mentalwelfare
commission for scotland

GOOD PRACTICE GUIDE

Carers & confidentiality

DECEMBER 2018

Contents

Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

About this guide

This guide is to help carers and families understand consent, confidentiality, and sharing of information, where the person they care for has a mental illness, dementia, learning disability, autism, personality disorder, or other related condition.

It will also guide health and social care practitioners, who can find themselves in difficult situations around the sharing of information. Maintaining confidentiality and keeping the best interests of a patient in mind is vital. So is having clear, open channels of communication with those who care for them.

In this guide we use the term ‘carer’ to mean family and friends who provide unpaid support to a relative, partner or friend. We use the term ‘individual’ to mean someone who has a mental illness, dementia, learning disability, autism, personality disorder, or a related condition. We also use the term ‘relative’ to include partner and friend.

Carer-practitioner collaboration

Over recent years there has been a greater acknowledgement of the role of carers and the need to support them to help make caring more sustainable.

Equal Partners in Care (EPiC)[1] is the Scottish national framework for workforce learning and development related to unpaid carers. It is based on the principle that carers are recognised and valued as equal partners in care.

The Triangle of Care[2] also emphasises a therapeutic relationship between the individual, staff member, and carer that promotes safety, supports communication, and sustains wellbeing.

The Mental Welfare Commission has published *Rights in Mind: A pathway to patients' rights in mental health services*[3]. This sets out some rights from the Carers Act[4]:

- With the patient's consent, carers have the right to be involved, and have their views and caring role considered, when determining the need for support and services for the patient.
- Carers have the right to an Adult Carer Support Plan or Young Carer Statement and to support if their needs meet local eligibility criteria.
- Carers have the right to be informed about and involved in discharge planning.

The Commission has a duty to monitor mental health and incapacity legislation and to promote the use of its principles.

These principles support the idea of carer and practitioner collaboration. We discuss carer involvement in all of our work across the country and regularly talk to individuals, carers, and service providers about this.

We are committed to promoting carer involvement as good practice.

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[1] http://www.knowledge.scot.nhs.uk/home/portals-and-topics/equal-partners-in-care/about-equal-partners-in-care.aspx

[2] The Triangle of Care

[3] Rights in Mind

[4] Carers (Scotland) Act 2016

Listening to carers

We frequently hear from people on our visits and via our advice line who have concerns about the care their relative is receiving.

They often feel their views, and/or the views of the individual, are not being listened to and that this is having a negative effect on the care that is being given.

We also hear from staff who are uncertain about how much information they should share with carers without the consent of the individual.

Confidentiality

Confidentiality is an issue that can be difficult for both carers and professionals. Confidentiality is something we all expect when we speak to a health or social work professional. We trust that our conversations and our health information will remain private.

Professionals have a ‘duty of confidentiality’ that is central to the trust between them and their patients. They can face disciplinary measures which can lead to dismissal or legal proceedings if this is breached.

However it is also important for staff to hear from carers, for example to get their views on how an individual is managing or what has led to a particular consultation or admission. Staff are usually aware that it may be in the best interests of the individual for their carer to be involved in their care. In many cases the individual will agree with this. But if they don’t, or can’t, agree, staff can find it difficult to know whether they can share information.

It can be challenging for professionals to balance their duties to their patient with the need to discuss issues with the carers involved.

Most professional bodies have guidance on confidentiality for their members. The General Medical Council (GMC)[5] has extensive advice on this as do the Nursing and Midwifery Council (NMC)[6] and the Scottish Social Services Council (SSSC)[7].

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[5] Confidentiality: good practice in handling patient information

[6] Professional standards of practice and behavior for nurses and midwives

[7] The Codes of Practice for Social Service Workers

Information sharing

Before any personal information about an individual is shared with a carer, a practitioner must understand the confidentiality issues involved. For someone to consent to information sharing, the practitioner must be sure they have sufficient capacity to fully understand and make an informed decision.

If the individual has capacity to consent, any sharing of their information must be agreed before any information is shared. The consent must be voluntary and informed. ‘Informed consent’ means the individual must be able to make a decision on their own without undue influence from anyone else and to fully understand the implications of both making the decision and of not making it.

Capacity

To have capacity an individual must be able to:

- Make decisions
- Act on decisions
- Communicate decisions
- Understand decisions and
- Retain memory of the decisions

Assessment of capacity is a medical decision but should be made in consultation with others involved in the individual’s care[8].

If an individual is felt to have capacity, and understands both the value of sharing information and the risks of not sharing certain information, then their wishes must be followed other than in exceptional circumstances, for example a serious risk to other people.

Sharing personal information with patient consent

If an individual has capacity to consent to information being shared, anyone working with them must make sure the individual understands the benefits of sharing their information and the implications of not sharing their information. Staff should discuss this with the individual and record the result in their notes. They should also get written consent from the individual if possible. It is good practice to have this conversation on first meeting an individual, if it is appropriate.

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[8] Communication and Assessing Capacity A guide for social work and health care staff

The agreement must be kept under review. The subject of information sharing should be revisited often as the opinion of the individual may change as their condition changes.

The individual may benefit from the support of an advocacy worker.

It is important to note that consent does not mean the carer has a right to access to the individual's records or to information that isn't relevant.

Case example
A carer asks a member of staff for information about her 35-year-old son.

The carer is unaware of confidentiality issues, so the staff member explains that he has a right to confidentiality and that that they cannot give out personal information without first asking permission from her son. The staff member discusses the request with the son and he is happy for his information to be shared with his mother.

The staff member then explains to the mother that her son has given permission to share information, that her input is important, and they see her as a partner in his care.

Without consent: learning from carers and sharing general information

If the individual decides they do not wish to share their information, this does not mean the member of staff cannot speak with their carer.

It is very important for professionals to be able to speak to someone who knows the individual well. They can often describe their concerns about the person's behaviour and recent events, and provide helpful background information.

It is also essential for professionals to share information about discharge arrangements if the individual will be discharged to, or is supported by, that carer in the community. The Carers (Scotland) Act 2016 (part 4, section 28[9]) places a duty on health boards to involve carers in hospital discharge of a cared-for person before they are discharged from hospital.

If the carer is aware of the individual's involvement with mental health services then staff can share information around general care and treatment without breaching confidentiality. Help, support, and general information around mental illness can be given to carers at any time even if their relative has refused to allow information sharing.

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[9] Carers Act

GMC guidance: s39

In most cases discussions with those close to the patient will take place with the patient’s knowledge and consent. But if someone close to the patient wants to discuss their concerns about the patient’s health without involving the patient, you should not refuse to listen to their views or concerns on the grounds of confidentiality. The information they give you might be helpful in your care of the patient.

It is rarely acceptable for practitioners to refuse to see carers simply because the individual has not given consent.

As long as everyone is clear about the wishes of the individual then professionals can meet carers on a listening basis. The individual might wish to be present at this meeting. This may or may not be a good idea. Professionals and carers should consider whether this might restrict the information some carers feel able to give, as they may not wish to risk jeopardising their relationship with the individual.

It may also be reassuring to an individual to have a member of staff not directly involved in their care handling this meeting.

If an individual has capacity and refuses to allow information sharing, the professional cannot disclose information. It is important however to explore the reasons for this and help the person see any benefits in including their carer.

The decision to refuse information sharing should be regularly reviewed by staff.

Case example

Mrs D phoned the Commission. She was distressed about the care of her 22-year-old son John who had been admitted to hospital for the second time with a psychotic illness. His first admission was voluntary; this one was under a compulsory order. She had a difficult time trying to look after him after the first admission. He became very negative about her. He was using illegal drugs and alcohol which she thought made him worse. She had been trying to get an appointment to speak to his consultant and get information about his current illness and treatment. However she had been told that this was impossible for reasons of confidentiality, because her son was unwilling to consent to such discussion.

The Commission advised that although John was unwilling for his information to be shared, the consultant should meet with Mrs D because the information she would be able to provide could be helpful. The consultant and other staff could offer Mrs D general advice about how to support someone with a psychotic illness without sharing John's personal information.

Partial information sharing

It may be that there is some information that the individual would not want to make available but that some other information might be acceptable.

For example, someone may be happy to discuss their treatment and discharge but not a previous drug problem.

Staff should discuss with the individual what they are happy to have disclosed.

In this sort of situation it may be possible to give general advice to a carer on the risks of drug taking in the context of a particular illness.

In all situations there should be ongoing discussions about decisions around information sharing. Individuals' feelings will change as levels of illness change, so this needs to be constantly reviewed.

Breaching confidentiality

It is very occasionally necessary for a practitioner to share information without consent from the individual. This is only justified if this is to prevent serious harm to either the individual or others. Professionals should refer to their own guidance in such situations. In all such situations it is important to consult the clinical team and record the reasoning behind the decision.

Information sharing where an individual lacks capacity

Capacity it is not an all-or-nothing concept.

Capacity can vary over the course of an illness and even over the course of a day. Some individuals, such as someone with a severe learning disability or late stage dementia, may have a permanent loss of capacity; but others, for example with a mental illness or earlier stage dementia, can be intermittently or temporarily impaired.

Adults with Incapacity (Scotland) Act 2000

If someone does not have capacity, then the Adults with Incapacity (Scotland) Act 2000 (AWI) is the legislation that provides protection for them. The act states that any intervention under the act should follow these principles:

- Be of benefit to the individual
- Be the least restrictive option available
- Take account of the past and present wishes of the individual
- Take account of the views of the nearest relative and the primary carer
- Take account of the views of relevant others e.g. welfare guardian or attorney
- Encourage the person to use their existing skills and develop new ones.

The principles of the AWI Act state clearly that any level of capacity the individual does have, and any views they make known, or have previously made known, must be taken into account when making decisions on their behalf.

Guardianship and Power of Attorney

Relatives and carers, or anyone with an interest in the individual, can apply to the sheriff court for financial and/or welfare guardianship powers. Powers relating to consent to medical treatment and access to medical records are welfare powers.

Staff need to be aware that such powers exist and should ask to see the legal certificates so that they are clear whether the guardian has relevant powers. If so, they should keep the guardian fully informed and consult them on decisions that the guardian has powers over.

Case example
Bill has dementia and his daughter is his main carer. He no longer has capacity to make decisions about his care and treatment.

His daughter could apply for a ***guardianship*** *order with appropriate powers regarding his welfare and finances to allow her to make decisions for him. Professionals involved in Bill's care should be ready to provide the necessary information to her about this and guide her to appropriate support if she is considering making an application.*

If Bill's daughter is granted guardianship with powers to access his information and take decisions about care and treatment, this should be made clear to staff involved in his care. It should be set out clearly in his records/care plan, so that all staff are absolutely clear about their legal duty to fully inform and consult with her.

An individual who has capacity can grant a Power of Attorney (POA) to someone else that they trust. To do this they must understand the nature and extent of the powers being granted. Powers of attorney can be for financial (continuing POA) and/or welfare matters (welfare POA).

Case example
Hanif has a mental illness which causes him to have times when he loses capacity.

He can, while well enough to do so, grant his carer POA. He would usually need a solicitor to do this. It would be his decision what powers to grant. If he chooses to include the power to make decisions about medical treatment, his carer must make sure that staff involved in Hanif's care know this and have a copy of the POA. Staff must then ensure that they keep the carer with POA fully informed and consult with them.

Hanif could choose to include a specific power to access part or all of his medical records, or to do so in particular circumstances. Professionals involved in his care should ensure that he understands fully the possible consequences of granting such a power.

Many people choose to grant a POA, often to relatives or friends, as a precaution against the possibility of losing capacity later in life (for example if they develop dementia).

Young people

In Scotland any person aged 16 or over is presumed to have capacity and to be able to make their own decisions.

Children under the age of 16 are able to make their own decisions about their own health care if the medical professional believes they are able to understand the nature and consequences of their treatment. If they are able to do this, then their consent must be sought before sharing any information about their health care with parents or carers.

If a young person under 16 is felt to have no capacity or to not yet have developed enough capacity for health care decisions, whoever has parental responsibilities can make decisions on their behalf. Health professionals should share information with them but must use what understanding the child has to involve them in the decision.

As with adults, the capacity to make decisions is not all or nothing. A child may fully understand a simple health decision but may struggle with a more complex one, such as a treatment decision involving something that might affect them in later life.

Parent carers of adults aged 16 or over

Every parent worries about their children. These concerns are magnified where their child has a learning disability, autism, or develops a mental illness in childhood or adolescence.

Being denied involvement in decision making for their child when they reach adulthood, at a very vulnerable time in their life, can be difficult for parents.

However, unless they have guardianship powers or POA, parents do not have legal powers to continue making decisions for their children beyond the age of 16.

Where it is likely that an individual will not gain capacity and be able to make their own decisions, parents may consider seeking welfare guardianship under the AWI Act. This could include seeking powers to access medical records and to consent to medical treatment.

Complaints

Sometimes carers contact us when they are very unhappy about a relative's care and treatment or support. They often wish to make a formal complaint.

A carer also has the right to make a complaint on their own behalf about their own experience of a service as a carer.

The Commission is not a complaints body and complaints need to be directed to the services involved. There is generally a second stage to this process if the complainer is not satisfied with the initial response.

If concerns about an individual's care are raised by carers, the Commission will sometimes make its own enquiries. When we do this, if we are satisfied that there is no cause for concern and that there has been no deficiency in the individual's care and treatment, we will take no further action. If we have concerns, we will pursue the matter until we are satisfied that the necessary action has been taken. However, without consent from the individual, we generally cannot share the outcome of our enquiries with the carer.

Can a carer make a complaint to a service about the individual's care and treatment?

Generally, to look into a complaint against a service, managers must have consent from the individual concerned. This can cause problems where the individual does not have capacity to consent.

If a person's previous wishes are known, or they are able to express some views, a service may undertake some level of inquiry but might not share the results with the carer.

It is important, however, that an individual is not disadvantaged by the fact that they are unable to make a complaint on their own behalf.

Services should look at each situation on a case-by-case basis to make sure concerns over vulnerable individuals are properly investigated. Independent advocacy can be very useful in these situations.

GMC guidance: s39

In most cases discussions with those close to the patient will take place with the patient's knowledge and consent. But if someone close to the patient wants to discuss their concerns about the patient's health without involving the patient, you should not refuse to listen to their views or concerns on the grounds of confidentiality. The information they give you might be helpful in your care of the patient.

The Commission's advice:

A complaint may be made about somebody else's care and treatment with the patient's consent, or by someone with a legitimate interest, when:

- The patient has given their consent (the patient would also need to agree that staff could look at their health records if necessary).
- The person making the complaint is a child's parent, guardian or main carer and the child is not mature enough to understand how to make a complaint.
- The person making the complaint has a welfare power of attorney or a welfare guardianship order for someone who cannot make decisions for themselves, and the order permits them to make a complaint about healthcare.
- The person making the complaint is a relative of, or had a relationship with, a patient who has died and is concerned about how they were treated before they died.
- The person making the complaint is acting as an advocate for the patient.

Where a patient is unable to give consent, the service provider can agree to investigate a complaint made on their behalf by a third party. However, before doing so they should satisfy themselves that the third party has:

- no conflict of interest; and
- a legitimate interest in the patient's welfare (for example parent of an adult, spouse).

If no consent has been given or the complaint has been raised, for example on behalf of a child or on behalf of someone who lacks capacity to complain, this will be taken into account and will affect the way the complaint is handled.

Help with complaints

The Patient Advice and Support Service (PASS) can assist relatives and carers wishing to make a complaint on behalf of a patient. They are accessed via Citizens' Advice Bureaux.

Named person

The Mental Health (Care and Treatment) (Scotland) Act 2003 introduced the safeguard of a ‘named person’ for individuals detained or compulsorily treated under this Act.

The named person has a right to be consulted about aspects of the individual’s care and treatment. They can also make applications to the Tribunal and attend and give their views.

The Mental Health (Scotland) Act 2015 has made changes in relation to named persons. An individual can now choose whether or not to nominate a named person to protect their interests. This nomination has to be written, signed by the individual, and witnessed.

The person who has been nominated also has to consent in writing to show their agreement and this again has to be witnessed. The named person can withdraw their consent if they decide they no longer wish to be in the role.

Previously, the next of kin would automatically be the named person unless the individual chose someone else. This might not have been the individual’s wish. Under the new legislation, adults who do not nominate someone to be their named person will not have a named person.

A named person can be anyone aged 16 or over who is not directly involved in a professional role in the individual’s care. Named persons for children under 16 will automatically be the parent or guardian, local authority, or primary carer.

Named person rights do not apply if the individual is being treated informally.

An additional protection introduced in the 2015 Act is the role of ‘listed initiator’***.*** If an individual is unable to nominate someone due to illness or lack of capacity, the 2015 Act makes provision for someone other than the patient to make applications or appeals to the tribunal about their Mental Health Act order.

These people are known as ‘listed initiators’. The patient’s nearest relative, primary carer, welfare guardian or attorney can act as a listed initiator.

Advance statements

The 2003 Act introduced ‘advance statements’.

An advance statement allows an individual to set out their wishes if in future they become too unwell to make decisions about treatment, and need compulsory treatment under the Mental Health Act. Anyone who makes decisions about their treatment must read the advance statement and consider their wishes. This includes doctors and the Mental Health Tribunal. When someone makes an advance statement, the Commission is informed of its existence and where it is kept. The Commission does not keep copies of advance statements.

Individuals can also make a ‘personal statement’ about any other information that will help staff care for them. This can include who they would like information shared with if they become unwell. This can help both carers and professionals follow their wishes in this situation.

It is good practice to encourage individuals to update their advance statements regularly. See the Commission’s Advance Statement Good Practice Guide, or our booklet explaining advance statements, for more information.

Do carers have a duty of confidentiality?

Carers do not have a specific legal duty (unless they are care staff under contract) with regard to confidentiality. However, it is important for a carer to respect the individual’s right to privacy. It is good practice to try to get an individual’s consent before discussing personal information. If carers know that the person would not want them to disclose certain details they should do their best to abide by this.

However, if information is important for the safety of the individual or others, the carer may have to consider sharing this with the appropriate agencies.

Caring can affect carers and families. Carer support groups and organisations provide a valuable opportunity for peer support, information, help, and advice.

It is often difficult for a carer to discuss personal situations in a carers’ group without revealing information about the person they care for. Carers should disclose only the minimum amount of personal information necessary and should consider how the individual would feel about being discussed. They should try to balance the importance of being supported with what they disclose and the potential benefit to them and to the individual, and not compromise the individual’s dignity and privacy.

Caring can sometimes be very frustrating. Some carers who have concerns about the individual’s care and treatment may want to express this on social media or in the press. However, they should be aware that this information can then be passed on with no control. Carers should carefully consider how the individual would feel about their personal details being publicised.

Conclusion

The personal experience and unique knowledge a carer has of the individual they care for can be invaluable to professionals. Working together and including carers in the treatment plan can help achieve better outcomes for the individual. If professionals are transparent and appreciate the input carers can offer, any problems can be minimised.

Much recent legislation, policy, and guidance has challenged service providers and practitioners to involve carers more in the treatment of the individuals that they care for, recognising the important part that they play.

We hope that this process will continue and that professionals will welcome carers as equal contributors, and not let issues of confidentiality adversely affect the care provided to the individual.

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