionals.
- I once asked about information, e.g. benefits, I was told I had to find out myself. Since then I am pleased to see/hear that there is more information available from the start.
- It was a research nurse that was informative and helpful with me and my wife by listening to us and giving us some books on Parkinson's. She was amazed we had no advice or information. Incidentally, this was at least 12 months after diagnosis. Even the first diagnosis given was incorrect, which was benign essential tremor, given after 2 years of testing. Our acting GP at that time was very supportive and helped.
- After having PD for 5 years and finding our own way to local PD group and information, Blyth OT gave us a big handbook of PD which has many aspects of information. We also gained a very informative PDNS.
- Answers to pages 1 to 7 have related to information at initial stages only i.e. diagnosis. As my illness progressed, more help i.e. PD nurses were available and much more information given. I also felt able to ask questions. Initially, it was an unknown area, even for my GP.
- After initial diagnosis, quite a lot was done by my own research. Without help of PDS services and PD nurse I would have had a breakdown. These were the prime movers – social services were abysmal and "passed the buck". GP was also most concerned and helpful (and helped monitor situation prior to PD nurses full involvement/coordination of services, personnel, telephone nos etc.
- The answers given relate to what happens on diagnosis 24 years ago – I hope it is much better now!