Information for family carers of adults with learning disabilities coming into hospital

This leaflet concentrates on your role as a family carer, what you can expect and how to help and work with the hospital staff. This leaflet aims to help you make sure that the person you care for receives the right level of care while they are in hospital. Arranging for the person you care for to go into hospital may involve many practical arrangements.

Useful numbers and information to keep:

Consultant’s name:  
Name of ward:  
Ward Sister's name:  
Ward telephone number:  
Patient telephone (direct):  
GP’s name and number:  
Community Learning Disability Team:  
Care Manager:  
Named nurse:  
Other useful contacts:  

Working in partnership with the hospital

The concern for both you and the hospital will be to see that the person you care for receives the best available treatment and that their stay in hospital is as relaxed as possible. This will be achieved by the carer and hospital staff working in partnership, respecting each other's roles.

What should I expect from hospital staff?

- Recognition of your role and experience in caring.
- Understanding of your specific knowledge of the patient and their circumstances.
- Understanding that the situation is stressful for you and for the person you care for.
- A willingness to make you feel comfortable on the ward.
- Proper introductions to any staff treating the person you care for.
- Jargon-free, simple, clear explanations.
- Adequate time and privacy to discuss issues surrounding the health of the person you care for.
- Courtesy at all times.
What should hospital staff expect from you?

- A willingness to introduce yourself to staff to help them put a name to a face.
- A contact telephone number for you as a carer.
- Polite and courteous behaviour, however stressed you are.
- Respect for hospital rules, such as visiting times, washing hands, and numbers of visitors.
- Understanding that the person you need to speak to may not always be available.

How can I help myself?

- Consider taking a friend or family member with you to key meetings as it is sometimes difficult to remember what has been said or agreed.
- If you do not understand something, do not be afraid to ask for it to be repeated, explained or written down.
- It is not always easy to remember all the questions you want to ask. Write them down before you visit – space is provided at the back of this leaflet for you to write notes.

Caring for the carer

What about me?

The admission to hospital of the person you care for can be an extremely difficult time for a carer. Some feel that they are suddenly sidelined and worry that the standard of care will drop. Do not be afraid to voice your concerns to ward staff.

It may also be that the person you care for appears to adopt a different attitude to you when they are in hospital and can seem either rather distant, grumpy or angry that you are ‘leaving them’ in hospital. This is very common. However, it is distressing and it can be difficult not to feel guilty.

All of this can and does take its toll on your own health. Try to make sure that you eat and sleep regularly and that you have some time away from the hospital to clear your mind. This may be a good time for you to see your GP for a check-up.

If you feel you would benefit from having someone to talk to, there are a number of people who may be able to help. Speak to PALS, the hospital chaplains or telephone the Carers’ Helpline. The numbers are listed at the back of this leaflet.

Hospital Passport

The Hospital Passport gives hospital staff important information about the person you care for. It stays with the person by the bedside and should go with them when they attend for investigations, such as an x-ray and other appointments. Please complete the passport with the person you care for and bring it with you when they come into hospital. Copies of the Hospital Passport can be obtained from the learning disability nurse at the hospital and from the community learning disability teams.
Consent and caring responsibilities

How can I find out about consent?


A patient might seem unable to understand enough to consent to, or refuse, proposed medical treatment. They might seem unable to communicate their wishes. No one should assume, either carers or health care professionals, that a patient with a learning disability is not capable of consenting. No one knows better than you that if time is spent explaining the options simply, they may be able to reach a decision.

Friends and relatives cannot make decisions on behalf of patients who can’t decide for themselves. Even so, they may be able to tell health care professionals about the person’s opinions and beliefs – for example whether they’ve ever accepted or refused certain kinds of treatment, or if they have strong views about particular health conditions or treatments.

You should never be asked to sign a consent form on behalf of the person you are looking after. However you may be asked to sign a form to say that you have been consulted.

Refusing treatment in advance

Sometimes people may decide that they would not want a particular treatment if something happened to them in the future and they were no longer capable of refusing consent. This is sometimes called a Living Will. What if this situation actually comes about:

- If you know that the person you care for has taken such a decision in the past, you should tell the health care professionals caring for them.
- If the patient has signed a document in which they refuse treatment, you should, if possible, give a copy to the health care professionals.
- Health care professionals are bound by that earlier decision, even if you disagree with it.

How do I know what my responsibilities are while the person I care for is in hospital?

A high percentage of carers feel compelled to stay with the person they support to comfort and reassure them but also to ensure their safety and their needs are understood and met. Many carers feel that there is a lack of awareness amongst staff of the condition of the person they care for and that time pressures mean that staff do not attempt to communicate with the patients properly.
Some carers worry this will result in inadequate care, particularly with regards to food, mobility and toileting arrangements.

If you want to use the time while the person you care for is in hospital as respite from caring, you should feel confident that the staff have all the relevant information about the person you care for to care for them effectively. If the patient is unable to communicate for themselves, the staff will consult their hospital passport (if they have one).

If you want to participate in the care of the person you are caring for while they are in hospital, make clear what it is you wish to do and make sure it is recorded in the care plan. If you are happy to take an active part in the care, you can help with day-to-day care such as washing, shaving or help with meals. Staff on the wards are extremely busy and are generally very grateful for any assistance of this type.

Regular visitors can buy a car parking ticket valid for up to either 7 or 14 days. Ticket details and prices are available in the car parks.

**What should I expect to be given upon discharge?**

A patient may be discharged with medication, prescriptions or a copy of a letter for the doctor. It is a good idea to check with the nurse if any of these things are needed before the person you care for leaves the ward.

**Contacts/Further information**

Patient Advice & Liaison Service (PALS) 01223 216756
Learning Disability Liaison Nurse 01223 216133
Hospital Chaplains 01223 217 769
Cambridge University Hospitals NHS Foundation Trust (switchboard)
www.cuh.org.uk 01223 245151

**Carers Trust Cambridgeshire Crossroads Carer Service**

https://www.carerstrustcambridgeshire.org/contact-us
01223 596463 (Cambridge City)
0345 241 0954 (Cambridgeshire)
01733 645234 (Cambridgeshire – Peterborough)

**Learning Disability Teams**

0345 045 5521 South Cambridgeshire and Cambridge City Learning Disability (LD) Team
01353 652240 East LD Team
01354 750084 Fenland Community Team
01480 372356 Huntingdonshire Community Team

For information about benefits and support available for disabled people and their carers, visit the government website at
www.direct.gov.uk/en/CaringForSomeone/MoneyMatters
References

1. This leaflet has been produced with thanks to the Royal Berkshire NHS Foundation Trust – ‘Information for carers of people coming into hospital’ Leaflet (September 2009)

Privacy and Dignity

We are committed to treating all patients with privacy and dignity in a safe, clean and comfortable environment. This means, with a few exceptions, we will care for you in same sex bays in wards with separate sanitary facilities for men and women.

We are now a smoke-free site: smoking will not be allowed anywhere on the hospital site. For advice and support in quitting, contact your GP or the free NHS stop smoking helpline on 0800 169 0 169.

Other formats:

If you would like this information in another language, large print or audio, please ask the department where you are being treated, to contact the patient information team: patient.information@addenbrookes.nhs.uk.

Please note: We do not currently hold many leaflets in other languages; written translation requests are funded and agreed by the department who has authored the leaflet.

Document history

Authors
Pharmacist
Department
Contact number
Publish/Review date
File name
Version number/Ref
Karen Thomson
n/a
Cambridge University Hospitals NHS Foundation Trust, Hills Road, Cambridge, CB2 0QQ www.cuh.org.uk
01223 245151
August 2016/August 2019
PIN3368_carers_learning_disabilities_v2.doc
2/PIN3368 / Document ID 29971