Centre for Disability Research
CeDR

Lancaster University

What information do people with learning disabilities want with their medications?

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Easy-read by Rebecca Fish

This blog is about the information that people receive about their medicine. The project was organised and paid for by the East Lancashire Clinical Commissioning Group (CCG).

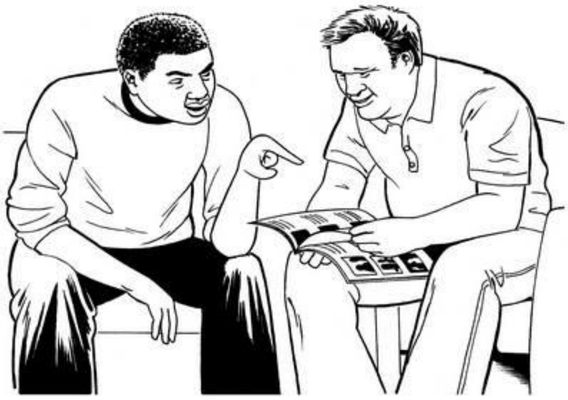
We wanted to find out what information people receive from their GP and Pharmacist about their medicines. We wanted to know if this information is good enough.

We got help from the people with learning disabilities at NWTDT and Pathways Associates to write the survey.

The survey was given to all the people who went to the North West Self Advocates Conference in Blackpool in February 2016.

Pathways Associates
Community Interest Company
TRAINING & DEVELOPMENT

The survey asked 5 questions:



- What information are you given when you get medicine from the doctor?
- Is it helpful?
- What else could the doctor do to help you understand your medicine?
- What information are you given when you get your medicine from the chemist?
- What other support would help people to understand their medicine?

58 people filled in a survey. Some were not fully completed, and some contained many different answers. We have divided the answers into how many people said the same thing.

Helpful Information received from GP

Half of the people said that they got helpful information from their GP. They said that they got information about when to take the medicine and how often. Some people said that the doctor took time to explain about the medicine and answer questions. A few people said that the doctor showed them how to take it.

This is what people said

- I am told how to take. When to take. What my medication is for.
- I am told the dosage, the days to take the medicine, how often to take the medicine and how it works in an easy to understand manner.
- My GP gets info up on his computer – he reads off the screen how much and how often – print out prescription with instructions. Just writing – no pictures or symbols, just tick boxes for free prescriptions.

Why is the information not helpful

Twenty people said that the information was not helpful. Some said they could not read it or understand it. Other people said they could not remember the instructions that the doctor told them. Two people said the information is given to their carer and not them.

This is what people said:

- He gives us the medicine. I can't read or write so then don't understand what's on it. He sometimes tells me but I don't always remember what's been said so ask friends or People First.
- Just gives me my new medicine does not explain well. Sometimes my support does not ask questions.
- No information really given, just what time to take them.

Information from Chemist

Most of the people received no information from the chemist. The people who got information said they just got a leaflet. Some people were told when to take medicine or how to take it.

Suggestions

This is what people said would help them:

Paper Information

Large print, easy read with no jargon, greater detail
Pictures or diagrams
Safety info, how not to overdose, what happens if not taken
Information about side effects and risks
Photos or videos of how to take it
Telephone helpline
Information about how to look after ourselves to avoid medicine

Face-to-face

Listen to patient, take time to explain, and answer questions
Support workers or families involved and informed
Verbal explanations with no difficult words
Explain why I need to take it and what it does to my body
Explain how the medicine works
Aids such as hearing loop, braille, sign language, interpreter
Talk to patient rather than carers
Explain about alternative medicines

Other

Regular reviews and health checks
Mobile alerts as reminder or a timetable
Label with space to write on

Some ideas

- Talk to me easier. Giving me pictures of when to take the tablets e.g. picture of sun = sunrise am x 2 tablets. Give me easy read info about what it is for.

- Make words bigger and easy-read. Spend time explaining things to me and not the support.
- Maybe having someone in the doctors who can sign because not all of us can hear very well.
- Support workers to check up how you are taking them and how often you miss them.
- I want to get the medication myself in the future. I want to be careful. I need things explaining to me.
- How to look after ourselves so we don't have to use our medicine for a long time / reduce amount.

Conclusion

This research shows that people do not get enough information with their medication.

There are many different places to find easy-read information on the internet. We think they should be collected and checked.

We also think that doctors and chemists need to spend more time with people to explain about medicines.

The Accessible Information Standard says that people should be given the information they can understand.

We wrote an article about this:

Fish, Rebecca, Chris Hatton, and Umesh Chauhan. **"Tell me what they do to my body": A survey to find out what information people with learning disabilities want with their medications**. *British Journal of Learning Disabilities* 45.3 (2017): 217-225.

You can find it here:

http://onlinelibrary.wiley.com/doi/10.1111/bld.12196/full

All pictures are from Change: www.Changepeople.org

CeDR Easy Read Summary 2018