

Carers and Confidentiality Guide

Know your
rights and have
your say about
your mental
health care
and treatment.

Introduction

This is a guide for anyone who is a carer for someone with a mental illness or learning disability. By 'carer,' we are referring to a family member, partner, or close friend who cares for someone with mental ill health or a learning disability.

This guide is specifically about information sharing and confidentiality. We have produced it because we are aware that people who are supporting someone with mental illness or learning disability can often feel unsure about whether doctors and other professionals should share information with them about the person they care for.

Sometimes information is not shared, and that can cause difficulties for a carer. We understand that, and we hope this guide will help answer some of your questions.

General

When any of us talk with a doctor, nurse or other health professional in a private consultation, we expect what we say to stay private. This principle of confidentiality is central to creating trust between patients and their doctor or other health professional.

All health professionals are bound by law and professional codes of conduct to this duty of confidentiality to their patients. If they breach confidentiality they could face disciplinary measures or legal proceedings, including being sued, dismissed or losing their licence to practice.

This principle remains the same, whether the patient has mental illness or a learning disability, or not. But we do understand that this can raise issues for carers. We aim to explain how you can expect professionals to work with you so that you have the information you need to care for your relative, partner or friend.

Do carers have a duty of confidentiality?

In thinking firstly about whether you should share information about the person you care for with doctors and other health care professionals, unless you are providing care under a contract, or the person you are caring for has made their views on confidentiality of information known to you, there is no legal requirement that you must respect confidentiality. Nevertheless, you should make every effort to respect the person's right to privacy, ideally talking to them before you talk to others. A professional would, in any event, seek to ensure that the confidentiality of their patient was not undermined before they could speak to you. The only time that might be different would be if the sharing of information was in the public interest.

It can, of course, be very useful for a professional to meet with you to discuss the likely course of treatment or care for the person you care for, and to talk about the best ways for you to help support them. When such a meeting takes place, the purpose of this discussion should be made clear to both you and the individual you care for. The individual may be reassured by being present at such a meeting.

However, this has to be balanced against the possible risks to the individual's relationship with you and other carers. The best way to manage this kind of meeting is by discussing the options with the professional and/or the person you care for in advance.

What should happen when you ask a doctor, social worker or nurse for information about the person you care for?

The professional should talk to the individual you care for about the sort of information that you may need. They should then agree what kind of information the individual is happy to have shared, and what information they might want to be kept confidential.

If the person you care for is willing to give consent to sharing some information, it is important that staff follow the individual's wishes. Giving them the opportunity to take part in any meeting between you and staff could also help to reassure them, if reassurance is required, that any limits on their consent are not being breached.

You may not realise that a question you ask a professional raises confidentiality issues. That is not unusual. Please don't be alarmed if a professional says they have to check the views of the individual you care for before they can give you any answer or information.

It may be helpful in some situations, if agreed with professionals, for you to speak with a member of the team who doesn't work frequently or directly with the person you care for. This can help when you wish to discuss general issues about a mental health condition or about learning disability, rather than specific issues that are personal to your family member, partner or friend.

In general, professionals should have ongoing discussions with individuals about the value of involving their carers, and should regularly review issues of consent with them.

And do remember, just because a professional agrees to share information with you, does not mean that you now have a general right of access to information about the person you're caring for. The medical or care team will always have to consider their own professional responsibilities related to confidentiality.

What if I am refused consent to getting information?

It is rarely acceptable for professionals to refuse to discuss information with you simply because the person you care for has refused to give blanket consent. If a professional cannot share information with you, they should:

- Explore the reasons why the person you care for does not want information to be disclosed. They should try to work with the person you care for to select relevant information that could be shared with you.

What about situations where the person I care for is going home from hospital?

- If you are involved in any way in ensuring that the person you care for is safe and well at home, you really need to be given adequate information about, for example, when the individual will be at home on discharge or overnight leave from hospital.
- You should also be told whether there are any particular changes with the person you care for, in their care or treatment, that you need to be aware of, or may want to seek help about.
- If you are involved in the support plan when an individual is on leave from hospital, it is important and very helpful that you give professionals information about how the time on leave has been.

What if I don't want some information to be shared with me?

There may also be times when you will not wish to have certain information. For example, there could be a situation where a doctor or other professional thinks that, it would be in the best interests of the person you care for, if certain information is shared with you.

But they, and you, may know from experience that this is an issue that is particularly fraught for you; one that you do not want to be involved in.

In such circumstances, it may be helpful to come to an agreement in advance that means you will not be involved in that specific sensitive matter.

Breaching confidentiality – what does this mean?

Occasionally, there can be times when a professional may be justified in sharing information with you without the individual's consent. That can happen if the sharing of personal information is to prevent serious harm to either the individual or to others.

For example, a professional could breach confidentiality, in spite of the individual's refusal, to prevent a serious crime. If that happened, the professional should warn you if there was a serious risk that the person you care for might harm you or someone else, or harm themselves, or commit a serious crime.

Guardianship and Power of Attorney

In some circumstances, a family member, partner or other carer can get legal powers from a court to make certain decisions, or take responsibility for actions, for an adult with incapacity, that is, someone who is unable to make their own decisions. This is known as Guardianship. This can also allow you to apply to access the medical records of the person you care for.

A person who understands the nature and extent of the powers they are granting, may give Power of Attorney to you in the event that, in future, they might lose the ability to make their own decisions. This can be for financial matters or welfare matters.

Named persons

If an individual is, or has been, detained under the Mental Health Act they can choose a named person to protect their interests.

A named person can be anyone aged over 16 who is not directly involved in a professional role in the individual's care. If you are a named person, you have the right to be consulted about aspects of an individual's care and treatment. You may also get information regarding Mental Health Tribunal hearings.

If the individual is detained in hospital, and is under 16, the named person will automatically be the parent or guardian, or the local authority or other carer.

If the person you care for has formally nominated you as their named person, and understands the implications of this decision, then professionals are obliged to disclose information when you request it.

Young people

In Scotland, any person over the age of 16 is presumed to have capacity and to be able to make decisions about their own health care, and also about the sharing of personal health information.

If a person over the age of 16 does not have this capacity, then mental health professionals will only be bound to share health information with you if you have appropriate guardianship powers.

In addition to this, any young person over the age of 12 is taken to be capable of decision-making about their own healthcare, and the sharing of personal health information unless there is evidence to suggest otherwise. It is the responsibility of the health professionals involved to satisfy themselves about this.

So, unless there is evidence to suggest a young person aged 12-16 is not able to make these decisions - a health professional should generally only disclose information to you with the consent of the young person involved.

In the case of any child or young person under 12, if the health professional is sure that they do have enough understanding about their own healthcare decisions, and about sharing of information, then sharing of information with you should only be with the consent of the young person.

Parent-carers

Any parent can have anxieties about their child progressing to adulthood, but when a young person has a learning disability, or has developed a mental illness in childhood or adolescence, these worries and concerns can be much greater.

If you are a parent, however, this does not give you the legal powers to continue making decisions for your child into adulthood, even though your child may continue to need your help and support. If your circumstances make this a particularly difficult issue, you are advised to seek legal advice on this area.

If you are caring for a young person and it is unlikely that they will develop the ability to make healthcare decisions, you may wish to seek these powers on your son or daughter's behalf through Guardianship.

Issues to consider if you are supporting someone with a chronic mental illness or learning disability, and you need to get support from other carers.

When you are caring for someone with a mental illness or learning disability, you may wish to share experiences and problems with other people in similar situations who have a real understanding of what you are going through. Clearly you cannot get this support without sharing personal details about the person you are caring for. That's understandable.

But you should always try to get the individual's consent to talk about their situation, provided they have the capacity to give it. If they do not have capacity to consent to sharing information, here is some helpful guidance you might follow:

- Take into account the individual's past and present wishes and feelings about their privacy.
- Perhaps consult other people who know the individual about whether to share information.
- Avoid sharing sensitive personal information unless necessary.
- You should not share sensitive information about an individual on social media such as Facebook and Twitter, or through online self-help resources, as it risks information being passed on by others without your control or consent.

Complaints

If you are unhappy about a professional's treatment of the person you care for, this section details the process of making a formal complaint. You should think carefully about publicising shortcomings, for example by contacting newspapers, or using social media, as this may well go against respecting the individual's right to privacy.

Because of data protection and confidentiality issues, service managers will need the consent of the individual to proceed with a complaint from you and to share the outcome of any investigation into a complaint with you.

If you have Power of Attorney or Guardianship that covers healthcare decisions and access to records, you do have the right to make a complaint and to see the outcome.

If the person you care for has previously indicated their wishes, or is able to make their views known, the service may take that as sufficient authority to undertake some level of inquiry but may not be able to share the outcome with you.

The person you care for should not be disadvantaged on the basis that they are not able to make a complaint on their own behalf. We would expect service managers to consider situations on a case-by-case basis to make sure any concerns about vulnerable individuals were not being overlooked.

As a person with a mental illness or learning disability, during your care, treatment and support you have the same rights as others to:

- Be treated with dignity and respect for your privacy, beliefs and individual needs.
- Not be discriminated against.
- Be given opportunities to use and develop your skills.
- Receive information about and be involved as much as possible in any assessment, planning and decision making about your care and treatment.
- Access the support of an independent advocate.
- Have your choices respected and taken fully into account.
- Involve relatives, friends or carers who are important to you in your care, who will be provided with the information they need.
- Receive care, treatment and support that benefits you and is the least restrictive option.
- Access information and help to challenge any restrictions placed upon you.
- Be kept safe and protected.

More information, as well as further downloadable guides, are available on our website: www.mwcscot.org.uk

More detailed information on this topic can be found in our Good Practice Guide on Carers and Confidentiality.

You can contact our advice line for service users and carers on: **0800 389 6809** or **0131 313 8777**.