FACTSHEET



Confidentiality and information sharing

For carers, friends and relatives

You might find that healthcare professionals do not give you information about the person you care for. This factsheet explains why this happens and how you can try to stop this in the future.



- Professionals can only share information about your relative if your relative tells them that they can. This is called 'giving consent'.
- In limited situations, a professional can share personal information without your relative's consent.
- Professionals should listen to you if you are concerned or want to give them information about your relative.
- Your relative should sign a consent form if they are happy for professionals to share their information with you.
- Your relative could fill out an advance statement to explain what they want to happen if they become unwell and their judgment is affected.

This factsheet covers:

- 1. Key Words
- 2. What is confidentiality?
- 3. When can a professional share information without consent?
- 4. Can a professional share information with me about my relative?
- 5. Can I give information about my relative to a professional?
- 6. I'm the nearest relative, what information can I get about my relative?
- 7. What arrangements can I make for the future?

1. Key words

Your relative: for the purpose of this factsheet, 'your relative' means the person that you want information about. You could be their carer, friend or relative.

Professional: a professional is someone who works in health and social care services. This could be a:

- psychiatrist,
- GP.
- social worker,
- nurse,
- housing officer,
- probation officer, or
- advocate.

Top

2. What is confidentiality?

A professional should not share any personal information about your relative with other people. They can only share this information if your relative has said that they can. This is called giving consent. It means their information is kept confidential.¹

Personal information about your relative can include:

- address or date of birth,
- sensitive information like a mental health diagnosis,
- treatment or care plans, or
- anything they have talked about in appointments or therapy sessions.

Professionals can share information with other people in teams who support your relative's care.²,³ They should only share information they need to.⁴ For example, your relative's psychiatrist may discuss your relative's treatment needs with your relative's care coordinator.

Professionals should get consent from your relative before they share confidential information with other services like the police or your relative's employer.⁵

You can find more information about '**Confidentiality**' at <u>www.rethink.org</u>. Or call 0121 522 7007 and ask us to send you a copy.

3. When can a professional share information without consent?

A professional can sometimes share personal information without consent. This is called 'breaching confidentiality'.⁶

A breach in confidentiality can only happen for these two reasons:

- when it is in the public's interest. For example, a doctor may decide to share information with the police if your relative might be a risk to other people, or⁷
- as part of a court order or law.⁸

A professional should tell your relative if they need to breach confidentiality through a court order. This should happen before the breach, but it can happen after. A professional may not tell your relative if it would put them or other people in danger. 10

You relative could take legal action if a professional shares information without consent without a good reason.¹¹

Top

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

Professionals might not talk to you about your relative's treatment or care if your relative does not give consent. 12 This is the same even with close family. This is because professionals must protect your relative's confidentiality.

Professionals should regularly talk to your relative about sharing information with carers, friends or relatives. This is to make sure that your relative has a chance to decide if they want information shared at different times. They should keep a record of what your relative says. ¹³

Your relative can give consent for the professional to share all, or some, of their information with you. At the end of this factsheet there is a template consent form. Your relative can fill this out and give it to their healthcare teams.

Top

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

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

The General Medical Council (GMC) make guidelines for doctors. The guidelines state that doctors should not refuse to listen to a carer, friend or relative's concerns because of confidentiality. This is because the information could help with your relative's care.¹⁴

But, if your relative has not given consent, professionals will 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.

Doctors might need to share the information you give with your relative. ¹⁵ You might worry that this will affect your relationship or trust. You could ask that any information you share is used as sensitively as possible. You could explain that this is needed to protect your relationship.

You might find that a professional will not speak to you if you try to give information about your relative. If this happens, you could write down your concerns in a letter or email. This might make it harder for them to ignore.

<u>Top</u>

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

If your relative is detained under the Mental Health Act 1983, you may be their nearest relative (NR). This is not always the same person as the next of kin.

NR is a term that is in the Mental Health Act, which is the law. The NR has certain rights under the act. The NR can:

- ask for a Mental Health Act assessment from social services to decide if your relative should be detained,¹⁶ and
- discharge your relative from a section of the Mental Health Act. 17

Confidentiality laws are the same, even if you are the NR. This means that you can't get information if your relative does not give consent.¹⁸

Your relative will decide what information they would like their NR and carers to know.¹⁹ With your relative's consent, it is good practice for professionals to discuss your relative's progress with carers.²⁰

You can get more information about 'Nearest Relative' at www.rethink.org. Or call 0121 522 7007 and ask us to send you a copy.

Top

7. What arrangements can I make for the future?

To try and stop any problems with confidentiality in the future, you could speak to your relative. You can talk about why it would be good to share information with you.

You could explain they don't have to give consent for healthcare staff to share everything. For example, they might be happy for information about their diagnosis to be shared, but not their treatment plan. Ask them what they would feel comfortable to share.

Consent form

Your relative should tell professionals what information they are happy for you to know. It may be helpful if your relative writes down their consent on a consent form. Your relative will need to have mental capacity when they fill out the form. Mental capacity means someone understands the decision they are making. Someone can have mental capacity when they are unwell in hospital.

You can find more information about 'Mental Capacity and Mental Illness' at www.rethink.org. Or call 0121 522 7007 and ask them to send you a copy.

Your relative should ask healthcare staff to put a note at the front of their care plan or medical records. This is so that professionals know about the consent form and know what information they can share. You can find an example consent form at the end of this factsheet.

Advance statements

Your relative could fill out an advance statement to explain what they would like to happen in the future if they become unwell. Sometimes people can lose the ability to make a decision for themselves when they are unwell. This is called lacking mental capacity.

An advance statement can explain what they would like professionals to share with you or other people.

You can find more information on advance statements in our 'Planning your care' factsheet. You can download this for free from www.rethink.org, or call 0121 522 7007 and us to send you a copy.

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 should speak to the professional involved. You should find out their reasons for not sharing information.

If you think the professional does not have good reasons you can make a complaint. You could also ask for a copy of the local policy on information sharing and confidentiality. You will be able to see if they have followed their policy correctly. If they haven't followed their policy you could use this evidence to help you put a complaint together.

You might be able to get some help making a complaint from an NHS complaints advocate. A complaints advocate does not work for the NHS and is free to use. You can find your local service online. Or you can contact us and we can try and find it for you.

You can find more information about:

- Complaints
- Advocacy

Top



Confidentiality and information sharing Consent Form

l	(full name)
Give consent for (for example, GP, CPN, social worker): To share information with (full name):	
My diagnosis and symptoms	
My medication (dose and how it is ta	aken) 🗌
Other treatment	
My care plan	
Discharge plans	
Other	
They are my (for example, my mothe	er, brother):
Their address:	
Their telephone number:	
Consent valid until:	
Signed Date	



Department of Health. Confidentiality: NHS Code of Practice. London: Department of Health; 2003. Para 9.

² General Medical Council (GMC). Confidentiality. Manchester: General Medical Council; 2009. Para 25.

³ As note 1 para 12

⁴ As note 1, Annex A, page 20 (d)

⁵ As note 2, para 34.

⁶ As note 1, Annex B, para 28.

⁷ As note 1, Annex B, para 30.

⁸ As note 1, Annex B, para 49-50.

⁹ As note 1, Annex B, para 50.

¹⁰ As note 1, Annex B, para 32.

¹¹ As note 1, para 29-37.

¹² As note 1, para 14.

¹³ Department of Health. Sharing mental health information with carers: pointers to good practice for service providers.

https://www.rethink.org/resources/s/sharing-mental-health-informationwith-carers page 6 (accessed 19 May 2016).

As note 2, para 66.

¹⁵ As note 2, para 66.

¹⁶ S13(4) Mental Health Act 1983.

¹⁷ As note 16, MHA 1983, s23(2a).

¹⁸ Department of Health. *Mental Health Act 1983: Code of Practice.* London: The Stationery Office; 2015. Para 4.32.

¹⁹ As note 18, para 4.32

²⁰ As note 18, para 4.43

© Rethink Mental Illness 2014

Last updated July 2016

Next update July 2019

Version: 3

This factsheet is available in large print.

Rethink Mental Illness Advice Service

Phone 0300 5000 927 Monday to Friday, 9:30am to 4pm (excluding bank holidays)

Email advice@rethink.org



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:

RAIS

PO Box 17106

Birmingham B9 9LL

or call us on 0300 5000 927.

We're open 9:30am to 4pm Monday to Friday (excluding bank holidays)



Leading the way to a better quality of life for everyone affected by severe mental illness.

For further information on Rethink Mental Illness Phone 0121 522 7007 Email info@rethink.org



facebook.com/rethinkcharity



twitter.com/rethink_



www.rethink.org



Need more help?

Go to **www.rethink.org** for information on symptoms, treatments, money and benefits and your rights.

Don't have access to the web?

Call us on 0121 522 7007. We are open Monday to Friday, 9am to 5pm, and we will send you the information you need in the post.

Need to talk to an adviser?

If you need practical advice, call us on 0300 5000 927 between 9:30am to 4pm, Monday to Friday. Our specialist advisers can help you with queries like how to apply for benefits, get access to care or make a complaint.

Can you help us to keep going?

We can only help people because of donations from people like you. If you can donate please go to **www.rethink.org/donate** or call 0121 522 7007 to make a gift. We are very grateful for all our donors' generous support.





