

All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback: [Feedback form](#)

Information Sharing, Confidentiality, Whistleblowing and Freedom of Information

This section of the Family Carer Advocacy Pack outlines confidentiality in health and social care, the legal frameworks underpinning it and how this impacts on your role as a family carer supporting your relative.

What is confidentiality

Confidentiality is about protecting a person's privacy. This means personal information should only be shared when consent has been given, it is in a person's best interests, and it is necessary to provide care and support and/or treatment.



Professionals in health and social care should act in accordance with confidentiality principles to protect your relative's right to privacy, but sometimes this information will need to be shared, particularly with yourself or others involved in your relative's care.

The Human Rights Act and information sharing and confidentiality

Article 8 of the Human Rights Act is the right to a private and family life. It includes:

- Respect for private and confidential information and how this is stored and shared (in the UK this is covered by the Data Protection Act 1998)
- The right to control how information about your private life is shared

This right is a qualified right which means there may be instances when it does not apply.

Read this information about [Article 8 of the Human Rights Act: Respect for private and family life](#)



Sharing information with family carers

“Carers need to be given sufficient clear information to help them provide more effective care - offering information to carers about care, support plans, medication, and giving them advice about ‘what to do in a crisis’, does not amount to breaking confidentiality.”

If your relative has been assessed as having the capacity to consent to sharing their personal information, health and social care professionals should discuss with them:

- How they would like their family involved in their care, support and/or treatment
- Agree what information they are happy to share, with who and when
- The advantages of sharing information, and how it can be of benefit in particular situations. For instance, if you (family carer) are responsible for helping your relative with their medication, you will need to know information about what the medication is, what it is for, dose, side effects to look out for and whether it is helping or not.

If your relative has been assessed as having the capacity to consent to information sharing and states they do not want you or other family members involved in their care and support and/or treatment, health and social care professionals may still share information, e.g. to help understand your relative's diagnosis, proposed treatment, or care and support needs on discharge.

Discussions about sharing information should take place more than once with your relative to give them the opportunity to change their mind.

If your relative is assessed as lacking the capacity to give consent to share information, then the principles of best interests should apply.

“Confidentiality should not be used as a reason for not listening to carers, nor for failing to discuss fully with individuals the need for their family and friends to receive information so that they can continue to support them”

Department of Health: Developing services for carers and families of people with mental illness, November 2002



Read this [fact sheet by Rethink Mental Illness](#) for family carers about confidentiality and

information sharing. If your relative has capacity to consent to share information, then the Rethink template for providing consent may be useful. You can keep a copy and your relative can ask for a copy to be kept in their records

Breaching confidentiality

On occasions health and social care professionals may breach your relative's confidentiality and share information

- When it is in the public's (e.g. the police think your relative might be a risk to other people) or your relative's (e.g. safeguarding) interests
- When a court or legislation (the law) says they have to

A professional should tell your relative if they need to breach their confidentiality

through a court order unless it would place your relative or other people in danger.

If a professional breaches confidentiality without good reason they may be breaking the law and your relative could take legal action against them.

All information shared about your relative should be accurate and up to date. You can help with this by ensuring:

- That all plans (e.g. communication passport) include:
 - a date on them (e.g. last reviewed on [date])
 - the names of the people involved in developing the plan
 - if your relative has capacity, who they have agreed to share the plan with or
 - if your relative has been assessed as not having capacity for this decision what is in their best interests
- Consider having a statement about information sharing and confidentiality on the front page of documents about your relative, including who can update and amend
- If you notice any inaccuracies in information e.g. a letter following a hospital appointment which includes a diagnosis which does not apply to your relative, ask (in writing - a letter or email) for this to be changed

Family carers sharing information about their relative

When sharing information about your relative, think about:

- Why does this person need to know this information?
- Will my relative feel embarrassed if they know I have shared this information?

Case Study

This case study explains the benefits of having an advance statement about information sharing.

Mary lives happily with her sister Carol. For the last two weeks, Mary has become increasingly manic with hyperactivity 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.

[Read the full case study and resource](#)



- Will it impact on how the person views my relative? e.g. if you share information about a mental health diagnosis or behaviour described as challenging
- Would I be happy if this type of information was shared about me in this situation?
- Will this information be recorded, where and for how long?

Family carers, information sharing and confidentiality

The same rules about information sharing and confidentiality apply to family carers. Health and social care professionals should not share information about you or your family without your consent.

Advocacy, information sharing and confidentiality

If an organisation has achieved the Advocacy Quality Performance Mark for confidentiality, here is what it should have in place:

- A Confidentiality Policy that reflects current legislation. It will be clear about how personal information held will be kept confidential and under what circumstances it may be shared, when a clear explanation will be recorded. Advocates must also be aware of situations that require making a safeguarding referral.
- A current Non-Instructed Advocacy Policy in place, which makes clear the organisation's approach to confidentiality and data sharing where a person is unable to consent.
- An up-to-date Data Protection Policy in place.
- The organisation complies with data protection legislation by creating, storing and disposing of electronic and manual records appropriately.
- Any accidental, negligent or wilful breaches of confidentiality are reported at the earliest opportunity to senior managers or Board members in line with the organisation's policies and procedures.
- People know that they have the right to see their own records and are supported to have access to them if they so wish.

Freedom of Information (FOI) Act

Using the Freedom of Information Act is a useful way for family carers to access information either about their relative's care and support and/or treatment or the service they are using.

Anybody has the right to submit an FOI request, and public bodies are legally required to respond to these requests within 20 days. Not all requests will be successful, however, as public bodies are able to refuse a request based on:

- Being too expensive to comply with
- If it is 'vexatious' (an inappropriate or improper request)
- If it is a repeat of a previous request



[Read about the exceptions to the FOI Act](#)

Information can also be withheld if it is exempt from the FOI Act, for instance if it might cause harm, or if it is already due for publication. A full explanation of exemptions has been published by the Information Commissioner's Office.

To improve your chances of accessing the information, it is important to:

- Submit your request in straightforward language
- Include your name, address and contact details
- State that you are requesting information under the Freedom of Information Act
- Be specific about the information you are requesting
- Try not to overload your request as this will make it more likely to be rejected - break it up into the separate parts you require, submitting separately if needed
- Make sure that the request is being sent to the right place

Most public organisations have webpages explaining how to submit an FOI request to them. There should be an online form, an email address, or postal address through which to contact them. See these examples from the [NHS](#) or [CQC](#).

Freedom of Information Requests

1

Planning your FOI request

Will the information you are requesting be covered under the FOI Act? Which organisation holds the information that you're trying to access? Check their website for information on their FOI process (and how to submit your request)

2

Prepare your FOI request

Clearly state the information that you are requesting, including details (if appropriate) around the time, location, department etc. relevant to where this information will be recorded. Follow the points listed above to increase the chances of success

3

Submit your FOI request

Using the correct address for submission, submit your FOI request. You may get a confirmation email with a reference code. You should get a full response within 20 days of submission

4

The response to your FOI request

If successful the organisation will respond and let you know if they have the information. If your request has been approved, you should receive the information (likely as an email or email attachment)

If not successful

The organisation should provide a reason for not approving your request. They may not have this information, or it might be excluded from coverage under the FOI Act. It might be possible to resubmit your request with adaptations made in line with their reason given

Further information



For more information on the Freedom of Information Act read this resource by the Campaign for Freedom Information

https://www.cfoi.org.uk/wp-content/uploads/2013/09/foi_guide.pdf

Information on Rethink Mental Illness website

<https://www.rethink.org/advice-and-information/carers-hub/confidentiality-information-and-your-loved-one-for-loved-ones-of-people-living-with-mental-illness/>

The Mental Health Act Code of Practice (Chapter 4 Information for Patients, Nearest Relative, Carers and Others) gives clear guidance about the involvement of you and your relative in their care, support and/or treatment, including information sharing and confidentiality

http://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF



We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@theCBF.org.uk, or visit our website: www.challengingbehaviour.org.uk

2023 The Challenging Behaviour Foundation.

www.challengingbehaviour.org.uk Tel. 01634 838739

Registered charity no. 1060714.

Reg office: The Old Courthouse, New Road Avenue, Chatham, Kent ME4 6BE