

SHARING INFORMATION WITH CARERS AND CONFIDENTIALITY

HOW TO FIND THE RIGHT BALANCE

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Introduction

Carers and family members should be seen as partners of clinical services as they provide effective support to service users. In this partnership, carers can provide important information that may help doctors, nurses and social workers to better understand the needs of service users. In order to be effective partners, carers and family members need clear information about the care and treatment of service users, their medication, potential side effects and any circumstances that may put service users at risk.

The information exchange between service users, carers and staff needs to happen in respect of:

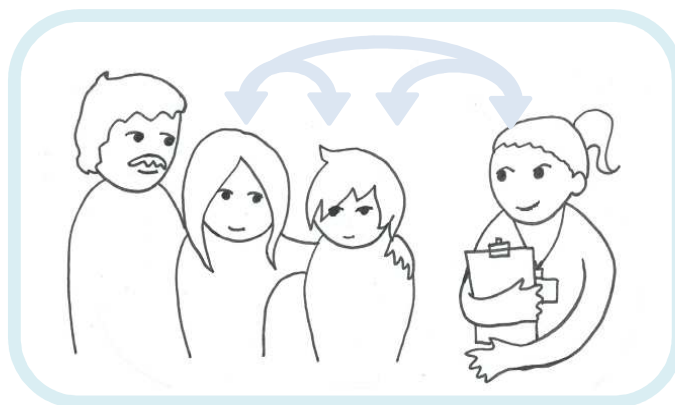


This booklet offers guidance on good practice, with a focus on finding the right balance between the duty of confidentiality to service users and carers, and the duty to share information with carers in the best interest of service users and for better treatment outcomes.

Confidential health related personal information is shared between care professionals like doctors and nurses involved in their care, so that service users get the safest and highest possible quality clinical care. In addition, staff need to include carers in the extended care and support team.

Staff should explain to service users the benefits of sharing information about their treatment and care.

Carers' roles require them to be well informed to be able to provide the essential support service users' needs. 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 its responsibility to actively form constructive and supportive working relationships with all carers who play an important part in the lives of service users.

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 also have the same right to expect that 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.

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, parents and young carers. It is important to ask the service user who they consider as 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.](#)

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 the service user's health, in order to provide the safest and best clinical care possible.

Agreement between service users, families, carers and staff about information sharing at an early stage of treatment and care can clarify future expectations and wishes of all parties.

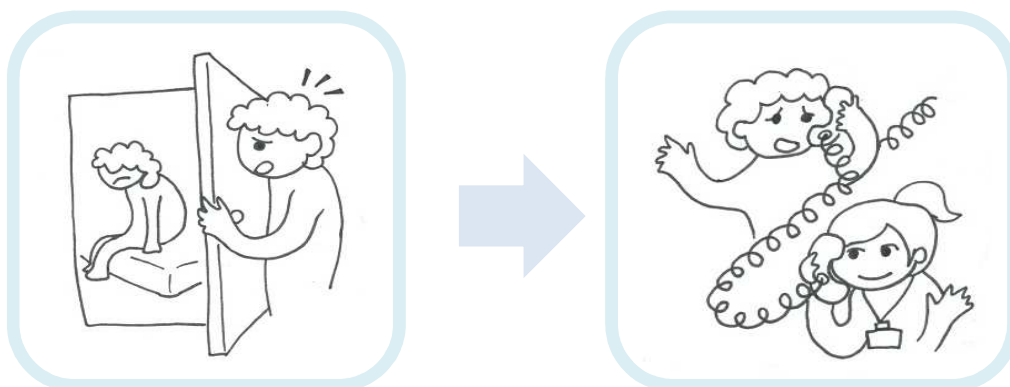


Good communication

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 service and intervention 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.

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



Consent to share information

Confidential information about a service user should be shared with the explicit permission of the service user.

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 a service users' refusal to share information with their carers. 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.

Example of Good Practice: Andrew's Story

Andrew is an inpatient who is known by staff to be close to his supportive family. 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 the multidisciplinary team meeting for a review of his care.

Tracy, his sister, is aware of Andrew'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 Andrew'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 to early relapse and readmission. She was aware that professionals believe that Andrew'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 Andrew and his family.

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

It's important to remember that although it is necessary for the 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, 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”. (Machin 2004)*

What Information is confidential?

People vary about what information they consider as 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 agreement) 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 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 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.



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.”

What if the service user objects to share information?

Even when the patient continues to withhold consent, 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.

When a service user has stated that they don’t want their confidential information to be disclosed to their carer, the following responses may be helpful.

The provision of general information about mental illness, emotional and practical support for carers does not breach confidentiality. (DH SDO Briefing Paper 2006)

Professional assessment and discretion of staff are critical when making decisions about confidentiality.



When a service user has stated that they don't want their confidential information to be disclosed to their carer, the following responses may be helpful.

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?"

Example of Good Practice: Oliver's Story

Oliver lived with his parents. He was regarded as a "good boy" until his 18th birthday, following which 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 Louise.

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.

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

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

Example of Good Practice: Iris' Story

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

This case study provides good example of how honesty, sensitivity, and respect for Iris' concern quickly improved communication, minimising any need for secrecy or collusion. In this way the family could be kept in the loop without undermining Iris's wish.

Advance Directives

Where someone has previously experienced acute illness, '**advance directives**' can be used, which should contain the service user's wishes about information sharing 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 their clearly dated signatures.



Example of Good Practice: Mary's Story

Mary has been married to Alison for 10 years. Although their relationship has always been strong, their lives have been troubled by Mary's experience of three serious mental health crises. Alison has been greatly supportive and understanding during these difficult times, despite Mary often showing anger and intolerance toward her during these episodes. After her recovery from the last one, Alison, Mary and her care co-ordinator designed an *advance directive* that would guide all those involved on how best to manage Mary's care in future. This was done with Mary's support and written agreement that this directive should ensure clear communication is maintained between Alison and Mary's care co-ordinator, even at times when Mary might become hostile towards Alison's presence and involvement. All parties agreed that Alison should activate this plan in the event of a future problem.

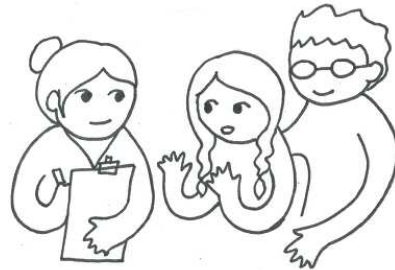
The *advance directive* described how things typically developed when a crisis struck, such as the usual presence of Mary's make-up suddenly becoming lurid, a sure early warning sign that her mental health was starting to deteriorate.

Quite quickly she would lose her judgement and start accusing friends and family, especially Alison, of wrongdoing. At these times she would most likely insist that Alison 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 Alison on Mary's care. Previous episodes had already shown how crucial Alison's views had been in ensuring that her hospital discharge was planned at the most suitable time.

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

Good practice points:

1. Pro-active planning – issues are discussed between service user, staff and carer when things are going well and service user feels sure of how their wishes and needs can best be met at times when their own judgement may be affected by their illness.



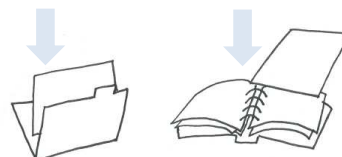
2. Early warning signs are identified.



3. Clear instructions are provided.



4. Several copies of the Directive are placed in different files to ensure it is available when needed.



5. It makes clear who should activate the directive in the event of future crisis.



Balancing carers' and service users' expectation of confidentiality

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 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.

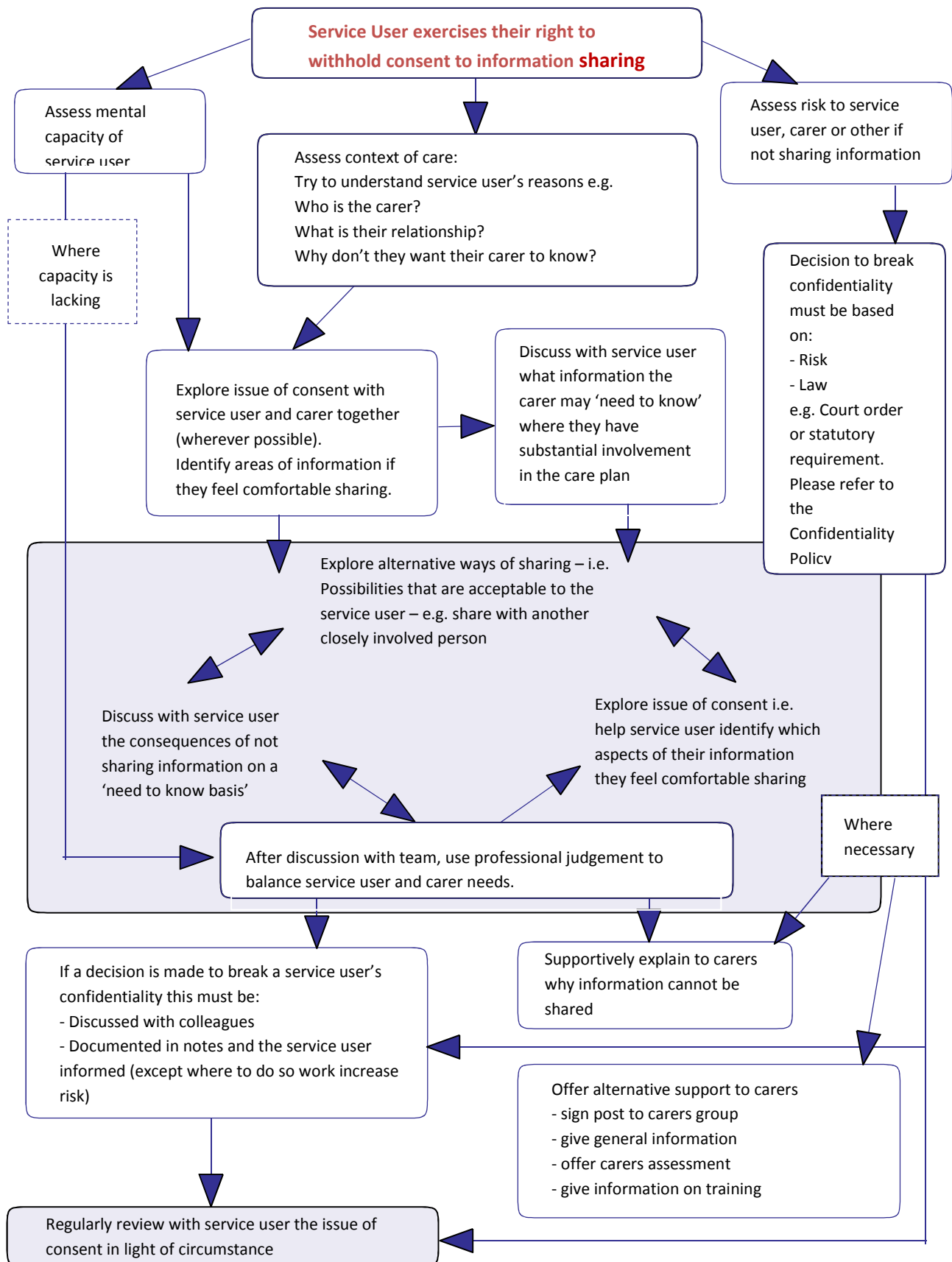
E.g. where a carer may hold the householder responsibilities to the home where the service user normally lives, they may not want to share details of financial burden or tenancy agreements.

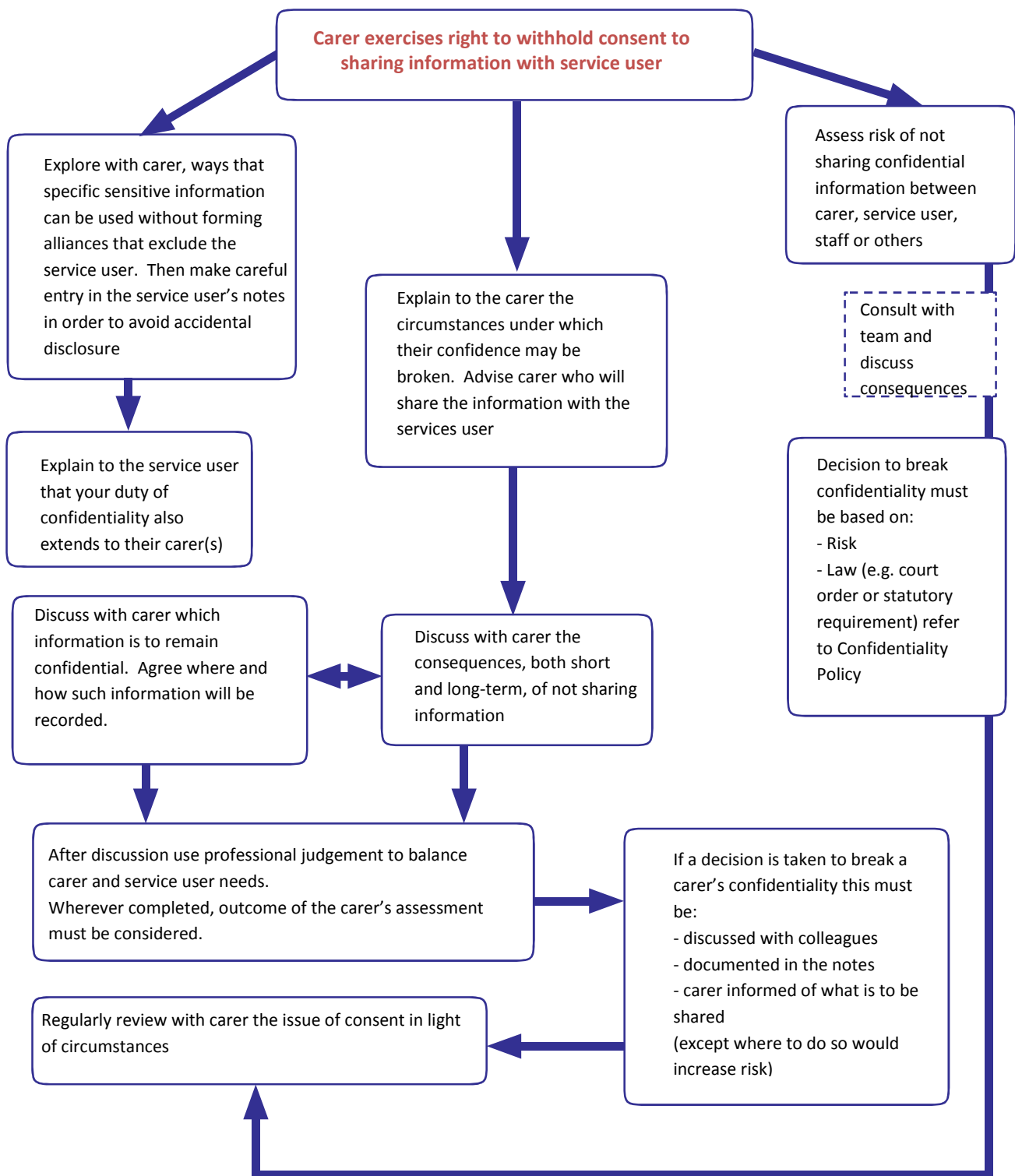
Similarly, carers' own health matters, which may be important to share with the care team, but which the carer may not wish the service user to know.

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

- Information about the carer or service user, which the carer considers confidential, should be entered under the carer/third party tab in the electronic patient journey system (ePJS). 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.







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 this 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. The ePJS has a carer/third party tab for recording confidential information which the carer does not want to share with their relatives. 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. This decision should be clearly noted on ePJS.

Summary

Some would argue that serious mental health problems present the greatest challenge in trying to maintain positive understanding and communication between those who care as partners, 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 the carers from the care of their loved ones.

It is critical especially for staff, who must take into account many factors when considering how best to proceed. 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 finding the right balance in 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, and recognise the vital contribution that so many make, often for long periods, with little respite and sometimes little sense of reward.

Further Information and Feedback:

For further advice, please contact informationgovernance@slam.nhs.uk

The Trust is constantly working to improve practices and understanding of effective information sharing. We welcome feedback from carers and service users on how useful they have found these guidelines by writing to:

***The Caldicott Guardian
Information Governance Department
Maudsley Hospital
Denmark Hill
SE5 8AZ***

Or email caldicottguardian@slam.nhs.uk

References

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3. Machin,G, 2004. *Carers and Confidentiality – Law and Good Practice* – Paper presented to Carers' Council Conference held at Edwinstowe on 23 April 2004
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