



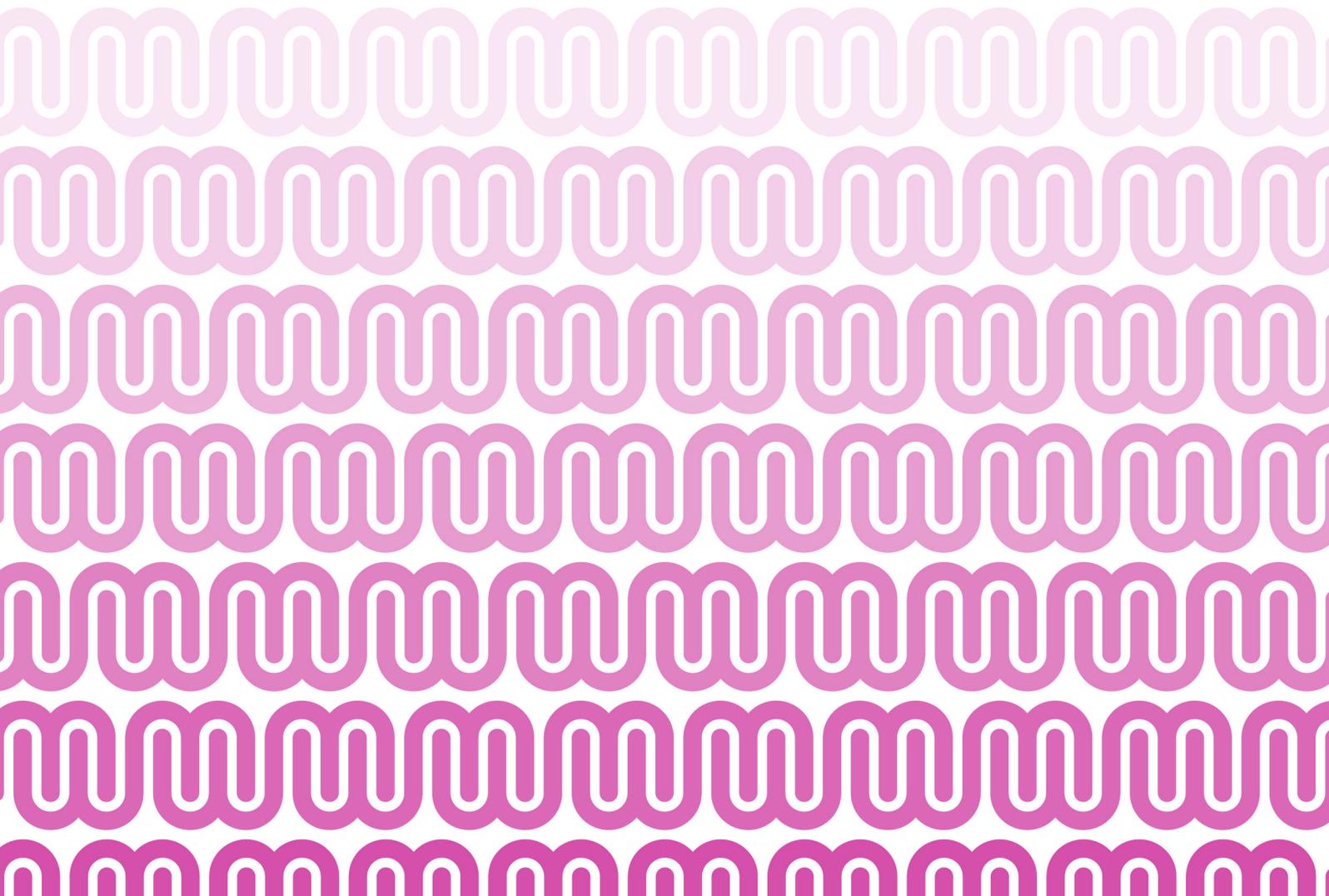
mental welfare
commission for scotland

Carers, consent, and confidentiality

How families can be involved in their relative's care and treatment

Good practice guides

April 2024



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

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Carers, consent, and confidentiality

About this guide

This guide is divided into two sections. Section one is designed to help family members and carers understand consent, capacity, and confidentiality, where the person they care for has a mental illness, dementia, a learning disability, autism, personality disorder or other related condition.

Section two is designed to inform health, social work, and social care professionals when considering confidentiality and sharing information, hearing from families and carers, and listening to what they have to say.

Looking after someone can be challenging for the individual, family members, and carers. Difficulties around confidentiality and information sharing between carers and services can add to the distress a family may already be experiencing. As a family member, friend or carer, knowing what your rights are can be helpful when navigating health, social work, and social care services.

Most unpaid carers are family members, partners or friends who provide unpaid support. Throughout this guide we will mainly use the term 'family' when referring to unpaid carers.

Our work with families

The Mental Welfare Commission knows that it is important to listen to families and their experiences. We speak directly with families when we visit services, through our enquires and investigations, and when they call our advice line. We often hear that families feel their views and the views of their relative are not being listened to by services, which has a negative effect on the care that is being given.

Our engagement and participation officer (carers) also directly engages with families and carers to:

- help ensure they are aware of their rights around communication with services;
- identify when discussions with staff are appropriate;
- make sure that families' voices are heard and incorporated into our work.

The information in this guide has been informed by using our experience of working with families and hearing about the difficulties that people face in relation to confidentiality and consent.

Section one: Including families

When people are unwell, it can often be difficult for them to explain to professionals how they feel. It is important for professionals to be able to speak to someone who knows the individual well. Families can often describe concerns about the person's behaviour, recent events and provide background information to help to inform their loved one's support, care and treatment.

Involving family members wherever possible means it is less likely that important information will be missed and helps families to maintain a supportive relationship with the individual.

Capacity and consent to share information – what does this mean?

A person who is accessing services can give their permission (consent) for health, social work, and social care staff to speak to their families about their health conditions and treatment, but they must have 'capacity' in order to give this consent.

In Scotland, everyone over the age of 16 years old is presumed to have capacity to make relevant decisions unless they have been formally assessed as not having the capacity to make some or all decisions about their lives.

To have **capacity**, a person must be able to:

- make decisions;
- act on decisions;
- communicate decisions;
- understand decisions; and
- retain memory of the decisions.

A person's capacity is usually formally assessed by a doctor, and families should be included in the discussion. Capacity can vary over the course of an illness and even over the course of a day, so it is important that capacity is reviewed regularly.

If a person has capacity, then they can give **consent**; this includes consent to have their medical information be shared with someone else.

A person's consent must be:

- **voluntary** - given without any pressure from anyone else; and
- **fully informed** - they have all the information available relevant to them and the decision that they are making presented in a way that they understand.¹

Health, social work, and social care staff should always ask a person for their consent to share information with their families.

¹ [General Medical Council: Decision making and consent \(https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/decision-making-and-consent\)](https://www.gmc-uk.org/professional-standards/professional-standards-for-doctors/decision-making-and-consent)

Confidentiality

Confidentiality around our personal information is a right we all have and something we all expect. This should be discussed from the outset when we speak to a health and/or social work/social care professional. Some of the most common problems families have in trying to help their relative are around confidentiality and information sharing. Confidentiality is respected for all individuals in mental health settings and will only be breached by staff if there is a danger to the person or others. If staff believe there is risk to the person and/or others, the health, social work, or social care professional should inform the individual.²

Staff should be aware that it is in the best interests of a person for their family to be involved in their care and treatment. In many cases the person 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.

Families tell us they feel staff sometimes use confidentiality to avoid having conversations with them, leaving them feeling helpless, dismissed, and ignored. This should never be the case. It is good practice for staff to talk with families as soon as possible and where the person's information cannot be shared by staff with families, staff can make it clear they can still listen to families' and carers' views.

Families should always be allowed and encouraged to offer information to professionals involved. They know the individual best and can provide valuable information that does not breach the confidentiality of the relationship between the individual and the professional team.

Families and confidentiality

If you are a family member trying to discuss your concerns with staff, there are three common situations you may come across:

1. If your relative has capacity to consent for staff to share their information with you, then staff can discuss your relative's care and treatment.
2. If your relative has capacity to make the decision and does not consent for their information to be shared with you, staff cannot breach your relative's right to confidentiality about the aspects of their care and treatment and other relevant information that they do not wish to be shared.
3. If your relative does not have capacity to decide about sharing the relevant information with you, they cannot give staff consent to share their information.

In all situations, and regardless of your relative's consent or capacity, you can give information to the professionals involved and staff should listen to you.

² [The Charter of Patient Rights and Responsibilities - Revised: June 2022 \(www.gov.scot\)](http://www.gov.scot) (page 19) highlights exceptions allowing NHS Scotland staff to share information without the person's consent

If your relative does not wish to share information

It is good practice for staff to discuss this with the person and try to find out why they do not want to include you in their care and treatment.

Even when consent is not given to share information, staff can still, and should, listen to you.

Staff will not be able to share personal information about the person they are looking after, but they can listen and can discuss the situation in general terms with you.

Help, support, and general information around mental illness can be given to you by staff at any time, even if your relative has refused to allow information sharing.

It may be that your relative will agree to some information being shared, for example, someone may be happy to discuss their treatment and discharge, but not a previous drug problem. This is known as partial information sharing.

Your relative may also change their mind about what can be shared as their mental state improves. Staff should discuss with the individual what they are happy to have disclosed, and review this regularly.³

If the person you care for is unable to provide their consent to share their information

In this situation, the principles of the Adults with Incapacity (Scotland) Act 2000 (the AWI Act) are relevant. The past and present wishes of the individual and views of people who are important to them will be looked at. The AWI Act is explained in detail on [our website \(www.mwcscot.org.uk/law-and-rights/adults-incapacity-act\)](http://www.mwcscot.org.uk/law-and-rights/adults-incapacity-act).

³[NHS inform: Information for carers using NHS services \(https://www.nhsinform.scot/care-support-and-rights/health-rights/communication-and-consent/information-for-carers-using-nhs-services/#rights-of-carers\)](https://www.nhsinform.scot/care-support-and-rights/health-rights/communication-and-consent/information-for-carers-using-nhs-services/#rights-of-carers)

Case study 1

Mary's son John is 26 years old and has been detained in hospital for four months after a period of psychosis.

Mary had found it very difficult to get services to listen to her when John became ill and the situation became so bad John required detention under the Mental Health Act.

Mary is John's named person⁴.

John has refused to let staff discuss his care and treatment with Mary and she has not been able to speak to anyone about her concerns.

Staff now plan to discharge John to Mary's care, but she is anxious about this as she does not know what is wrong or how she can best support John.

She wants to know what to do now.

The Commission advises:

Mary can contact the ward and explain she is John's named person and has a right to be involved in discussions about John's care.

Although John does not want his mum to have his information, it is vital that staff speak to her and hear her concerns. Staff should ensure that Mary has access to the members of the clinical team and her views should be recorded in the records relating to John's care.

Staff should speak to John again and explain it will be difficult to be discharged home if his mum is not aware of any problems and see if he will change his mind now he is getting close to discharge.

Staff should also make sure they give Mary contact details for after discharge so she can quickly get help if her son becomes ill again.

⁴ A named person is someone who can be chosen by a person over the age of 16 years to help protect their interests when receiving treatment under the Mental Health Act. Scottish Government has published [Mental health law in Scotland: guide to named persons](https://www.gov.scot/publications/mental-health-law-scotland-guide-named-persons/) (<https://www.gov.scot/publications/mental-health-law-scotland-guide-named-persons/>)

Case study 2

Omar has advanced dementia and is in hospital with a bowel obstruction. A decision needs to be made about how health services will treat him.

Omar's daughter, Nadia, is his welfare guardian. She is distressed and not sure what to do.

The Commission's advice

Having advanced dementia, Omar is unlikely to be able to give an informed opinion about his care and treatment, but where possible, he should be supported with day-to-day decisions. Omar has a guardianship order in place which has been granted by a Sherrif. The guardianship order will list the powers that Nadia has to make decisions for Omar. This may include decisions about Omar's medical treatment.

As his welfare guardian, Nadia can make decisions about his treatment, with advice of the medical staff, where there are powers granted in the guardianship order.

Any treatment decisions will need to be informed by the principles of the AWI Act.

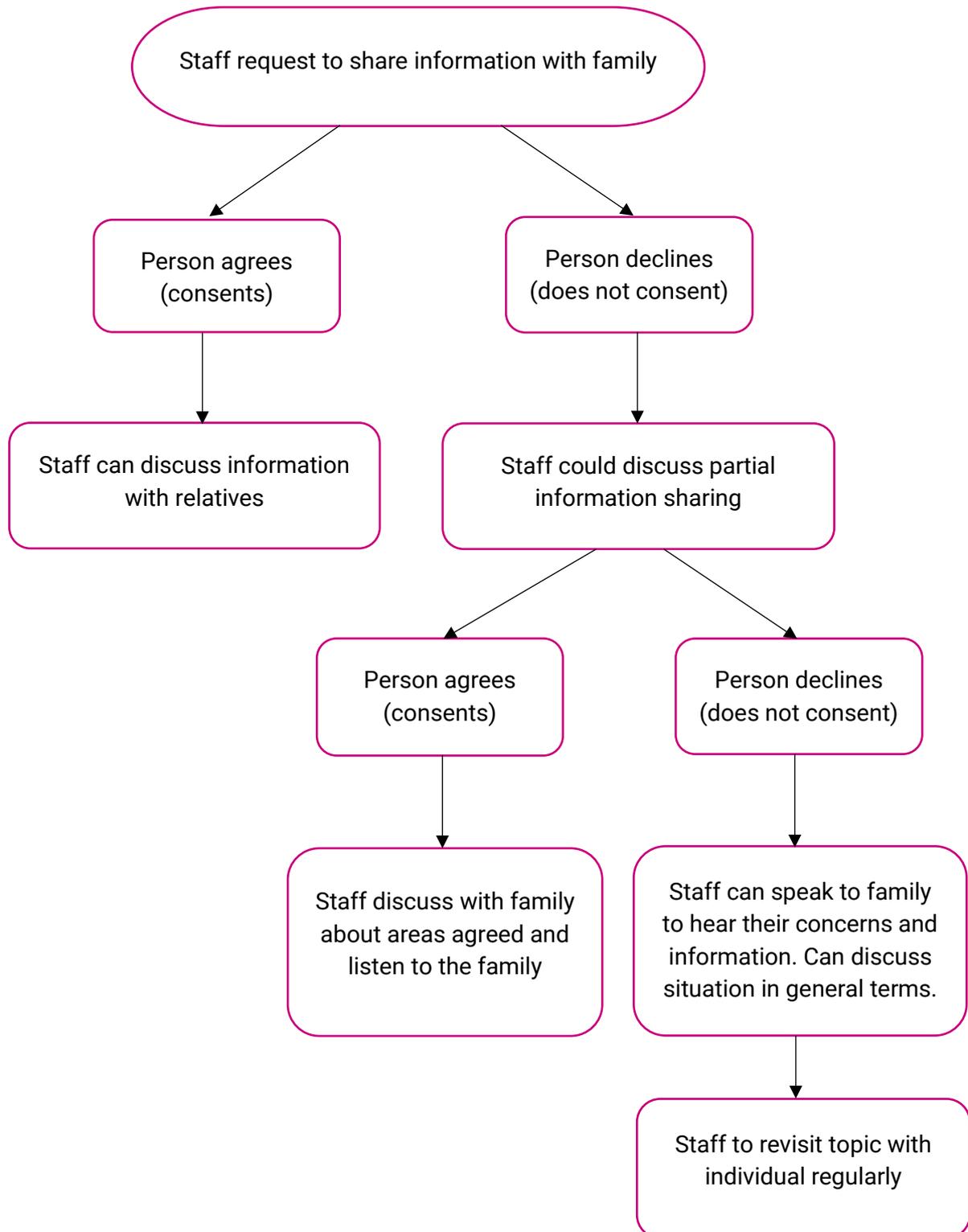
Nadia will be able to tell the staff what her father would have wanted if he was able to give his view and she can discuss with other family members also.

Lastly, Nadia can consider whether any treatments will benefit her father physically or whether intervention would cause more suffering.

Involving the medical staff and other friends and family, will help support Nadia in her decision, and ultimately ensure that Omar receives the care and treatment that is best for his needs.

Process for information sharing

The flow chart below shows how the process should work when a staff member wants to talk to family members about the person's specific circumstances. In all instances, staff can listen to the family's views even where the person has declined permission to share their information. Staff should also consider the offer of an independent advocate for the person to discuss and have their views represented.



Confidentiality between families and staff

It is also important that families are given the same rights to confidentiality.

Members of the family should be able to talk freely to staff. If they ask for the information to remain confidential between themselves, staff should respect this, wherever possible.

Case study 3

Jo is the named person for her partner, Alex, who has been in hospital. Alex feels well enough to be discharged, but Jo disagrees.

Alex's discharge was discussed at the multi-disciplinary team meeting (MDT) on the ward, which Jo was not invited to.

Jo doesn't want to upset Alex but doesn't know what to do next.

The Commission's advice

Under the Carers Act and as Alex's named person⁵, Jo should be involved in any discharge planning and should be able to speak to staff on her own to express her concerns.

Jo should have been invited to the MDT meeting unless Alex said they didn't want her there.

Arranging an appointment for Jo to speak to the senior charge nurse or Alex's responsible medical officer would be a good first step.

Jo could speak to the team confidentially, to talk about her concerns and the reasons for disagreeing with Alex's discharge at the moment.

⁵ A named person is someone who can be chosen by a person over the age of 16 years to help protect their interests when receiving treatment under the Mental Health Act. Scottish Government has published [Mental health law in Scotland: guide to named persons](https://www.gov.scot/publications/mental-health-law-scotland-guide-named-persons/) (<https://www.gov.scot/publications/mental-health-law-scotland-guide-named-persons/>)

Carer rights in law

Families have rights under the mental health law in Scotland.

Mental Health (Care and Treatment) (Scotland) Act 2003 (Mental Health Act)

The Mental Health Act states that the views of a carer should be taken into account, and:

- that they should be given respect for their experience,
- be given appropriate information, and
- have their needs considered.

It also allows people who are detained under the Mental Health Act to nominate a named person to support them. Further information about named persons can be found on our [website \(www.mwcscot.org.uk/looking-help/help-carers#993\)](http://www.mwcscot.org.uk/looking-help/help-carers#993).

Adults with Incapacity (Scotland) Act 2000 (AWI Act)

The AWI Act also has as one of its principles that the views of family and friends should be considered.

It states that the past and present wishes of the person should be considered and family and friends will often be the best people to provide that information.

The AWI Act provides the safeguards of powers of attorney and guardianship orders for people who have lost capacity to make some or all decisions or may lose it in the future.

In partnership with the Office of the Public Guardian and NES we have produced the [webinar 'Exploring Power of Attorney and Guardianship' \(https://learn.nes.nhs.scot/72230/adults-with-incapacity-awi/awi-for-everyone\)](https://learn.nes.nhs.scot/72230/adults-with-incapacity-awi/awi-for-everyone).

Carers (Scotland) Act 2016 (Carers Act)

The Carers Act introduced the adult carer support plan and young carer statement, which all unpaid carers have a right to be offered or this can be requested by the adult or young carer. If a carer accepts or requests a support plan or young carer statement, local authorities have a duty to provide the adult carer support plan or young carer statement to the carer.

If consent is given, families can be involved in looking at the services needed for their relative and have their views considered.

The Carers Act also states that families should be involved in discharge planning for their relative and that they should receive information and support for themselves.

More information on mental health laws can be found on our [website \(www.mwcscot.org.uk/law-and-rights\)](http://www.mwcscot.org.uk/law-and-rights).

Do families have a duty of confidentiality?

There is no specific legal duty on families regarding confidentiality, but they need to respect their relative's right to privacy.

If sharing information is important to the safety of their relative or others, then it is important to tell services about this.

Support groups often have rules around the confidentiality of information discussed at meetings, as it can be difficult for families to discuss their concerns and worries without revealing some information about their relative's situation.

Some families become so frustrated that they consider taking their concerns to different services, such as the Scottish Public Services Ombudsman (SPSO), or the media; this should be approached very carefully, always considering what their relative would want revealed about them publicly. We would suggest that when families are considering sharing information about their relative(s) through the press or social media, the express consent of the person should be given.

Children and young people

Caring for a child who has a mental illness, learning disability, autism or similar condition can have significant, long term, and life changing consequences.

It is good practice to allow families to be involved as much as possible and it is important that they can speak to staff on their own.

Maintaining good relationships with the child is vital for staff but more so for families who will be supporting the child throughout their illness; they may want to discuss some issues without their child present to avoid conflict.

Parents will have vital information on their child's condition and will require help and support themselves to deal with a child who is ill.

Protection of the child is paramount but unless there is good reason to exclude them, families should be fully involved in the care and treatment of their child.

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

Children under 16 however, can also make their own decisions if they are felt to understand the consequences of them and they also therefore need to give consent for information to be shared with their parents.

Whoever has parental responsibilities can make decisions for children who do not have capacity or who may not have a developed understanding to an extent which allows them to make their own decisions.

Young carers

Young carers and young adult carers are young people who look after family members.

They often have a complex and challenging role supporting a family member while also, perhaps caring for siblings and managing their own education.

Young carers make a significant contribution in caring for parents or siblings and their role should be respected and supported by services and schools.

Under the Carers Act they are entitled to a young carer statement to identify what needs they have in their role; social work should help implement this.

Young carer groups are especially helpful to try and support the young person, give them a break from caring and try to minimise the stress they may have with their caring role.

Some schools have appointed 'carer champions' from their staff group and provide peer support which is welcomed by many young people.

Many young carers report feeling dismissed by staff caring for their relatives despite their knowledge, insight, and vital role in supporting their family members.

Case study 4

Sam is 14 and looks after their mum who has a bipolar disorder and addictions.

Sam has two younger siblings aged 12 and 8. Their dad left several years ago.

When their mum is ill, Sam has to help out with shopping, cooking, looking after the younger children, and making sure their mum is safe.

The children are finding it hard to stay awake at school and are falling behind with their schoolwork.

Exams are approaching and they don't know what to do to make their situation better.

Sam has tried to discuss this with their mum's community psychiatric nurse (CPN). The CPN tends to talk down to Sam, and when the CPN is talking to his mum, they ask Sam to leave the room.

The Commission's advice

Sam is a young carer and is entitled to a young carer statement via social work to highlight the difficulties they are facing and to see what supports can be put in place to help.

If the family has a social worker, they could approach them to get this done. If there is no social work involvement, a referral should be made to local social work services.

Sam could speak to a staff member they trust at school about their situation, and they might find there is a young carer champion or group within the school who can provide support.

Involving an advocate for Sam would also be useful.

The social worker should also be able to put them in touch with the local young carer support group who can link in with them, provide time away from their caring, information and advice, peer support and a listening ear.

A social worker could also help Sam discuss with the CPN and psychiatrist how important it is for them to be involved in care decisions as they manage medication and appointments.

In addition, discussing Sam's needs with school could lead to support, including the provision of training in life skills, wellbeing, and organising activities and short breaks.

Linking in with a local group will provide Sam with much needed support. Many young carer groups also support young adults up to 25 years and this can include employment and further education advice.

Complaints

Sometimes carers contact us when they are very unhappy about a relative's care and treatment or support, or about their own experience of being a carer. They often wish to make a formal complaint about services.

The Commission is not a complaints organisation and cannot deal with complaints directly. The Commission will advise that complaints need to go through the services that are involved.

If you need further advice about what you can complain about or where to direct your complaint, you can contact the [Patient Advice and Support Service](http://www.pass-scotland.org.uk) (PASS) (www.pass-scotland.org.uk).

If you are not satisfied with the response you get after a complaint has been made, the next step is to contact the [Scottish Public Services Ombudsman](http://www.spsso.org.uk) (SPSO) (www.spsso.org.uk)

Independent advocacy can be very helpful in these situations. The [Scottish Independent Advocacy Alliance](http://www.siaa.org.uk) (SIAA) (www.siaa.org.uk) has information about advocacy and provides a search facility to find an advocacy service in your health and social care area.

Conclusion

The expert knowledge family members have about the person they care for is important for staff to be aware of, even where staff do not have consent to share a person's information.

It is vital that families have a means to discuss their concerns and share them with the professionals looking after their relatives.

Families need to be confident in challenging staff and insist that they are spoken to and, most importantly, listened to.

Useful contacts

Organisation	Contact
Carers Scotland	www.carersuk.org/scotland
Carers Trust Scotland	https://carers.org/our-work-in-scotland/our-work-in-scotland
Coalition of Carers in Scotland	www.alliance-scotland.org.uk/blog/our_members/coalition-of-carers-in-scotland
Shared Care Scotland	www.sharedcarescotland.org.uk
Scottish Young Carers Service Alliance	https://carers.org/young-carer-and-young-adult-carer-work-in-scotland/scottish-young-carers-services-alliance
Local carers centres	Contact your local authority area for information
Mental Welfare Commission	<p>Advice line phone number: 0800 389 6809 (freephone)</p> <p>www.mwcscot.org.uk/contact-us</p> <p>Individuals, parents, family members, friends and carers can phone for advice. If we cannot help directly, we can refer you to other organisations who can.</p>

Section two: Confidentiality. What should I consider as a professional?

It can be a challenging time for families when a family member develops a mental health crisis. For example, watching a relative whose symptoms of dementia become more debilitating can be extremely distressing; dealing with this, in addition to the pressures of caring for a relative with mental illness, learning difficulty, autism or a brain injury can be a major challenge.

It is good practice for professionals to try and connect with families as soon as possible after seeing their relative. In the first instance, staff should acknowledge the caring responsibilities they have been facing, often over a period of years. These can be difficult conversations, and families might be distressed or confused. However, when handled sensitively, engagement with an empathic, compassionate staff member can make a major difference to how a family copes and subsequently how well they are able to support their family member.

We often hear from families that professionals are reluctant to speak to them even if their relative has given consent to share their information. In these circumstances, families tell us they feel excluded and dismissed, and this can lead to a breakdown in the relationship both with staff and their relative.

Maintaining confidentiality and keeping the best interests of the person in mind is vital, and so is having clear, open channels of communication with those who care for them. People must be able to trust in the professionals treating them and be confident they are acting in their best interests. Effectively engaging with relatives in these circumstances is a core skill for professionals.

One of the most important things staff can do is **listen** to families and carers. This equally applies where the individual has not given their consent to share information and where there is no power of attorney or guardianship order in place. It is important to recognise that families have a unique knowledge of their relative and have vital information that could help with diagnosis and treatment that the person is unable to give themselves.

Triangle of care

The triangle of care is a therapeutic alliance between families/carers, professionals, and individuals. It aims to promote safety and recovery and sustain mental wellbeing by including and supporting carers.

It is made up of six principles:

1. Carers and the essential role they play are identified as soon as possible;
2. Staff are 'carer aware' and trained in carer engagement strategies;
3. Policy and practice protocols on confidentiality and sharing information are in place;
4. Defined posts responsible for carers are in place;
5. A carer introduction to the service is available, with a relevant range of information across the care pathway;
6. A range of carer support services is available.

It is good practice for staff to apply these principles when dealing with families.

Mental health law

One of the principles of the Mental Health Act states that anyone making a decision under the Act shall have regard to:

"the views of a carer, named person, guardian or welfare attorney into account".⁶

The AWI Act states that the views of relevant others should be sought on any decision made under the AWI Act and that the past and present wishes of the individual should be taken into account. Family and friends may be the most appropriate people to provide key information.

Under the Carers Act, family should be consulted and involved in any discharge plans. We hear from professionals that they can be placed in very difficult situations when faced with a person who does not want their information shared and a family desperate to be involved and desperate to help. However, professionals must note that families, friends, and carers can be listened to without breaching a person's confidentiality.

Breaching confidentiality

Maintaining confidentiality in clinical, social work and social care settings is a priority for all professionals. However, the complexity of cases and challenges faced by staff mean situations can arise that are unclear. In situations where there may be a risk to the person or to someone else it can be appropriate to breach a person's confidentiality.

When there is doubt about breaching a person's confidentiality, professionals should consult with their managers and senior staff and record the discussion, decision, and rationale for the decision. This should be clearly documented and placed in the person's file. Please see case study 6 for a practice example.

⁶ Mental Health (Care and Treatment) (Scotland) Act 2003 s.1(3)(b)

Professionals can also consult organisational policies, raise the issue with their information governance department, and/or data protection officer (or equivalent title/role) or the organisation's Caldicott Guardian. In addition, further information in relation to data protection can be sought from the [Information Commissioners Office \(https://ico.org.uk/\)](https://ico.org.uk/).

Advice from professional bodies

Most professional bodies have guidance on confidentiality for their members. The General Medical Council (GMC)⁷ has advice on this in their document, *Confidentiality: good practice in handling patient information*. This also has a section on sharing information with family members:

"...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 Nursing and Midwifery Council (NMC)⁸ has advice in their document *The Code* which contains the professional standards that members must uphold. Section 5: 'Respect people's right to privacy and confidentiality', gives guidance on this and highlights that nurses should:

"share with people, their families and their carers, as far as the law allows, the information they want or need to know about their health care and ongoing treatment sensitively and in a way they can understand".⁹

The Code of Practice for Social Services Workers from the Scottish Social Services Council (SSSC)¹⁰ states that social service registered workers must *"create and maintain the trust and confidence of people who use services and carers"*.¹¹ There is a requirement that social work and social care workers respect confidential information of people who access services and carers¹² whilst communicating openly, honestly and in a straightforward manner. In addition, all social care employers must ensure that systems are in place to listen to and consider feedback from people who access services and carers.¹³

The Royal College of Psychiatrists acknowledges that sharing Information with, and listening to, family or carers can be beneficial to all concerned. They directly advise their members that:

"There is nothing to prevent you, or any other healthcare professional, from receiving information provided by any third party about the patient, as receiving information does

⁷ [Confidentiality: good practice in handling patient information](#)

⁸ [Professional standards of practice and behaviour for nurses and midwives](#)

⁹ Professional standards of practice and behaviour for nurses and midwives, section 5

¹⁰ [The Codes of Practice for Social Service Workers](#)

¹¹ SSSC Codes of practice, 2

¹² SSSC Codes of practice 2.3 (workers)

¹³ SSSC Code of practice 2.3 (employers)

not equate to disclosure... It is rarely acceptable for practitioners to refuse to see carers simply because the individual has not given consent."¹⁴

All professional codes of practice acknowledge that there can be difficult situations without clear answers and advise consulting with colleagues and managers if a member is unsure about sharing information. However, it is clear that professional care and treatment can benefit from connecting with and listening to family members. This can be done even if the person accessing services has refused information sharing as long as no personal information about them is disclosed.

Having a conversation with the person accessing services on a regular basis may reveal that it is a specific fact or incident that they do not want shared and that they are happy to discuss current care and treatment plans. In this instance 'partial information sharing' may solve difficult issues when talking to families.

If a person does not have capacity to make a decision about sharing their information, then a decision about any disclosure can be made using the principles of the AWI act and discussion with a Caldicott Guardian¹⁵ in relation to health information. Discussing the situation in general terms can be very helpful to families also. Facing a wall of silence when trying to understand what has happened to their relative produces more anxiety and anger and allows deeper frustrations to develop.

The National Confidential Inquiry into Suicide and Homicide emphasised that "working more closely with families could improve suicide prevention."¹⁶

We know that better communication with and support for families leads to better family involvement. This means that families may be then able to help keep their loved ones safe, limit access to means of self-harm, and be more confident in providing key information to professionals.¹⁷

¹⁴ Good Psychiatric Practice, Confidentiality and Information Sharing 2017

¹⁵ UK Caldicott Guardian Council: <https://www.gov.uk/government/groups/uk-caldicott-guardian-council>

¹⁶ The National Confidential Inquiry into Suicide and Homicide by People with Mental Illness Annual Report 2015: England, Northern Ireland, Scotland and Wales July 2015. University of Manchester. [national-confidential-inquiry-into-suicide-and-homicide-ncish-annual-report-2015.pdf \(hqip.org.uk\)](https://www.ncish.org.uk/national-confidential-inquiry-into-suicide-and-homicide-ncish-annual-report-2015.pdf)

¹⁷ Gorman LS, Littlewood DL, Quinlivan L et al, Family involvement, patient safety and suicide prevention in mental healthcare: ethnographic study. *BJPsych Open*. 2023 Mar 23;9(2):e54

Case study 5

Linda is a staff nurse in a busy adult acute ward. A relative wants to know about the changes that have been made to the medication of their family member.

The patient has capacity and has said he does not want his treatment discussed with his family.

Linda must explain to the family and carers that she cannot breach her patient's confidentiality and cannot give any personal information.

However, she should offer to speak to the patient again and see if the person still wishes no information to be shared.

Linda should then also speak to the relative and listen to any information that they have which may be relevant to the care and treatment of their relative.

It is good practice for staff to speak to relatives as soon as possible after admission as they often have vital information.

Linda can also talk to the relative in general terms about mental health and treatment without revealing any personal information about her patient, in addition to offering signpost information to carer support.

Families appreciate transparent, honest conversations from a senior staff member.

Case study 6

Callum is a community psychiatric nurse visiting one of his patients at home.

The person he is visiting is distressed and voicing ideas of suicide. Callum spends some time with her, and she reveals she has a plan to end her life that night.

Callum suggests they should maybe consider going into hospital until she feels better but she becomes angry and says she does not want Callum to tell anyone what she has said.

She says she knows about confidentiality and that Callum will be breaking the law if she repeats anything she has told him. She asks Callum to leave.

Callum contacts his line manager immediately and discusses the situation saying he wants to arrange an emergency admission.

His line manager agrees that he can breach confidentiality in this circumstance where there is risk to his patient. Callum should contact the local team to arrange for the person to be assessed under the Mental Health Act.

In circumstances where there is risk of harm to an individual or to others it is acceptable to breach a person's confidentiality to ensure their safety.

Conclusion

Including families in the care and treatment of people is of significant benefit to the person, their family, and the professionals involved.

Families and carers often have extensive, vital information that will help in decisions around care and treatment. Where a person refuses to have their information shared, listening to and having a general conversation with families can still be beneficial to all concerned.

Families can be distressed by the time services become involved, and relationships may be strained, often for good reason; open, transparent, and honest dialogue from staff can reassure them that their relative is getting the care and treatment they need.

Best practice is to engage with families early and include them wherever possible in the ongoing care and treatment of their relative. This allows vital relationships to be maintained ensuring ongoing support moving forward.



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Mental Welfare Commission 2024