

Confidentiality

A guide for families and carers



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Introduction

This factsheet offers advice and help to carers of relatives, partners or friends on how to understand confidentiality and information sharing issues. It sets out the standard of practice on information sharing that carers should expect from Cumbria Partnership NHS Foundation Trust.

As a carer you may be the only constant support in the person's life. It is therefore important you are given information that is relevant to the care that you provide. Carers should be given as much general information as possible about the illness being experienced.

Why information should be shared with carers

The sharing of information with carers is crucial to the ongoing well-being of both patients and carers. It is essential that carers are involved in important discussions about the care to be provided. When carers are given information about care plans and medication and advice on managing in a crisis, then they may be able to divert or reduce the impact of a difficult situation until other assistance is available. This is particularly crucial if this happens outside working hours.

What are the issues in information sharing?

Healthcare is a partnership between patients, families and professional care staff. The very sensitive nature of mental and physical health problems however, means that there can be particular difficulties in relation to confidentiality and the sharing of information. When a patient wishes to withhold information then these wishes must be respected by the professional staff responsible for the care. The carer must be informed whenever this is the declared wish of the patient. All staff working within the Trust are bound by law and professional codes of conduct to a duty of confidentiality to their patients.

Staff also have the same duty of confidentiality to carers under the Data Protection Act 1998, the Human Rights Act 1998 and the common law Duty of Confidentiality. Our staff are given clear guidelines on information that can be shared and how consent is discussed, obtained and recorded. Good practice is that confidentiality is discussed at an early stage and views on information sharing are recorded.

“I need to know what you are trying to achieve for my son and how you are planning to do it. I need to understand the treatment that he is receiving so that I can play my part in his recovery programme. What I do not need to know are the personal details of what takes place between him and the professionals concerned.”

(Quote from a member of Rethink whose son has a mental illness.)



How information can be shared

“Issues around confidentiality should not be used as a reason for not listening to carers nor for not discussing fully with service users the need for carers to receive information so that they can continue to support them. Carers should be given sufficient information in a way that they can readily understand to help them provide care efficiently.” (Department of Health: Developing services for carers and families of people with mental illness November 2002).

Even when the patient continues to withhold consent, carers must be given sufficient knowledge to enable them to provide care. Carers will be given the opportunity to discuss any difficulties they are experiencing in their caring role with the person’s healthcare professional. This must happen from an early stage. The provision of general information about mental or physical illness, emotional and practical support for carers does not breach confidentiality.

General information can include:

- information about the condition and the behaviour which may result
- advice on managing the behaviour particularly in a crisis situation
- contact details of the Care Co-ordinator or main healthcare professional
- background information on medication and possible side effects
- information about the care programme approach and what it involves
- contact details for local and national support organisations

To improve practice, the following approaches are also in place in the Trust:

- staff will help patients to distinguish between sensitive and personal issues (for example, about their sexuality) which are to remain confidential and more general information about the illness which can be shared
- issues regarding confidentiality will be recorded in the patient’s notes so that all staff are aware of any changes in the patient’s attitude regarding confidentiality
- the use of advanced directives will be encouraged. These allow patients to plan their care when they are well, explaining what they would like to happen if they become unwell.
- our staff will help service users to understand the benefits of sharing appropriate information with their carer
- the Care Co-ordinator or main healthcare professional will provide carers with the support and help needed on issues relating to information sharing and confidentiality
- carers must be encouraged to ask questions. Time must be made available to answer questions
- professionals will involve carers in treatment plans and in major decisions about the patient

Carers have the right to be given information on:

- background information about the condition and diagnosis, what behaviour is likely to occur and how to manage it
- medication – benefits and possible side effects local in-patient and community services the Care Programme Approach (CPA) local and national support groups and services for both carers and patients

Carers are helped to understand:

- the present situation
- any confidentiality restrictions requested by the patient
- the patient's treatment plan and its aims
- any written care plan, crisis plan or recovery programme
- the role of each professional involved in the patient's care
- how to access help, including out of hours services

Carers are given the right to:

- see a professional member of staff from the Trust on their own without the consent of the service user
- confidentiality when talking to a professional
- encouragement to feel like a valued member of the care team
- confidence to voice their views and any concerns that they may have
- emotional and practical support
- an assessment of their own needs with their own
- written care plan (if the patient has a serious mental illness or learning disability)

How to report concerns about confidentiality

The Trust takes the need to protect your personal information very seriously. If you feel that your confidentiality has been breached then you should raise your concerns through the Trust complaints procedure.

This can be done either by contacting the Complaints Manager in the **Patient Experience Team**: (PET) Cumbria Partnership NHS Foundation Trust, The Coppice, Carleton Clinic, Cumwhinton Drive, Carlisle, CA1 3SX

Freephone: 0800 633 5547

Landline: 01228 608257

Text: 07827 312 699

Email: PET@cumbria.nhs.uk

Or by writing to the **Chief Executive**, Cumbria Partnership NHS Foundation Trust, Voreda, Portland Place, Penrith, CA11 7QQ

Further information

For further information about the way information is used within Cumbria Partnership NHS Foundation Trust, please contact the **Head of Information Governance**, Cumbria Partnership NHS Foundation Trust, Maglona House, 68 Kingstown Broadway, Carlisle CA3 0HA.

E: information.governance@cumbria.nhs.uk

T: 01228 608998

The Patient Experience Team (address above) offers confidential information and advice for anyone with concerns, queries or suggestions about NHS services.

If you would like this factsheet in another language or format, for example Braille, large print or audio, please call:

01228 603890

E: communications.helpdesk@cumbria.nhs.uk

Or write to Engagement and Communications
Voreda House | Portland Place | Penrith | CA11 7QQ



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