

Learning disability and mental health: working in partnership with psychiatrists and carers

Introduction

This leaflet is aimed at:

- the carers of people with learning disability who provide continuing help and support, without payment, to a relative or friend;
- the doctors and other members of the team involved in the healthcare and treatment of a person with learning disability;
- paid care support workers offering direct support to people living in their own home or in residential care.

It suggests ways of improving communication and partnerships between carers, health professionals and people with learning disability and mental health problems.

For the carer

When a person with learning disability has mental health problems, carers may notice changes in their general health and well-being, and in their behaviour.

As a carer you may notice:

- changes in appetite or sleep
- loss of skills
- changes in behaviour or mood
- loss of interest in daily activities.

Finding out what is wrong

A lot will depend on how much the person can communicate about how they feel or any pain they have. Usually, careful observation by a carer who knows the person well is also needed. For this reason, the doctor will need to talk to a close relative, or regular support worker as well as the person themselves. Sometimes, it is difficult to know if the symptoms are due to a physical or mental health problem. The health professional will try to

understand the person's recent history, and any changes in their circumstances. They will consider all possible causes of their symptoms.

As a carer you will need to help the health professional distinguish between behaviour which is part of the learning disability, and any changes which make you think something else is the matter.

- Jot down the things you are worried about, or which have changed, however small they are.
- Make sure you write down the date and the time. A diary like this soon builds into a picture of how a person is changing.

It can help you decide what to tell the doctor. It can also help you detect their reactions to drugs or other treatments which might not otherwise be noticed. It can become a record of the whole illness, and this can be very useful if the person becomes ill again.

Tips for carers

In partnership with your doctor and the health care team

Good communication between a doctor, members of the health care team, the person with a learning disability and their regular carers is important, but it takes time and effort. In England, everyone with a learning disability is encouraged to have a Health Action Plan. The person can ask for help to decide what to put in their own Health Action Plan. They may need a health facilitator to work with them and their carers and/or paid support worker on what needs to happen to keep them healthy.

Sometimes, a family carer or support worker will be the health facilitator. Sometimes, it will be a

member of the community team for people with learning disability, or a health professional working in the general practitioner's surgery. A Health Action Plan may be about the support a particular person needs to keep healthy, or may be drawn up to support a planned hospital admission.

Questions to ask the doctor

- What does the diagnosis mean?
- Can you explain it in a way that we will understand?
- Are there any treatments?
- Are there other things we can do to help ourselves?
- Can these health needs be included in a Health Action Plan?
- What can we expect in the near future and over time?
- How often should we come and see you?
- Do you have any easy to read, written or illustrated material on this illness? If not, who does?
- Is there anything that we can change at home to make things easier or safer?
- Are there any organisations or community services that can help?
- Which health service worker is our main contact for guidance and advice?

Remember to arrange your next visit before you leave.

The following advice may help you prepare for follow-up visits to the doctor.

Before your visit:

- Keep track of changes in the person's behaviour and medication in a notebook, along with any concerns or questions that have arisen since you last visited the doctor.



- Look at all the information you have collected since your last visit. Ask the person you care for what they want to say to the doctor, or if they have things they would like you to discuss. Write down your top concerns in the diary with the date. Writing down this information means you do not have to worry about remembering it, and you can be sure to talk about the things that matter most during your visit. For example, this may include questions about:
 - changes in symptoms
 - side-effects of medicines
 - general health
 - mental and emotional health
 - carer's health
 - help needed.

During your visit:

- If you do not understand something, ask questions until you do. Don't be afraid to speak up. Do encourage the doctor to explain things directly to the patient in a language they can understand.
- Take notes during the visit. At the end, look over your notes and tell the doctor what you understood. This gives the doctor a chance to correct any information or repeat something that was missed.

Tips for carers – dealing with doctors

Doctors can be reluctant to discuss a person's diagnosis with their carer as there is a duty of confidentiality between a doctor and the patient. However, when the person who is ill is not able to understand what is happening, doctors usually recognise the need to involve the carer in discussions and decisions.

If the doctor is still unwilling to involve you as a carer, there are a

number of things you can do:

- Ask the person you are caring for if you can stay with them when he or she sees the doctor. If the person consents, then the doctor will probably agree.
- Talk with other carers as they may have some helpful suggestions.
- Try to talk to other health professionals, such as nurses.

For the professional

As a professional working with people with learning disability and their carers, we hope that the following is a helpful guide to good practice.

By the very nature of the job, family carers may be extremely tired. If they have been waiting a long time for an appointment while they care for a person, they may be emotionally exhausted as well.

- Remember that the family carer will know more about the patient when well than anyone else.
- The patient will have more difficulty in explaining how they feel, not just because they lack the speech, language or understanding in which to do it, but because they have always had a disability. They do not know what it feels like not to have it!
- It may be difficult for you to understand what is usual for them, and how their current illness is making them feel or behave differently. It's too easy to put everything down to their learning disability.

When doing an assessment, do you?

- try to see the person with learning disability and the carer separately, as well as seeing them together
- try to see them at home first

Do you allow enough time to?

- listen, ask, listen
- obtain a life history and a family history
- remember to ask about any losses, possible abuse or other traumatic life events
- leave time for questions and discussion
- explain how you arrived at a diagnosis
- talk about prognosis

In the management of the illness, do you?

- discuss possible treatments
- talk about the possible side-effects of drugs
- spend time asking about the carer's health – both physical and emotional
- discuss how to meet the health needs of both the person with learning disability and the carer

Points to remember:

- Everyone needs some respite.
- Make it clear that you will be happy to talk to any other members of the family.
- Tell everyone you see about voluntary organisations which can offer information and put people in touch with each other.
- Make it clear that you are always available.
- Give a telephone number where you can be reached for further questions.
- Make sure that there is a named professional person whom the family can contact at any time.
- When you write your letter to the general practitioner or specialist, send copies to the carer and an easy to read letter for the patient.
- Try to talk to other professionals on the telephone as well as writing.



Further Help

Mencap

123 Golden Lane, London EC1Y 0RT
Learning Disability Helpline 0808
808 1111

email: help@mencap.org.uk

Fax: 020 7608 3254; Minicom: 0808
808 8181;

www.mencap.org.uk

For answers to questions about
learning disability, go to
www.askmencap.info.

UK's leading learning disability
charity working with people with
learning disability and their families
and carers.

The Princess Royal Trust for Carers

Further information for carers is
also available from The Princess
Royal Trust for Carers. Tel: 020 7480
7788; www.carers.org.

Home Farm Trust

Merchants House, Wapping Road,
Bristol BS1 4RW

Tel: 0117 930 2600; www.hft.org.uk

A national charity supporting
people with learning disability and
their carers, and hosting the
National Family Carer Network,
which aims to bring together
organisations supporting family
carers of adult relatives with
learning disability.

The Royal College of Psychiatrists
has published a series of picture
books for use by people with
learning disability. Entitled 'Books
Beyond Words', these books are
produced to make communication
easier and enable discussion about
difficult topics. Tel: 020 7235 2351
ext. 146; www.rcpsych.ac.uk.

Health Resources for

People with Learning Disability

- To find out more about Health
Action Plans:
www.valuingpeople.gov.uk
- The Scottish Health Needs
Assessment for People with
Learning Disability is available
from www.phis.org.uk
- Information about health issues
for people with learning disability
is available at
www.intellectualdisability.info.
This website is designed for
healthcare professionals and
students.