Carers and confidentiality

Guidance to carers, family and friends about information sharing

A person holding a folder to a person

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Together we care better

Introduction

Providing healthcare is an essential partnership between patients, carers, families, social networks and professional care staff.

Sharing information is important to provide the best care to meet the needs of patients.

This leaflet provides guidance to carers, family and friends,

on how they can share information with staff at LPT, and how staff can share information with them.

**The key principle is that there are often limits to how much information staff can share, but carers, family and friends can share as much information as they like with staff.**

Who is a carer?

A carer is someone who spends time, with or without payment, providing help and support to a relative, friend or neighbour with illness, frailty or disability including mental health and substance use difficulties, who would otherwise find it difficult to manage [1]. Support may include helping with personal care, medication, shopping, housework, and emotional support.



Why is it important to share information?

The sharing of information is vital to the care and treatment of patients. Carers often provide valuable insights into the well-being of the patient. This can form an important part of an assessment.

The NHS constitution pledges to fully involve patients, families and carers in decisions about their individual care and treatment [2].

However, there are limits on how much information can be shared by staff, in order to protect patients.

The three C’s of confidentiality for carers.

Our partnered approach to providing the highest quality of care to all of our patients and carers is based on the principles of:

1) Confidentiality, 2) Consent and 3) Capacity.

What is confidentiality?

All NHS employees are bound by a legal duty [3,4] to protect and not disclose personal patient information (unless given permission to do so by the patient) such as:

* Address or date of birth
* Diagnosis
* Treatment or care plans

The Caldicott principles [5] guide staff on how to protect patient information. There is an emphasis on establishing a balance between maintaining confidentiality and keeping patients safe by sharing information.

What is consent?

Informed consent or agreement is required from patients, for them to receive care or treatment from LPT. For patients to be able to provide ‘informed’ consent, they need to understand exactly what is going to happen because staff have explained it in a way that is understandable.

In law, a person’s 18th birthday draws the line between childhood and adulthood. In healthcare decisions, an 18 year old has as much autonomy as any other adult. Like adults, young people aged 16 or 17 are able to decide on their own medical treatment, unless there's significant evidence to suggest they do not have the capacity to do this [6].

The rights of younger children to provide independent consent is proportionate to their competence. Children under 16 years of age who are able to make decisions about their assessment and treatment are referred to as being Gillick Competent.

A Gillick Competent child is a child who has attained sufficient understanding and intelligence, to be able to fully understand what is involved in the proposed intervention and is regarded as competent to consent to a particular intervention, such as assessment and treatment of a mental health difficulty/disorder.

The concept of Gillick competence reflects the child’s increasing development to maturity.

Key points of Gillick competence are:

* Competence may vary depending on type of decision
* Competence must be assessed for each decision
* Competence may fluctuate

What is capacity?

The Mental Capacity Act (2005) states that individuals aged 16 or over who have the ability to understand, weigh-up and communicate decisions have full legal capacity to make decisions for themselves. If someone is unable to do this due to physical or mental health difficulties, they are considered to ‘lack capacity’.

Sharing information with carers

Staff at LPT will ensure that you receive as much information as possible to help you in your caring role. Although they are bound by law and professional codes of conduct to uphold a duty of confidentiality to all patients, they can explain the information that can and cannot be shared.

If staff have the consent of the patient, they are able to provide information such as:

* Care plans
* Crisis management plans
* Medication details

Staff have the same duty of confidentiality to you as a carer in relation to any information you discuss. You can request that information is not shared with the patient.



Staff will document patient and carer preferences about information sharing on the electronic patient record.­

What issues arise in sharing information?

Sometimes it is not possible for staff to share information about the patient, for example when they wish to withhold information from the carer.

In some circumstances, there may also be other specific reasons for withholding information including:

* If there is any legal documentation in place to prevent sharing
* If any previous wishes are recorded which would prevent sharing of information
* If there are any safeguarding issues

These reasons must be respected by professional staff, but you as a carer may be informed of this decision.

When a patient “lacks capacity”

In some circumstances the patient might struggle to make decisions about the care that they are receiving, and care professionals will act in the patient’s best interests which may include sharing information with you as the carer.

How can information be shared with LPT?

LPT values carers’ views and perspectives. Information can be shared with any staff members including the patient’s lead professional or care co-ordinator. These members of staff plan and organise the range of support that patients get from different healthcare professionals.

Information that it can be particularly helpful for staff to be made aware of includes:

* Religious and cultural sensitivities
* Well established patterns of behaviour
* Historical information

The good practice checklist

The Royal College of Psychiatrists have designed a good practice guide about managing confidentiality and sharing information [7].

What if I have a comment, suggestion, compliment or complaint about the service?

We are always looking at ways to improve our services. Your feedback allows us to monitor the quality of our services and act on issues that you bring to our attention. To make a comment, suggestion, compliment or complaint:

* Discuss your concerns with the people directly involved in the patient’s care
* Complete a feedback form online by clicking the relevant tab on: [www.leicspart.nhs.uk/contact/feedback/](http://www.leicspart.nhs.uk/contact/feedback/)
* Telephone the Patient Advice and Liaison Service (PALS) on 0116 295 0830 or email them on [lpt.pals@nhs.net](mailto:lpt.pals@nhs.net)

References and further reading

1. NHSE: Who is considered a carer? Available From: <https://www.england.nhs.uk/commissioning/comm-carers/carers/>
2. The NHS Constitution for England. Available From: <https://www.gov.uk/government/publications/the-nhs-constitution-for-england>
3. Data Protection Act 2018. Available from: <https://www.legislation.gov.uk/ukpga/2018/12/contents/enacted>
4. NHSE Confidentiality Policy. Available From: <https://www.england.nhs.uk/publication/confidentiality-policy/>
5. The Caldicott Principles. Available from: <https://www.ukcgc.uk/manual/principles>
6. NHSE Children and young people: consent to treatment. Available from: <https://www.nhs.uk/conditions/consent-to-treatment/children/>
7. Royal College of Psychiatrists: Good Psychiatric Practice: Confidentiality and Information Sharing. Available from: <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2017-college-reports/good-psychiatric-practice-confidentiality-and-information-sharing-2nd-edition-cr209-nov-2017>

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