Confidentiality

A common sense guide for carers, family and friends

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Introduction
This guide about confidentiality is for carers, family and friends of people over the age of 18 receiving services from Oxleas NHS Foundation Trust.

The importance of sharing information with carers
We recognise that sharing information with you is vital to the care and treatment of the person you care for.

We will provide you with information about care plans and medication, and can advise you on managing an emergency, as this may help you to deal with difficult situations until other assistance is available.

Sharing information
Healthcare is a partnership between patients, families and health and social care professionals*. Sometimes there can be difficulties around confidentiality and sharing information. A patient's desire to withhold information must be respected by staff other than in some exceptional circumstances. In these circumstances staff will inform you. They will ensure that you receive as much information as possible to help you in your caring role.

* Please see note on page 7.

Staff will:
- discuss with the patient whether there is particular information they wish to withhold
- discuss the importance of confidentiality with you at an early stage and ensure that your views on information sharing are recorded
- explain to you what information can be shared and why some information cannot be shared
- explain that they are bound by law and professional codes of conduct and have a duty of confidentiality to their patients
- explain that some information may be shared without consent, for example information needed to safeguard children.

Staff will also explain that they will treat any information you give as a carer, confidentially.

How can information be shared?
Issues around confidentiality should not be used as a reason for staff not listening to you or for not discussing fully with patients the need for you to receive information so that you can continue to support them.

Even when the patient continues to withhold consent to share information, you must be given enough information to enable you to provide effective care. You will be given the opportunity to discuss any difficulties you are experiencing in your caring role with the patient's health and social care professional. This must happen from an early stage.
Giving out general information
Providing general information about the illness, emotional and practical support does not breach confidentiality.

General information can include:
- information about the condition and the behaviour it may cause
- advice on managing the condition, particularly in an emergency
- contact details of the health and social care professional
- background information on medication and possible side effects
- information about the care plan and what it involves
- contact details for local and national support organisations.

If the patient gives consent to share information
If the patient agrees to you being fully involved, you can expect to be:
- invited to participate in care planning meetings such as ward rounds, discharge meetings, care review meetings
- provided with details about the illness and treatment that they need to help them support the patient
- be actively involved in planning care, and where appropriate receive a copy of the care plan.

If the patient does not give consent to share information
If the patient does not agree to the care team sharing their information, staff can work with the patient to:
- lessen any concern they might have about sharing their information
- help them understand why sharing information with you will benefit them
- find out if there is some information they are happy to share and reach a compromise
- explain to you what kind of information cannot be shared.

Regardless of whether or not the patient gives permission to share information, you are always entitled to give information to staff. You can expect your views to be listened to and taken into consideration when making decisions about the patient’s care. Your right to confidentiality will be respected.

If the patient is unable to give consent
There may be situations when the patient does not have the capacity to agree to information being shared, for example when the patient has a learning disability, suffers from dementia or has had a stroke. In these circumstances, staff may disclose information about the patient only when it is in the best interests of the patient concerned to do so, or when there is some other lawful reason.
Sometimes it will be fairly obvious that staff should disclose information. For example, a doctor would need to tell you about what drugs a patient needs and the side effects. This is clearly in the patient’s best interests.

**If staff need to share information without the patient’s consent**

This will only happen after careful consideration of the situation and the degree of risk.

**Such information is needed, for example:**
- where there is a risk of serious harm or serious crime
- following request for information required by law, ie a court order
- in an emergency situation in which the patient or carer is involved
- where there is a risk to children.

Staff will only share the minimum amount required on a ‘need to know’ basis. The care team will explain to the patient clearly and fully the reasons why this was necessary and a note will be made in the patient’s clinical record.

If you feel that information has been shared unnecessarily, you can discuss this with the health and social care professional or team leader. You could also discuss this with the Patient Advice and Liaison Service (PALS). PALS can be contacted on: 0800 917 7159 or email pals@oxleas.nhs.uk

**How to complain**

You can make a formal complaint if you feel the health and social care professional, team leader or PALS cannot help by contacting:

Head of Complaints
Oxleas NHS Foundation Trust
Pinewood House, Pinewood Place
Dartford, Kent DA2 7WG
Tel 01322 625751

**Acknowledgement**

We are grateful to Northumberland, Tyne and Wear NHS Foundation Trust for their permission to use information from their leaflet ‘Common Sense Confidentiality, A guide for carers, family and friends’.

**Note**

* **Health and social care professionals** are qualified professionals involved in the patient’s treatment and care. There may be more than one professional involved depending on the patient’s condition.

**Here are some examples:**
- doctor
- nurse
- health visitor
- social worker
- psychiatrist
- community psychiatric nurse (CPN)
- occupational therapist.