Rethink Mental Illness.

FACTSHEET

Confidentiality and information sharing

For carers, friends and relatives

If you care for someone with a mental illness, the rules on confidentiality can often be frustrating. You might find that health professionals or staff do not give you information about the person you care for. This factsheet looks at these problems and how you can try to prevent them happening in the future.

In this factsheet we use the word 'carer', which can also include friends and relatives.

We use the word 'relative' for the person you care for or are supporting.

We also use the word 'professionals'. This covers people who work in health and social care services, such as psychiatrists, GPs, social workers and nurses. It also includes people who work in other services, such as housing officers, probation officers and advocates.

KEY POINTS

- Professionals can only share information about your relative with you or other people if your relative tells them that they can.
- A professional can sometimes share personal information without your relative agreeing, but only in very limited situations. This can include when it is in the public's interests.
- If you are concerned about your relative or want to give professionals some information about them, professionals can listen to you. However, some might say they cannot.
- If your relative is happy for professionals to share information with you, it could help for them to put this in writing on a consent form.
- Your relative could also draw up an advance statement which explains what they would like to happen if they become unwell and their judgement is affected.

This factsheet covers:

1. What is confidentiality?
2. Can a professional share information with me about my relative?
3. Can I give information about my relative to a professional?
4. I'm the nearest relative, what information can I get about my relative?
5. What arrangements can I make for the future?

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1. What is confidentiality?

If someone shares personal information with a professional, the professional should not share it with other people. This means the information is confidential. Personal information can include:

- your address or date of birth
- sensitive information such as a diagnosis of a mental illness
- treatment or care plans
- anything discussed in therapy sessions.

Professionals can share information with each other. For example, your relative's psychiatrist at the Community Mental Health Team (CMHT) may discuss your relative with other CMHT staff. However, they cannot share information about your relative automatically with people in other services like housing officers or the police.

You can find out more information in our '**Confidentiality**' factsheet, which you can download from www.rethink.org or call 0300 5000 927 and ask for the information to be sent to you.

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2. Can a professional share information with me about my relative?

You might find that professionals won't talk to you about your relative's treatment or care. This might make you feel less able to support them.

Generally, professionals can only share information with you or other people if your relative 'consents' (tells them that they can). This is the case even with close family. This is because professionals have to work in a confidential way. They have to work in line with professional guidance and the law of confidence.[1]

If your relative does give consent, then professionals can talk to you about their care or treatment. Your relative may decide to only share certain things about their care or treatment. Section 5 goes into this in more detail.

Even though professionals must work in a confidential way, they should talk to people under their care about sharing information with loved ones.

They should regularly ask whether they want information to be shared and keep a record.[2]

When can a professional share information without consent?

A professional can sometimes share personal information without consent, but only in very limited situations. This is called 'breaching confidentiality'.

This can happen if:

- it is in the public's interests. For example, a doctor may decide to share information with the police if the person might be a risk to other people
- it is through a court order or other legal obligation.[3]

If this happens to your relative, the professional should let them know that they are doing this and why.

If a professional shares information without consent and it is not under exceptional circumstances, your relative could take legal action.[4] This means that most professionals are very careful about sticking to the rules.

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3. Can I give information about my relative to a professional?

Yes. There is no rule that says that a professional cannot listen to your concerns as a carer.

Some professional guidance covers this specifically. The General Medical Council covers the work of doctors. They say that doctors should not refuse to listen to a carer's concerns because of confidentiality. This is because the information could be help with the care of the person.[5]

However, unless your relative agrees, the professional will still not be able to:

- discuss your relative's care or treatment with you or
- tell you whether they plan to do anything with your information.

You might find that if you try and give information to a professional face-to-face or by phone, they will not speak to you. In this case, you could try putting your concerns in writing, by letter or email. This might make it less easy for them to ignore.

You may worry that if you share information or concerns, professionals will share this information directly with your relative. If this happens, it could have an impact on your relationship or trust. If you share concerns verbally or in writing, you could ask that any information you share is used as sensitively as possible. You could explain that this is necessary to protect your relationship.

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4. I'm the nearest relative, what information can I get about my relative?

If your relative is detained under the Mental Health Act (also known as being 'sectioned'), you may be their nearest relative. This means you have important rights where the Mental Health Act is used, including being able to request an assessment to decide if your relative should be detained under the Mental Health Act. You can also request that your relative is discharged from hospital.

However, it does not change the rules on confidentiality. This means that you still can't get information if your relative does not consent to this. The only exception is where the 'Approved Mental Health Professional (AMHP) needs to consult the nearest relative for admission under section 3.

For more information on the role of the nearest relative, see our factsheet on the '**Nearest relative'**, which you can download for free from www.rethink.org.

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5. What arrangements can I make for the future?

To try and prevent any problems with confidentiality in the future, you could speak to your relative generally about sharing information.

You could explain to your relative that they don't have to give consent for everything to be shared. For example, they might be happy for information about their diagnosis to be shared, but not about their treatment plan. Talk to them to see what they might be open to. You could also bring up why sharing certain information could be important.

Consent form

If your relative is happy for professionals to share information with you, it could help for them to put this in writing on a consent form. If they complete this while they are well and understand the decision, it should mean that professionals can share information with you. Your relative should ask for a note to be placed on their care plan or medical records, so that professionals know about it. You can find an example form at the end of this factsheet.

Advance statements

Sometimes people can lose the ability to make a decision for themselves when they are unwell.

Your relative could draw up an 'advance statement' which explains what they would like to happen if they become unwell and their judgement is

affected. This can include what information they would like professionals to share with you or any other people.

You can find out more information in our '**Advance statements**' factsheet, which you can download for free from www.rethink.org, or call 0300 5000 927 and ask for the information to be sent to you.

What if professionals still don't share information with me?

You might find it difficult to get information from professionals even when your relative has given consent. If this happens, you could make a complaint. You could also ask for a copy of the local policy on information sharing and confidentiality, to see if they are following this correctly. If they aren't, this could help you put a complaint together.

You can find out more about complaints at www.rethink.org.

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Confidentiality and information sharing Consent Form

I _____ (full name)

Give consent for (for example, GP, CPN, social worker):

_____

To share information with:

_____

They are my (for example, my mother, brother):

_____

Their address:

_____

Their telephone number:

_____

About the following aspects about my care and treatment:

My diagnosis and symptoms ☐

My medication (dose and how it is taken) ☐

Other treatment ☐

My care plan ☐

Discharge plans ☐

Other ☐

_____

Consent valid until:

_____

Signed _____ Date _____

[1] *Hunter v Mann* (1974) QB 767
[2] Sharing mental health information with carers: pointers to good practice for service providers, Department of Health (2006). Available at http://www.carersandconfidentiality.org.uk/wp-content/uploads/2008/12/1110_54-briefing-paper.pdf
[3] Confidentiality: NHS Code of Practice, Department of Health (2003) Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/200146/Confidentiality_-_NHS_Code_of_Practice.pdf
[4] See reference 4
[5] Confidentiality: guidance for doctors, General Medical Council (2009) para 66. Available at http://www.gmc-uk.org/static/documents/content/Confidentiality_0910.pdf

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Rethink Mental Illness

Phone 0300 5000 927
Monday to Friday, 10am to 2pm

Email advice@rethink.org

Did this help?

We'd love to know if this information helped you.

Drop us a line at: feedback@rethink.org

or write to us at Rethink Mental Illness:
Feedback
PO Box 68795
London SE1 4PN

or call us on 0300 5000 927.

We're open 9am to 5.30pm, Monday to Friday.

Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights. Or talk to others about your problem at **www.rethink.org/talk**.

Don't have access to the web?

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Need to talk to an adviser?

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