

Confidentiality and information sharing

For carers, friends and family

Confidentiality is a subject which can cause frustration for carers, friends and family. Carers are sometimes denied information about the person they care for because of confidentiality policies, and this may affect their ability to provide effective support. This factsheet considers the effect of the law of confidentiality and how the problems it can cause carers might be resolved.

In this factsheet, we have used the word 'carer' to refer to friends, relatives or people actually providing care.

KEY POINTS

- Unless a person consents, confidential information about them cannot be passed on to others except in very limited circumstances, such as where it is required by law or where someone would be at risk unless the information were shared
- In Rethink Mental Illness's experience, some staff in the NHS and social services refuse to talk to carers under any circumstances, and this should not be the case. Professionals are able to listen to carers' concerns and take them on board without breaching confidentiality.
- A nearest relative does not have a general right to information about a person detained under the Mental Health Act 1983
- To overcome information sharing issues, the service user can draw up an advance statement about what information they would like shared with carers or relatives if they become unwell in the future

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1) The duty on professionals

The law of confidence protects people from having their personal information shared against their wishes. If a person gives private information to another person or organisation and reasonably expects that information to be kept confidential, they can take legal action for any loss they suffer if this information is passed on without their consent.¹ The threat of possible legal or disciplinary action may cause staff in the NHS and social services to be wary about disclosing personal information about patients and service users.

Doctors have a duty of confidentiality to their patients. It is set out in their professional codes and based on the law of confidence.² Generally, personal information may only be disclosed, even to a person's close family, if he or she consents. But this duty of confidentiality can be breached if there is a strong need to do so in the 'public interest' or in the interests of the patient. A doctor may choose to breach confidentiality if there is foreseeable harm to a patient or to others, like a significant risk of suicide. There are also other circumstances where a doctor will be allowed by law, or even have a legal obligation, to provide information about a patient.³

Similarly, the British Association of Social Workers' ethical guidance⁴ states that personal information given to social workers by service users should be kept confidential and only disclosed where this could be in the public interest, where there is risk, or where there is a legal obligation to disclose.

In practice, this means that a professional will normally abide by a patient's wishes not to share information with family members. This will normally be the case even if that person is having a psychotic episode and is making their decision based on delusional beliefs. A professional could decide to breach their duty of confidentiality and give information to a carer, but this would normally only happen where a person with a mental health condition poses a risk to themselves or to others. So, for example, it could be appropriate for a professional to disclose information about a person's diagnosis or other circumstances to a carer if that person was at risk of suicide or hurting other people and disclosure could help to prevent this.

2) Seeking agreement to disclose

When asking a patient to agree to information sharing, professionals must always explain fully why they think it's necessary and the potential risks of not doing so. They must keep a careful record and regularly check whether the person wants information to be shared.⁵ Rethink Mental Illness believes that people with severe mental illnesses should generally be encouraged to involve their carers in their medical treatment.

If a person is happy for the professionals involved with their care to disclose information, it may be best for them to put this in writing and to

ask for a note to be placed on their care plan or medical records. There is a sample form at the end of this factsheet that can be used for this purpose.

Some carers find it difficult to get information from professionals even when the person they are caring for has specifically agreed for this information to be shared. If this problem cannot be resolved informally, it may be necessary to make a complaint.

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3) Can a professional talk to me if consent hasn't been given?

A Rethink Mental Illness survey showed that one in five carers have been prevented from giving information to a doctor because of 'confidentiality rules'.⁶ There is no rule that says that a doctor cannot listen to your concerns as a carer.

The doctor will be able to listen to and record your concerns, but will not be able to tell you confidential information about the patient. The General Medical Council guidance on confidentiality for doctors states:

If anyone close to the patient wants to discuss their concerns about the patient's health, you should make it clear to them that, while it is not a breach of confidentiality to listen to their concerns, you cannot guarantee that you will not tell the patient about the conversation. You might need to share with a patient information you have received from others, for example, if it has influenced your assessment and treatment of the patient.

You should not refuse to listen to a patient's partner, carers or others on the basis of confidentiality. Their views or the information they provide might be helpful in your care of the patient. You will, though, need to consider whether your patient would consider you listening to the concerns of others about your patient's health or care to be a breach of trust, particularly if they have asked you not to listen to particular people.⁷

Although the guidance is clear, in Rethink Mental Illness' experience, some professionals refuse to accept information from carers in any circumstances, and this may be because they believe they may be sued or disciplined if they do.⁸ This can be difficult to manage in practice, but if a doctor is preventing you from sharing important information, then you could try showing him or her the above guidance. Other professionals, including social workers and community psychiatric nurses (CPNs) are also able to listen to your concerns.

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4) Do professionals have a duty of confidentiality to carers?

Some carers are worried that, if they tell a doctor information about the person they care for, this information will get back to the patient. Perhaps

the doctor will tell the patient exactly who said what, or perhaps it will be obvious to the patient that a carer must have shared information. This is a very difficult situation. As the guidance in the last section states, doctors may not be able to guarantee that they will not share information with their patient. However, the guidance given to doctors is conflicting, and the Mental Health Act Code of Practice (which applies when patients are 'sectioned' under the Mental Health Act 1983) states:

Carers, relatives, friends and other people also have a right to expect that any personal information about themselves, or any information about the patient which they pass on to professionals in confidence, will be treated as confidential. Unless there is an overriding reason that makes it necessary and there is legal authority to do so, information they provide about patients should not be repeated to patients in a way that might reveal its source, unless the carer, relative, friend or other person was made aware that that could happen and has not objected to it.⁹

This guidance only applies to patients detained under the Mental Health Act 1983. However, it shows that there can be circumstances in which professionals are expected to respect the confidentiality of information given by a carer. However, in practice, doctors are likely to abide by their local policy and so perhaps you could ask for a copy of this.

Many carers do not want the person they care for to think that they are 'interfering', and would not want the person to know that they have talked to their doctors or social workers because they feel that it could have a negative effect on their relationship. In order to prevent this, a carer could ask a professional to treat any information they provide as confidentially as possible and to use the information sensitively. Even if the doctor agrees not to reveal the source of information given to them, a patient may realise that their carer is the only person who knew that information. Given that it is good practice for a doctor to share any information with a patient that has been used in deciding a diagnosis or treatment, this poses a difficult practical problem.

A carer may want to request that their information be treated confidentially and then wait for the professional's response before sharing any information or concerns. It can be useful to spell out why confidentiality is so important. You could make it clear that confidentiality is needed to protect the trust in the relationship with the person you care for, and it may be that you are passing information about your loved one that professional services may not be aware of and that only you are in a position to get.

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5) What about the 'nearest relative'?

The 'nearest relative' has important rights with regard to the Mental Health Act 1983, but having the status of 'nearest relative' does not give a person any additional rights to be given confidential information about a person's treatment whether or not they are detained under the Mental

Health Act. The nearest relative has the right to be informed or consulted about applications to detain their relative under the Mental Health Act, but these are not absolute. This may not happen if there would be a detrimental impact on the patient, which would result in infringement of the patient's right to a private and family life under Article 8 of the European Convention on Human Rights and which could not be justified by the benefit of the involvement of the nearest relative.¹⁰

For more information on the role of the nearest relative, see our factsheet on the '**Nearest Relative**', which is available to download for free from www.rethink.org/factsheets or by contacting the Rethink Advice & Information Service directly. Our contact details are at the end of this factsheet.

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6) What can be done about the problem of confidentiality?

a) *Planning Ahead*

In order to prevent problems with carers getting the information they need during times of crisis or during acute episodes, a service user could draw up an advance statement which explains what information they want to be shared if a future episode of illness affects their judgement. Further information can be found in our factsheet on '**Advance Statements**', which is available to download for free from www.rethink.org/factsheets or by contacting the Rethink Advice & Information Service directly. Our contact details are at the end of this factsheet.

You could also ask the person you care for to complete a consent form which can be given to professionals involved with their care. If they complete this while they are well, it may prevent problems arising when they become unwell provided professionals are aware of it and are satisfied that the person had mental capacity when they agreed to this. An example form is at the [end of this factsheet](#).

b) *If no plan is in place*

If the person you care for is particularly unwell and is refusing to share information with their family, a doctor is unlikely to go against the patient's wishes and share this information without their consent. This can be a very confusing, frustrating and worrying time for carers because they may not know how a person is being treated and what difficulties they are going through. You may wish to ask for a copy of the local policy on information sharing and confidentiality to see whether this is being followed correctly.

If a patient is particularly unwell, it may be that a doctor will be satisfied that they do not have the mental capacity to make decisions about information sharing. A doctor could be justified in disclosing information about a patient if this is in their best interests in the circumstances. However, this does not seem to happen very often in practice.

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You can find information about patient confidentiality and access to health records on the Department of Health website at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4069254.pdf

The Department of Health also produces guidance on Information Sharing in Mental Health, which is available at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_104948.pdf

Some useful ways for carers to approach the problem of confidentiality and disclosure with friends and family can be found on the Mental Health Care website at: <http://www.mentalhealthcare.org.uk/confidentiality>



¹ See the following document produced by the Information Commissioner's Office (accessed 19/09/11) http://www.ico.gov.uk/upload/documents/library/freedom_of_information/detailed_specialist_guides/awareness_guidance_2_-_information_provided_in_confidance.pdf

² *Hunter v Mann* (1974) QB 767

³ For example, a doctor may be required to disclose confidential information by a court order. Disclosure of patient information is sometimes also required for research purposes under s60 of the Health and Social Care Act 2001

⁴ Available at <http://www.basw.co.uk/>

⁵ Confidentiality: NHS Code of Practice (2003), Department of Health at para 16. Accessed 09/05/11 at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4069254.pdf

⁶ *Rethink (Not yet published) Your Treatment Your Choice survey findings*

⁷ Confidentiality: guidance for doctors, General Medical Council (2009) para 66. Available at http://www.gmc-uk.org/static/documents/content/Confidentiality_0910.pdf, accessed 20/04/11.

⁸ Leggatt, M. 2001. 'Carers and carer organisations' in Thornicroft, G. and Szmukler, G. (eds) *Textbook of Community psychiatry*, pp.475-486. Oxford: Oxford University Press.

⁹ The Mental Health Act Code of Practice (2008) Department of Health at para 2.31 Accessed 26/05/11 at http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_087073.pdf

¹⁰ As note 11, at para 4.60



Confidentiality and information sharing with carers: Consent Form

I _____ (full name)

Give consent for _____
(Name of GP, psychiatrist, social worker, CPN, ward manager, social worker etc.)

To share information with _____ (Full name)

They are my _____
(Relationship to you e.g. mother)

Their address

Their telephone number _____

About the following aspects of my care and treatment:

- 1 My diagnosis and symptoms
- 2 My medication (dose and how it is taken)
- 3 Side effects of my medication
- 4 Other treatment I am having
- 5 My care plan
- 6 Care planning meetings
- 7 Discharge/ leave from hospital
- 8 Future appointments
- 9 Other (specified below)

This consent is valid until _____ (review date)

Signed _____ **Date** _____

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Last updated June 2012

Next update June 2014



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