



Northumbria Healthcare
NHS Foundation Trust



Patient and Carer Experiences

Northumbria Healthcare NHS
Foundation Trust & Parkinson's
Disease Society Pilot

Helen Kirrane – PDS

**Kate Greenwell – Project
Manager**

Input from patients and carers

1. Stakeholder event
2. Surveys
3. Session with PDS volunteer support groups

Stakeholder event

Participating:

- People with Parkinson's
- Carers
- Healthcare professionals
- Social workers
- Information professionals (librarians, PDS Community Support Worker, NHS Direct staff)

Stakeholder event

Key comments from patient and carers

- Information good once seen by specialist team - improvements needed in areas without specialist service
- Little or no information received at diagnosis – patients left to look up condition on internet
- Written information not enough – want somebody to talk things through with, to answer questions etc
- Information required about how to access specialist services and social care; how to find out about local support groups
- Variety of formats required

Baseline Surveys

- To assess current information provision
- Patients and carers of the North East branch of the PDS and those who attended outpatients at Northumbria Healthcare NHS Trust
- Health and Social Care professionals
- In general, patients and carers were satisfied with the information provision at Northumberland PD service
- Those attending other services did not report such good information services
- The aim of this project is to reduce the variability between services

PDS volunteer support group meeting

- Importance of information/advice about employment, benefits, financial issues, carers entitlements
- Information days
- One-one advice most valued by patients/carers, written information of secondary importance
- Concerns about receiving information from non-specialists

IP Process with PDS

Prescribing IPs (Doctors/Nurse/GP/PDS
Community Support Workers)



Dispensing IPs from PDS Directory
(PD Service/NHS-Direct/GP via MoM)

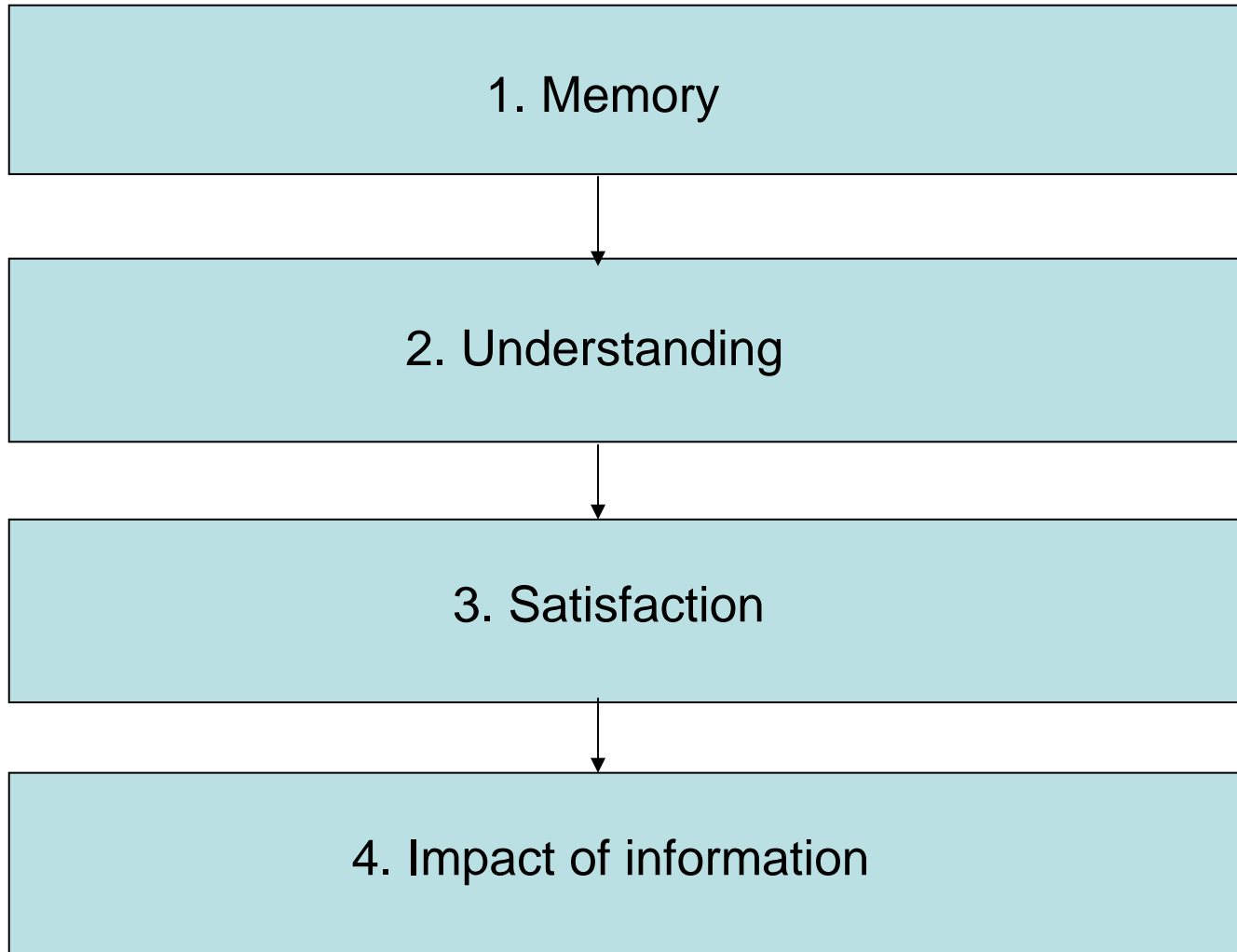


Follow-up phone call



Referral (PDS helpline, PDNS, social services)

Evaluation – Ley's model



1. Barriers to information

- Carer A: Can't remember asking for or receiving the information
 - Carer responsibilities – 'finding the time'
- Patient A: Did not receive the information
 - Importance of follow-up

2. Importance of 'someone to talk to'

- It is less important how the information is accessed as long as it is proceeded by an expert follow-up and one-one discussions if needed
- Follow-up phone call as routine
- Copy of IP in patient notes for follow-up during next consultation
- Referral to PDS helpline or contact with a community support worker regarding further information or clarification

2. Importance of 'someone to talk to'

- Patient B: Found the leaflet on depression quite complicated to understand which deterred him from reading it
- Very stressed at present and often finds it hard to read and take things in
- He felt it would be useful to have someone to talk to about the leaflet
- Difficulties in referring to psychiatry
- Referral to PDS helpline

3. Importance of format

- Patient C: Unable to read the leaflet as she is visually impaired and needs larger print
- Importance of asking for appropriate formats at point of issue

4. Importance of tailored and timely information

Users:

- Too much information early on can be upsetting and detrimental
- It is crucial that information is given by someone who is able to assess how much or how little information is required

4. Importance of tailored and timely information

- Patient D: Spent a lot of time on the internet prior to diagnosis to find out about PD and had felt overloaded with 'too much information'
- Felt she had to withdraw and stop looking ('I don't want to find out too much just now as I am at the early stages').
- She had been quite frightened by what she read and wasn't sure if it all applied to her
- IPs were a good way to receive information as she just wanted to get information as and when she needed it
- Patient B: Information was relevant to his needs at present and was given at the right time as he needed time to 'get settled' and 'squared up' following diagnosis.

5. Impact of information

Patient B:

- Before the information he was in 'no man's land' and found it had improved his knowledge of blood pressure and how to manage it
- He found the recommended exercises in the leaflet very useful and had followed the advice given in the leaflet

5. Impact of information

Patient D:

- Information didn't tell her anything she did not know already
- But it was reassuring to know that what she was doing was the right thing
- She felt as though there is a little group at the hospital looking after her and they are available if she needed someone to talk to

Summary

1. Importance of user involvement
2. Importance of training for IP dispensers
3. Barriers to information giving
4. Importance of having someone to talk to
5. Importance of right format
6. Importance of timely and tailored information
7. Impact of information



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