

# Information for Carers

## Confidentiality

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**It is unfortunately common for family members who wish to discuss their relative who has a mental illness with a psychiatrist or other member of the mental health team to be told that this is not possible because of 'patient confidentiality'.**

The family may wish to provide information they believe would be helpful for treatment or which might prevent a worsening of their relative's condition. Or they may wish to offer care or seek advice to help them cope better with the impact of the illness on themselves, other members of family or friends. Carers may lack basic knowledge about the illness, or not know how best to deal with burdensome behaviours; they may not even know to whom they can turn for help.

If a person expressly bars contact with the family of carer, mental health professionals often find it difficult to decide when to breach confidentiality.

### **Advice to carers: Ways of approaching the problem**

#### **1. Get early agreement**

Get early agreement with your relative or friend and the treatment team. We suggest that much can be achieved in avoiding later dilemmas by setting out with the treatment team at the earliest possible stage an agreement about confidentiality. This is best done when your relative is reasonably well and able to participate with you and the treatment team in a meeting, spelling out the circumstances under which discussions with you can take place, and what information can be exchanged.

For example, there might be agreement that if the person shows particular early warning signs of becoming ill again, the treatment team can discuss this with the carer so as to reduce the likelihood of further worsening. It could also be agreed what help the carer might require from the treatment team on an ongoing basis in order to cope better with their relative's illness.

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## **2. Learn how to discuss disclosure**

Learn how to discuss disclosure against your relative or friend's wishes when it might be in their 'best interests'. As mentioned above, there is no consensus about the seriousness of the harm that justifies disclosure.

We suggest that carers can help mental health professionals to think through the issues at stake. Try to discuss the following questions:

Does your relative have the 'capacity' to make treatment choices? Carer involvement can be seen to be a 'treatment choice'. 'Capacity' involves a person's ability to :

- understand the nature of the treatment being offered including the likely consequences of having or not having that treatment
- appreciate that he or she suffers from a disorder (or at least a problem affecting their mental health) requiring treatment or special help
- reason with the information they now have about their illness and treatment

If your relative or friend had serious difficulty with any of these, they could be regarded as lacking capacity.

If this is so you might want to put forward to the treatment team a further set of considerations, such as the following, to guide them in deciding whether maintaining confidentiality is in your relative's best interests.

- What is the nature of seriousness of the harm faced by your relative and the probability of it occurring?
- Are there alternatives available that might reduce the likelihood of harm? Other people or helping agencies, to whom your relative does not at this stage object, may be able to reduce the risk of harm.
- How would contact with you or another family member or friend against your relative's wishes be likely to be received by your relative? For example, a close family with good relationships but which the patient, as the result of a psychotic illness, see as rejecting might be regarded differently compared to one with long-standing disharmony. There might have been previous discussion with the patient implying that contact would be acceptable under the current circumstances. It might also be asked whether the patient, following recovery, would be likely to see family involvement as having been, after all, desirable.

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- Is the principle of the 'least restrictive alternative' relevant? Will your involvement reduce the likelihood of even greater restrictions on your relative's freedom becoming necessary (e.g. later involvement admission to hospital)? This principle is implied in certain circumstances, as in the requirement to consult the nearest relative before compelling admission under some sections of the Mental Health Act in England and Wales.

By talking through these issues with the mental health team, reasons for breaching or not breaching confidentiality should become clearer to all.

Learn how to discuss disclosure against your relative or friend's wishes for the sake of the well being of other family members. At present probably few clinicians would agree to involve the family against a person's wishes out of concern for the family's well being (short of serious, usually physical danger). This seems unfair to families and friends struggling with enormous difficulties as a result of the illness.

### **3. Ask about 'duty of care'**

Ask the clinician whether he or she might have a 'duty of care', although with some limitations, towards carers, over and above that to the patient. Until recently, this question has been largely ignored. However, there is now a trend towards the recognition of the interests of carers and this is likely to grow in parallel with the expanding role of informal carers as members of the 'care team' in the community.

## **'Carer status'**

We suggest there is now sufficient recognition of a special carer status (with its associated rights) to argue that information necessary for carers to cope adequately with the demands placed on them should be made available. This has been reinforced by one of the standards set by the National Service Framework for Mental Health published in 1999. This framework sets out the standards the Department of Health expects from its mental health services. It states that all individuals who provide regular and substantial care for a person on the Care Programme Approach should:

- Have an assessment of their caring, physical and mental health needs, repeated on at least an annual basis
- Have their own written care plan, which is given to them and implemented in discussion with them

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How traditional notions of confidentiality will fit with this is unclear. There is a footnote stating that 'the service user's consent should always be explicitly sought before information (about medication, other treatment and care) is passed on to their carer and that 'if the service user is incapacitated, information may be passed to the carer if it is in the service user's best interests'.

Whatever the interpretation, the standards set in the National Service Framework provide new opportunities for carers to talk to professionals about their situation in new ways. These should be grasped.

## **How professionals think about confidentiality**

Carers should first understand how professionals think about the problem. They regard listening to carers as good practice; trainee psychiatrists are usually taught that an assessment of someone's mental health is incomplete until they have consulted another family member or friend for more background information; for example, what a person was like before their illness started.

On the other hand, for doctors, confidentiality is a basic aspect of their relationship with patients. Confidentiality is based on:

- Privacy, which is in turn related to the notion of respect for the person - people have a right to decide how information about themselves should be shared with others.
- Public interest - good medical care requires patients to be frank to enable the doctor to make an accurate diagnosis and plan treatment; if patients could not trust clinicians to keep 'secrets', honesty would become less likely and this would undermine medical care.

## **Guidelines**

Principles governing confidentiality for doctors can be found; for example, in guidelines produced by the UK General Medical Council (GMC):

'You must respect requests by patients that information should not be disclosed to third parties, save in exceptional circumstances (for example, where the health or safety of others would otherwise be at serious risk).'

The GMC guidelines state that disclosure may be made in the patient's medical interest if;

*'You consider that a patient is incapable of giving consent to treatment...and you have tried unsuccessfully to persuade the patient to allow an appropriate person to be involved in the consultation. If you are convinced that it is essential in the patient's medical interests, you may disclose relevant information to an appropriate person or authority.'*

Disclosure may be made in the interests of others '..where a failure to disclose the information may expose the patient, or others, to risk of death or serious harm'.

These guidelines, and similar ones for other health professionals, seem to set a high threshold for disclosure by speaking; for example, about serious harm. In the mental health arena it is not entirely clear what is meant by such terms and the profession involved have not reached a consensus in their views. Most would agree that a risk of death or serious physical harm, either to the patient or to others, would clearly justify a disclosure aimed at preventing such harm.

## **Legislation**

Some recent legislation in the UK and abroad has recognised a formal status of 'carer'. For example, in England there is a need for carers to be consulted, with or without the patient's consent, before a 'Supervised Discharge Order' under the Mental Health (Patients in the Community) Act (1995) can be implemented. Guidance from the Department of Health concerning the protection of patient information is unfortunately inconsistent over the question of whether or not carers are members of the patient's 'care team' in the community and so entitled to information relevant to the team providing that care.

**Source: [www.mentalhealthcare.org.uk](http://www.mentalhealthcare.org.uk)**

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