

# Carers and confidentiality in mental health

## Issues involved in information-sharing

*"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 serious mental illness)

### Introduction

This leaflet is about confidentiality issues which arise between mental health professionals and carers of adults with mental health problems, in particular those who provide on-going help and support, without payment, to a relative, partner or friend.

The issues of confidentiality and information-sharing between mental health professionals and carers are complex and difficult to resolve. Some of these problems are described, together with examples of good practice which may help address them, and hopefully provide more positive results for all concerned.

### Why is it important that appropriate information is shared with carers?

The sharing of information may be difficult, but is often crucial to the ongoing wellbeing of both patients and carers. If carers are excluded from important discussions and decisions involving the patient, this can have serious practical, financial and personal consequences for both the carer and the patient. Not being involved increases feelings of isolation, grief and loss which are common to many carers.

*"Her GP will not discuss her condition with me and I feel isolated from the situation, despite being her full-time carer."*

- The carer is often the one who knows the patient best. They may have regular, even daily, contact over many years, often with on-going responsibility for all aspects of the patient's welfare.
- The carer is often the only constant support in a patient's life, as friends lose touch and professionals move away. Many patients experience regular and sudden changes in the professional team caring for them. This can make the building of trusting relationships difficult and important information about the patient may be lost if the carer is not included in regular discussions.
- The changing nature of mental illness can cause sudden crises, often out of hours, to which the carer may have to respond. This can be very stressful as immediate and appropriate professional support is not always available. However, if the carer has knowledge and understanding of the crisis plan, they can often persuade the patient to follow it, for example by agreeing to contact their key worker or by taking the recommended medication.
- The wellbeing of the carer can be greatly improved if they are encouraged to feel part of a supportive team, with ready access to up-to-date information. Without

this, the carer may feel unable to continue giving the practical and emotional support that is so important to the patient.

### What are the particular problems in information-sharing in mental health?

In the long-term care of any patient, a wide range of people may be involved and usually information is exchanged freely between professionals.

Healthcare generally has increasingly been seen as a partnership between providers, patients and their families. However, in mental health there are differences of opinion about which information can be shared with carers. The sensitive nature of mental health problems means that there can be particular difficulties in relation to confidentiality and the sharing of information. Examples of the difficulties faced by professionals are:

- **ethical and legal obligations:** all professionals working in mental health services are bound by law and professional codes of conduct to a duty of confidentiality to their patients. A breach of confidence can lead to the professional facing disciplinary measures and legal proceedings, including being sued or dismissed.

*"I understand that if I am guilty of a breach of code of conduct on confidentiality, this could be regarded as gross professional misconduct and may result in serious disciplinary action being taken against me, up to and including dismissal."*



- **consent:** for the professionals, the most important issue is the agreement of the patient to the disclosure of information to the carer. Many patients and carers are unaware of this and do not realise that the patient must give consent before any information can be shared. Complex issues can arise when the patient is unable to give 'informed consent', for example at certain times during an acute episode or when the patient has dementia.

Carers may also face problems with information-sharing, for example they can be the first to notice worrying changes in the patient's behaviour or sleep patterns. The patient may not realise that they are ill and may not want professionals to be contacted. This can cause serious problems for the carer as the patient may interpret any action as a breach of their trust and confidentiality.

### **Barriers to the sharing of information**

Although there is a move towards involving carers as 'partners in care', there are still many reasons why they do not receive the information they need. For example:

- The patient does not consent to the sharing of information with the carer.
- Professionals involved in patient care have a duty to follow professional codes of practice, common law and statute regarding confidentiality.
- Some professionals worry that by involving carers more fully, they will not have sufficient time for their patients.
- At times of crisis, relationships can be strained and the family may be exhausted and stressed. The professionals may get a false picture of the true long-term situation.

*Mary lives amicably with her sister Carol. For the last two weeks, Mary has become increasingly manic with heightened activity and agitated conversations lasting well into the night. Carol finally persuades Mary that she needs professional help. By now they are both stressed, exhausted and angry. Mary tells the doctor she wants no further contact with her sister and doesn't want her involved in any discussions about her care. Fortunately, there was a note in Mary's records stating that, when she was well, she had given permission for information and decisions to be shared with her sister if she became ill again.*

- Members of the mental health team may never have received training in how to deal with complex issues, such as confidentiality, and how to address the different needs of the patient and the carer. Because of this, they lack confidence and so avoid giving any information, often citing confidentiality as the reason.

### **Examples of good practice which overcome these barriers**

*"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 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)

For a number of years, a large number of successful mental health teams throughout the country have involved carers in true partnership

with information-sharing. From their success have come the following examples of good practice:

- The issue of confidentiality is discussed with the patient at an early stage when they are not acutely ill.
- Issues regarding confidentiality are prominently recorded in the patient's notes to allow for continuity of care.

The following question is part of a NHS Trust's care plan documentation which is signed by the patient.

### **Has the patient requested any confidentiality restrictions?**

- The use of advanced directives is encouraged. These allow patients to plan, when they are well, what they would like to happen in the event of them becoming unwell.
- Professionals encourage patients to understand the benefits of sharing appropriate information with their carer.

*"When the issue of meeting his parents was raised with Tim, he said he did not want them involved. His key nurse on the ward took time to sit down to discuss his concerns with him. It transpired that Tim's main concern was that he would have to disclose the fact that he had taken drugs in the past. He was happy for other information to be shared, in fact, he was pleased that someone wanted to offer support to his parents whom he knew were finding it hard to understand what was going on."*

- Professionals involve the carer in treatment plans and in major decisions about the patient. Carers are seen as an asset and not a burden.
- Mental health teams reach an agreed confidentiality policy after discussions which help

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professionals, from all disciplines, understand their different concerns about information-sharing. In this way, they reach a policy which includes agreed principles for everyday practice.

***Because the team had concerns about issues relating to confidentiality, the team leader organised a series of training workshops facilitated jointly by a professional, a carer and a patient. A number of scenarios were drawn up highlighting particular common areas of concern relating to confidentiality; e.g. a son not wanting information shared with his parents; a wife making contact with a key worker, but not wanting the patient, her husband, to know she had done so; a father wanting to discuss his suicidal thoughts in a family meeting attended by his two young children; a mother not knowing whether to share her learning disabled son's history of childhood abuse. The scenarios helped team members to reflect on, and discuss, the issues involved – legally and ethically. They then had an opportunity, through roleplay, to try different ways of managing the situation and testing the outcomes of different approaches. At the end of the training sessions, a set of guidelines was drawn up to ensure good practice in relation to handling information-sharing.***

- Professionals are aware of the possible changes in personal circumstances, particularly in terms of long-term relationships between carer and patient, which can influence attitudes towards confidentiality.

***Stephen had his first psychotic episode when he was a student living away from home and insisted that his family was not told about this. After more episodes, he***

***gradually realised that he did need on-going help and support and went to live with his father. Together, they were able to find out about different treatments and access to psychotherapy.***

- If the patient has refused permission for information to be shared with the carer, this record in the medical notes is regularly updated so that all staff are aware of any changes in the patient's attitude regarding confidentiality.
- Carers are given the confidence to ask the right questions at the right time and are helped to realise that information-giving is a gradual and continuous process. The *Partners in Care* campaign has produced a checklist of questions for carers of people with mental health problems which is designed to help carers get all the information they need about the diagnosis and treatment of the person they care for.

***"I was so ill and agitated that I couldn't take in what the psychiatrist was telling me. I needed my partner with me so that she could make a note of all this new and scary information."***

- A member of the care team is identified as the right person to deal with specific issues, e.g. a care co-ordinator may have more time to explain a crisis plan to a carer than the psychiatrist.
- The patient and the carer are helped to distinguish between sensitive and personal issues (for example about their sexuality) which are to remain confidential, and more general information about the illness and its management which can be shared.

***People vary about what they regard as sensitive and confidential. A psychiatrist with 30 years' experience describes how she will always see the patient on their own, then the carer alone (with the patient's consent) and finally both together. In this way, she gets the maximum information from both the patient and the carer, learns what the sensitive and confidential areas are for them both and, what they are willing to share.***

- Even when the patient continues to withhold consent, carers are given sufficient knowledge to enable them to provide effective care. They are also given the opportunity to discuss any difficulties they are experiencing in their caring role and help to try and resolve these. The provision of general information about mental illness, emotional and practical support for carers does not breach confidentiality.

**Good practice checklist**

**Carers are given general verbal and written factual information 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

**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 opportunity to see a professional on their own
- The right to their own confidentiality when talking to a professional, unless disclosure is essential to the patient's care
- 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
- An assessment of their own needs with their own written care plan (ie if the patient has a serious mental illness or learning disability).

Trust is essential in good care. Confidentiality issues between patients and professionals, carers and patients, and carers and professionals need to be explored and debated.

Carers will differ in the quantity of information they want, when they want it and from which member of the mental health team they receive it. Many will get information directly from the patient, most will gain it gradually and some will have access to general information outside the local care team.

If information is not shared, as well as frustration and anger at being excluded, there can be serious consequences:

***"When my daughter was discharged from hospital, I was given no information or advice on***

***how to help her with her on-going problems with anorexia. I could see that she was becoming dangerously thin, but I had not been given any information about her eating plan or what to do when she told me that she didn't have to eat certain food. I felt she was manipulating me but I had no one to turn to for support or guidance and was despairing of her future."***

**Partners in Care campaign**

This leaflet has been produced as part of a year-long joint campaign between the Royal College of Psychiatrists and The Princess Royal Trust for Carers (2004).

One of the main aims of the campaign is to show that if all those involved in the care of people with mental health problems and learning disabilities can work together, a trusting partnership can develop between carers, patients and professionals which will be of benefit to all.

***"Good practice is built on partnerships – not only between doctor and patient, but between patient and carer and between carer and doctor"***

**Dr Mike Shooter, President the Royal College of Psychiatrists**

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Further information about the campaign can be downloaded from [www.partnersincare.co.uk](http://www.partnersincare.co.uk).