



Resources for Carers, Young Carers and Staff:

6. Confidentiality and Information Sharing

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1. Introduction and Summary

Carers, young carers and family members should be seen as working in partnership with those who provide clinical services. They provide important information that may help doctors, nurses and social workers to have a better understanding of the needs of service users.

In order to effectively work in partnership, children, carers and family members need clear information about the service user's care and treatment, their medication, potential side effects and any other relevant circumstances.

Summary

Living with a mental health condition can create challenges when trying to maintain positive understanding and communication between those who care (as partners, children or parents, friends or relatives), clinical staff and the service users themselves.

These guidelines have been designed to provide advice and direction for all involved including staff, service users and their carers, on how to avoid compromising service users' confidentiality or excluding carers from the care of their loved ones.

Staff recognise that they have a duty of care not just to the service user, but to the whole social network that is so often vital in the recovery and restoration of wellbeing.

In order to find the right balance when sharing information with all parties, staff must consider the carer's, as well as the service user's own health needs, cultural expectations, willingness and capability. It is crucial to recognise the vital contribution that so many carers make, often for long periods, with little respite and sometimes little sense of reward.

This booklet offers guidance on good practice, with a focus on finding the right balance between a duty of confidentiality to service users and carers, and a duty to share information with carers and young carers in the best interest of service users and for better treatment outcomes.

Confidential health-related personal information is shared between care professionals, such as, doctors and nurses involved in a service user's care, so that they get the safest and highest possible quality clinical care. In addition, staff need to include carers and young carers in the extended care and support team.

Carers' roles require them to be well informed to be able to provide the essential support that service users need.

Effective care and better clinical outcomes rely on this **three-way partnership** between people who experience mental health problems, their families and carers, and our staff.

The trust is committed to forming constructive and supportive working relationships with all carers and young carers who play an important part in the lives of service users.

2. Duty of Confidentiality

Service users have a right to expect that information about them will be held in confidence. This is central to the trust between them, their professional care team and their carer. Carers and young carers also have the same right to expect that the information they provide will be held in confidence by the professional care team and that this is equally crucial to maintain the trust between all parties.

3. Definition of Carer

We use the term ‘carer’ in its broadest sense to include the most significant people in the life of the service user, including spouses, partners, parents and young carers. It is important to ask the service user who they consider to be their carer. Young people living with someone suffering from mental illness can also be considered as carers

It is also important to note that the carer is not always the “nearest relative”.

The term “nearest relative” is defined in the Mental Health Act.

4. Duty to Share Information

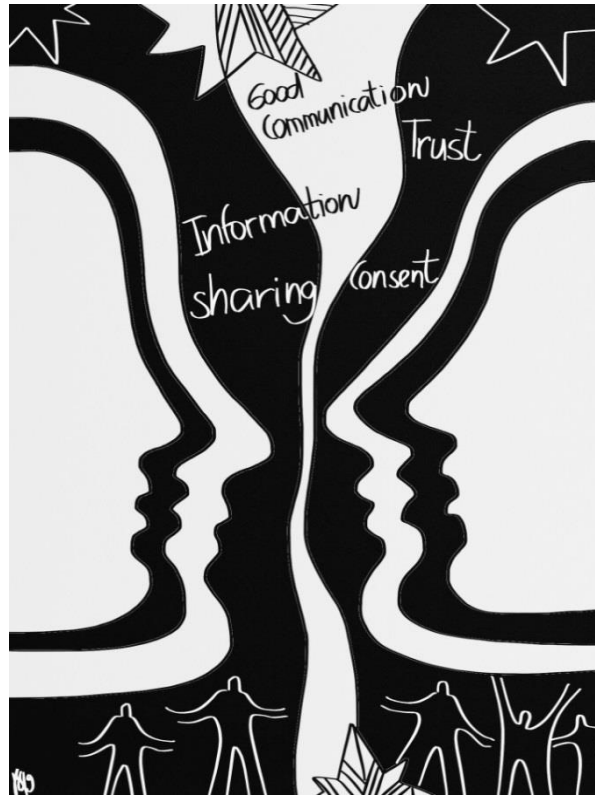
Doctors, nurses and other members of the care team have a duty to share information about the care, treatment, medication and other important information about a person’s health, in order to provide the safest and best clinical care possible.

5. Good Communication

Carers are more likely to recognise subtle changes at an early stage of illness or relapse, as they know the service user when they’re well. This information can often prove crucial to ensure early access to appropriate services and interventions by professionals.

Wherever possible, communication between staff and carers must start as early as possible. Staff must avoid professional jargon and communicate clearly. In most situations, face-to-face communication is better, in order to develop a mutually trusting and beneficial working relationship. It is important to consider a carer or a young carer's situation as some might be in education and unable to meet outside school hours.

Carers often value information and encouragement to learn what effective support and services may be available for their relatives.



6. Consent to Share Information

Confidential information about a service user should only be shared (or not shared) with their explicit permission.

If the service user doesn't give permission, confidential information can only be disclosed in exceptional situations, such as, where the service user's, or others' health and wellbeing is under serious risk, or where there is a public interest or legal reason for disclosure without consent.

The care team should always **revisit and review** a service user's refusal to share information with their carers/loved ones. Many service users often agree to sharing information with carers when their condition improves.

The decision to override duty of confidentiality in the best interest of the service user must always be made by staff authorised to make a disclosure, following the strict guidelines laid out in the trust's confidentiality policy.

It's important to remember that although it is necessary for a service user to give consent for information about their treatment to be shared with their carer; other information that is not confidential or personal can still be given **without** breaching confidentiality.

Care professionals may engage with carers, young carers, talk to them and provide general information, advice and support.

It is important to bear in mind that the care professionals “are not prevented from talking to carers about facts they already know; a breach of confidentiality only occurs when personal information is newly disclosed.

7. Example of Good Practice: Brian's Story

Brian is an inpatient who is known by staff to be close to his family, who are supportive.

He instructs staff that he does not wish to see any member of his family and does not want any of them to be invited to a multidisciplinary team meeting for a review of his care.

Mel, his sister, is aware of Brian's instruction but asks to be invited to the meeting as a representative of the family. Arrangements were made to see the sister separately from her brother. She was given the opportunity to express her concerns about the frequency of Brian's readmission recently, and wondered if he is being treated with appropriate medication.

She reported that he had responded well to a particular depot medication in the past, but that he had been given different types of medication in his recent admissions which in the family's view, resulted in early relapse and readmission. She was aware that professionals believe that Brian's preoccupation with his bowel was delusional. However, she was able to confirm that there is a significant history of death from bowel cancer in his family, thus reinforcing the team's plan to investigate his physical complaints more assertively, which reassured both Brian and his family.

It was agreed that Brian will be encouraged to write an advance directive when he is well, to make sure that his family continue to be engaged with the professionals in his care.



This advice from a service user represents best practice when service users are in mental health care for the first time:

“

When I am well and stable, I should write down somewhere prominent the things I want done and things I don't want done when I become ill. It may be too late to get my opinion and permission, when I am too ill.

”

8. Example of Good Practice: Luke's Story

Luke has a Learning Disability and Autism and is going through a difficult time. Recently, there has been an increase in challenging behaviour; self-injury and physical aggression. He has also been spending more time on his own, refusing activities and there has been a change to his sleep pattern. The Supported Living service who support him and his parents (John and May) are becoming very concerned about him.

Luke's Supported Living service wish to refer him to the Community Learning Disability Team (CLDT) for support. The Supported Living service undertook an assessment of his capacity (under the Mental Capacity Act, 2005) to consent to the referral and information sharing between different parties. Luke was deemed not to

have the capacity required to consent to these interventions.

A best interests decision was made between all of the parties involved in his life; the Supported Living service, John and May, his GP, his Social Worker and his Key Worker. It was deemed to be in his best interests to refer him to the CLDT and to share information. Luke's views and opinions were also taken into account in this decision.

Luke was referred to the CLDT and information from clinicians is shared with his Supported Living service, John and May, his GP, his Social Worker and his Key Worker. This ensures that everyone involved in his life is able to contribute and support in his care and have all the information required to support him.

9. What Information is Confidential?

People have varying opinions on what they consider to be sensitive and confidential.

An example of good practice is where a service user is first seen on their own, then the carer alone (with the service user's consent) and finally both together. In this way, care teams can understand both the service user and the carer's wishes, learn what each considers to be sensitive and confidential and what they are willing to share.

Where communication/language barriers make effective communication difficult, staff should make all effort to clearly understand individual needs, including using an interpreter or getting advice if necessary. Staff also need to consider a carer's age and provide information that is age-appropriate.

Staff must be mindful of the way cultural difference and attitude may affect the role of carers and their understanding about confidentiality. It is possible that the service user and the carer might have differing expectations.

Staff should be open and informative but sensitive where individual autonomy and freedom of choice may not be part of the carer's values. In all cases where the carer's role is critical to the recovery of the service user, the principles set out here will guide practice regardless of culture, religion, social status, disability, sexuality or gender.

10. What if the Service User Objects to Sharing Information?

Even when the patient continues to withhold consent, carers and young carers must be given enough knowledge to enable them to provide effective care. They should also be given the opportunity to discuss any difficulties they are experiencing in their caring role and help to try and resolve these.

Professional judgement and discretion are critical when staff are making decisions about sharing information.

11. Example of Good Practice: Ali's Story

Ali lived with his parents. He was regarded as a "good boy" until his 18th birthday, when he started to fall behind with his coursework.

He stopped getting up to go to work and stopped attending college. He cut himself off from his friends and spent more time isolated in his bedroom watching TV and playing his music very loudly. He also thought "everyone was out to get him", including his mother Amina.

He was admitted to an inpatient ward. During assessment, he told the nursing staff that he did not want any information passed on to his mother.

Amina was his carer, so the ward staff invited her to meet Ali's key worker.

The nurse listened to Amina's story and recorded her concerns. She also gave Amina important information about the ward, some relevant mental health awareness and advice as to where she could find out more, besides letting Amina know that she could contact the key worker if she had questions and needed support. Amina was not told anything confidential about Ali.

As Ali got to know his key worker better, he told her that he was worried about his mother finding out about his cannabis use.

A staff member might say to a carer:



What sort of things do you want to know? I can talk about this but not that.

I can't talk about your relative but we can talk about general aspects.

For example, we might talk about why people who appear to talk to themselves might be doing that.

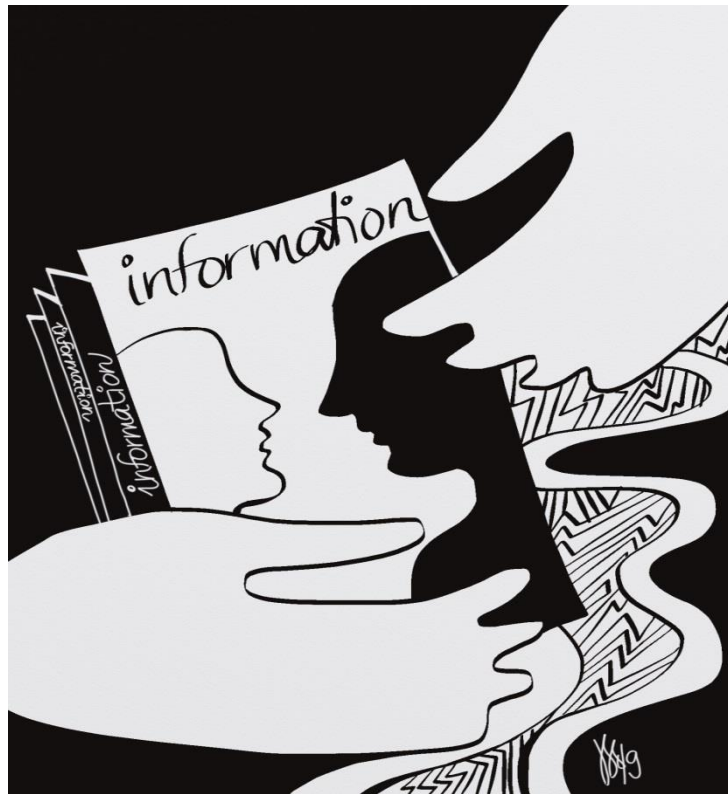
A carer might say to a member of staff:



What I need is help and advice to manage the situation – so that I don't make things worse.

I have heard doctors mention psychosis. Can you explain what this means? How do people deal with this as carers?

Can you suggest any leaflets, books or helplines to help me find more information?



12. Example of Good Practice: Marion's Story

Marion was adamant that she didn't want her family to be told anything about her involvement with Gender Identity services. When her worker took the time to explore the reasons for this attitude, Marion revealed that she was concerned that something which she had been keeping secret from her family might be revealed to them. The worker was able to reassure her that this was not the case and negotiated with Marion what information she was comfortable with being shared with her family. This

case study provides a good example of how honesty, sensitivity, and respect for Marion's concern quickly improved communication, minimising any need for secrecy or collusion.

In this way, the family could be kept in the loop without undermining Marion's wishes.

13. Advance Directives

Where someone has previously experienced acute illness, '**advance directives**' can be used. This should contain a service user's wishes about information sharing (or not sharing information) with family and carers.

When discussing advance directives, staff should emphasise to service users the importance of their duty to share information to provide effective care.

If the service user refuses to share information, staff need to explore further to find out whether, for example, this applies to all information or just some sensitive areas.

This will need to be revisited regularly to reflect the service user's latest wishes, health and care needs.

Relatives and carers should be involved in decisions surrounding care and treatment, particularly when a service user lacks the capacity to consent.

It is important to check that relatives and carers named in an advance directive are consulted to make sure they're willing to act.

People named should be encouraged to sign up to the document with dated signatures.

14. Example of Good Practice: Deb's Story

Debs has been married to Sue for 8 years. Although their relationship has always been strong, their lives have been troubled by Debs' experience of three serious mental health crises. Sue has been supportive and understanding during these difficult times, despite Debs often showing anger and intolerance toward her during these episodes. After her recovery from the last one, Sue, Debs and her care co-ordinator designed an advance directive that would guide all those involved on how best to manage Debs' care in future. This was done with Sue's support and written agreement that this directive should ensure clear communication is

maintained between Sue and Debs' care co-ordinator, even at times when Debs might become hostile towards Sue's presence and involvement. All parties agreed that Sue should activate this plan in the event of a future problem.

The advance directive described how things typically developed when a crisis struck, such as the usual presence of Debs' make-up suddenly becoming lurid, a sure early warning sign that her mental health was starting to deteriorate.

Quite quickly she would lose her judgement and start accusing friends and family, especially Sue, of wrongdoing. At these times she would most likely insist that Sue be excluded from being involved in her care. The advance directive made it clear that at such times her mental health team must ignore the things she said and should continue to consult with Sue on Debs' care. Previous episodes had already shown how crucial Sue's views had been in ensuring that her hospital discharge was planned at the most suitable time.

Debs signed several copies of this document and asked that her consultant, care coordinator and her GP each keep a copy in her medical files.

15. Balancing Carers' and Service Users' Expectations

The Carer's (Equal Opportunities) Act 2004 requires that carers who devote much time and resource to someone else's needs also get consideration of their own.

Where a carer's needs appear to conflict with the needs of those they care for, staff must recognise the right of carers to maintain privacy, even on matters that may directly impact upon the service user.

For example, where a carer may hold householder responsibilities for the home where the service user lives, they may not want to share details of financial burden or tenancy agreements.

Similarly, a carer's own health matters, which may be important to share with the care team, but which the carer may not wish the service user to know.

In such situations, staff must use professional judgement to promote and uphold the needs, rights and wishes of the service user and their carer.

The carer should be informed that such information may in some circumstances be released to other parties, for example if ordered by a court of law or to the police for the prevention and detection of crime.



16. Example of Good Practice: Alex and Louise's Story

Alex is 23 years old, adopted by Louise after suffering abuse and neglect in infancy. Her birth mother died from an overdose and Alex was diagnosed with ADHD at school.

Alex has experimented with many drugs and now uses cocaine, alcohol and cannabis. She smokes cannabis daily, and binges on alcohol and cocaine when she is feeling stressed.

Alex referred herself to START substance misuse service and initially attended with her mum. Louise controls Alex's finances closely, keeps her bank card and gives her small amounts of money each day. Alex has previously taken money from the home, and has been aggressive towards Louise when challenged.

Alex consented to sharing information with her mum and said she wanted to regain her trust. Alex began seeing her drug worker for fortnightly sessions to learn new coping strategies for stressful situations, and better ways to manage her emotions and communicate when she feels upset.

Louise was referred to the Families in Recovery service, which provides a support

group and 1:1 sessions for relatives of substance users. She attended regularly and also repeatedly contacted the service to ask for feedback on her daughter's attendance and progress.

Alex did reduce her drug and alcohol use but she expressed feelings that her mum was constantly watching her, and treated her like a child. After a few months, Alex decided she no longer wanted us to share information with her mum. We invited Louise in to discuss the benefits for Alex of taking more personal responsibility for her own recovery, and explained we would not be sharing information with her at this time because Alex wished to have more privacy and independence. Families in Recovery continued to support Louise to look after her own needs and encouraged her to step back from trying to control Alex's life.

17. Principles of Best Practice

Principles of best practice:

- Staff should seek service users' views on sharing information as early as possible. This will usually be during assessment or admission.
- This is the time when it is most likely the service user will refuse permission. This may be because they may be very unwell, feel betrayed by their carer, or be very angry about the carer's role in their assessment or possible detention.
- There needs to be a clear understanding that sharing information will need to be re-visited when things have calmed down. Regular review of the situation by the care team is essential.
- Even if permission to share information is refused at this point staff must still give general information about mental illness and treatment options, discuss the carer's concerns or fears and signpost them to carer's support services. The carer may need help and support to understand their relative's decision to exclude them.
- Deciding what information is general and what is personal will be a clinical judgement in each case.
- The same principle of confidentiality applies to information given by carers. Staff must clarify the carer's expectation as to who the information can be shared with. Information recorded in the carer/third party section will not be disclosed to a service user even when they make a subject access request unless the carer gives their express permission.
- Where the service user withholds consent or lacks capacity and cannot express their wishes clearly, personal information will only be shared on a strictly 'need to know' basis. It is essential that staff explain how and why the decision to overrule their wish is thought to be in their best interest.

18. Carers and Young Carers: Good Practice Checklist

A carer/young carer's copy

I was given general, factual, verbal or written information about:

- Any confidentiality/ privacy restrictions/ difficulties requested by the service user; the person I support. This must be regularly reviewed by the professionals involved
- General information about mental health diagnoses
- General information about medications; benefits and possible side-effects, timings and age restrictions.
- Local in-patient and community services (including crisis and out of hours numbers)
- Local and national support groups (helpful numbers etc)
- General information about the Care Programme Approach, if relevant

I was also given:

- The opportunity to see a professional on my own
- The right to my own confidentiality when talking to a professional
- Confidence to voice my views and any concerns I may have
- A carer's assessment or a signpost to the Sheffield Carers Centre and/or Sheffield Young Carers Centre

If the service user consents, I can also receive information about:

- The mental health problems experienced by the service user
- Their specific treatment plans including medical information

19. Carers and Young Carers: Good Practice Checklist

A staff member's copy

I gave general, factual, verbal or written information (relevant to the person's age) about:

- Any confidentiality restrictions requested by the service user; the person I support. This must be regularly reviewed by the professionals involved
- General information about mental health diagnoses
- General information about medications; benefits and possible side-effects, timings and age restrictions
- Local in-patient and community services (including crisis and out of hours numbers)
- Local and national support groups
- General information about the Care Programme Approach, if relevant

I also gave:

- The opportunity to see a professional on their own
- The right to their own confidentiality when talking to a professional
- Confidence to voice their views and any concerns they may have
- A carer's assessment or a signpost to the Sheffield Carers Centre and/or Sheffield Young Carers Centre

If the service user consents, I also gave information about:

- The mental health problems experienced by the service user
- Their specific treatment plans including medical information

20. Useful Resources

Information and leaflets are available to download from www.shsc.nhs.uk/service-users-and-carers/carers-and-young-carers. The following resources are available for carers, young carers and staff:

1. Advocacy
2. Carers' and Young Carers' Charter
3. Carers' and Young Carers' Assessments
4. Carers' and Young Carers' Checklist
5. Community Teams
6. Confidentiality and Information Sharing
7. Hospital Admissions and the Mental Health Act
8. How to Get Involved
9. Mental Health Crisis
10. Understanding Mental Health Conditions and Medication
11. Useful Contacts Leaflet
12. Information Pack

These resources were designed in partnership with carers and young carers. SHSC worked collaboratively with Sheffield Carers Centre, Sheffield Young Carers and Chilypep and we would like to acknowledge their hard work, advice and support. These resources were updated in 2019 to ensure accuracy of information. With thanks to Jana Sandford for the artwork throughout.

For further information, contact:

- Sheffield Carers Centre on 0114 272 8363 or www.sheffieldcarers.org.uk
- Sheffield Young Carers on 0114 258 4595 or www.sheffieldyoungcarers.org.uk
- Carers Trust on 0300 772 9600 or www.carers.org

Or alternatively, contact your local SHSC team to get more information.

This guide has been adapted from the South London and Maudsley NHS Foundation Trust: Confidentiality and sharing information with carers (2018).



This document was accurate as of January 2020.