

Sheffield Carers' and Young Carers' Information Leaflet on Confidentiality



Introduction

This guide about confidentiality is for carers, family and friends of people receiving services from Sheffield Health and Social Care Trust. It gives advice about how, why and when information can be shared.

It also recognises that a carer may be the only constant support in the cared for person's life. As such it is important that carers are given as much general information as possible about their cared for person's illness to help them in the care they provide.

The guide also recognises that fear about breaching patient confidentiality has frequently created a barrier to effective involvement of carers in health care, particularly in mental health.

(Sharing Mental Health Information with Carers: pointers to good practice for service providers; Briefing Paper, Department of Health – 2006)



Why it is important to share information with Carers

Information sharing is important because:

- ❖ Carers hold important information about the person they care for and this can be essential to the care and treatment offered.
- ❖ Sharing relevant information in a timely manner can have an impact on the wellbeing of both the carer and the cared for person.
- ❖ Agreement at an early date over information sharing can prevent problems from occurring later on.
- ❖ Carers being involved in discussions about the care being provided, such as care plans, medication and advice on managing in a crisis, means they are more likely to be able to respond appropriately if a difficult situation arises. This is particularly crucial if a crisis happens outside working hours.

What issues are there in sharing information?

The very sensitive nature of mental and physical health problems means that there can be particular difficulties in relation to confidentiality and the sharing of information. When a service user wishes to withhold information then their wishes must be respected by the professional staff responsible for their care. However, the carer must be informed whenever this is the declared wish of the cared for person. The care provided by Sheffield Health and Social Care Trust is a partnership between carers, service users and professionals but all staff working within the Trust are bound by law and professional codes of conduct with a duty of confidentiality to their **service users**.

Staff should:

- ❖ Discuss with the service user whether there is particular information they wish to withhold.
- ❖ Discuss the importance of confidentiality with carers at an early stage and ensure that carers' views on information sharing are recorded.
- ❖ Explain to carers what information can be shared and why some information cannot be shared.
- ❖ Explain that services are bound by the law and professional codes of conduct, and have a duty of confidentiality to their service users.
- ❖ Explain that some information may be shared without consent, for example information needed to safeguard children.
- ❖ Only disclose information about a service user when it is in the service user's best interests or when there is some other lawful reason. Such lawful reasons may include ensuring a carer's safety or the service user lacking the capacity to give consent (for example they may have a learning disability, suffer from dementia or have had a stroke).

Staff 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.



How information can be shared

Even when the service user continues to withhold consent, carers must be given sufficient information 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 cared for 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, the behaviour which may result and how to manage this.
- ❖ Advice on managing in a crisis situation.
- ❖ How to contact the main healthcare professional or Care Co-ordinator.
- ❖ Information on medication and possible side effects.
- ❖ Information about any care planning such as the care programme approach and what this may entail.
- ❖ Information about local and national support organisations.



"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." (Department of Health: Developing services for carers and families of people with mental illness, November 2002)

What Carers Need to Know

Carers should be informed about:

- ❖ **The present situation.**
- ❖ **Any confidentiality restrictions requested by the service user.**
- ❖ **The service user's treatment plan and its aims.**
- ❖ **Any written care plan, crisis plan or recovery programme.**
- ❖ **The role of each professional involved in the service user's care.**
- ❖ **How to access help, including out of hours services.**

Carers' Rights

Carers have a 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.**
- ❖ **Feel confident to voice their views and concerns.**
- ❖ **Emotional and practical support.**
- ❖ **An assessment of their own needs.**



Best Practice

In accordance with Sheffield Health and Social Care Trust's commitment to working in partnership with carers, recognising them and valuing them as experts in the care they provide, **Trust staff will:**

- ❖ **Support service users to distinguish between sensitive and personal issues which should remain confidential and more general issues which can be shared (e.g. about the illness).**
- ❖ **Record issues regarding confidentiality in service user's notes so that staff are aware of any changes.**
- ❖ **Encourage the use of advanced directives which allows service users to plan their care when they are well in anticipation of when they may be unwell.**
- ❖ **Support service users to understand the benefits of sharing appropriate information with their carer.**
- ❖ **Provide carers with the support and help needed on issues relating to information sharing and confidentiality.**
- ❖ **Involve carers in treatment plans and major decisions about the cared for person and give time for carers to ask questions.**
- ❖ **Understand that a parent may not want to inform their child of their condition to protect them; but be aware that the child will be taking on a caring role, at the minimum in an emotional capacity.**



Good Practice Checklist for Carers

Carers are given general factual information, verbal and written about:

- The mental health 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.

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- Any written care plan, crisis plan or recovery programme.
- The role of each professional involved in the service user's care.
- How to access help, including out-of-hours services.

Carers are given:

- The opportunity to see a professional on their own.
- The right to their own confidentiality when talking to a professional.
- Encouragement to feel a valued member of the care team.
- Confidence to voice their views and any concerns they may have.
- Emotional and practical support.
- A carers' assessment. An assessment of their own needs with their own written care plan (i.e. if the service user has a serious mental illness or learning disability).

<http://www.rcpsych.ac.uk/healthadvice/partnersincarecampaign/carersandconfidentiality.aspx>

Useful Resources

Information and leaflets are available from staff or to download from <http://shsc.nhs.uk/need-help/help-for-carers-and-relatives/carer-information/>

The following information is available from staff:

- ❖ Carers' and Young Carers'. How to Get Involved
- ❖ Carers' and Young Carers' Charter
- ❖ Understanding Confidentiality
- ❖ Need Help in a Crisis?
- ❖ Advocacy
- ❖ Carers and Young Carers Assessments
- ❖ Community Mental Health Teams
- ❖ Hospital Admissions and the Mental Health Act
- ❖ Understanding Mental Health Conditions and Medication
- ❖ Carers' and Young Carers' Checklist. Getting the Information You Need
- ❖ Useful Contacts: Services for Carers and Young Carers

Further information can be found on <http://shsc.nhs.uk/need-help/help-for-carers-and-relatives/helpful-publications/>

This information leaflet was designed in partnership with carers and young carers. The Trust worked collaboratively with Sheffield Young Carers Project, Sheffield Carers Centre and Chilypep to develop the leaflet and we would like to acknowledge their hard work, advice and support.

This information can be made available in a range of formats on request (e.g. Braille, audio, larger print, BSL, easy read or other languages). Please contact the service the person you care for uses to obtain a different format.

For Further Information Contact:

Sheffield Young Carers Project on 0114 2584595

www.sheffieldyoungcarers.org.uk

Sheffield Carers Centre on 0114 2728362

www.sheffieldcarers.org.uk

Carers Trust on 0844 800 4361 (local rate if calling from a landline, varies on mobiles)

www.carers.org



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