

Confidentiality & Carers Guidelines

The subject of confidentiality and sharing of information is a significant concern for service users, their families or carers, and staff.

The purpose of this document is to provide guidelines which will clarify and support best practice.

It addresses the issues surrounding confidentiality between:-

- **service users and staff,**
- **carers and staff, both of which require independent consideration.**

It recognises that from the outset, the bounds of confidentiality need to be explained and understood by carers, just as it is usual good practice to ensure that service users are properly informed as to who information may be shared with when working toward their recovery.

This guidance will form the basis for future training for staff, service users and carers.

The Devon Partnership Trust is committed to working in partnership with people who experience mental health problems and with their families and carers. It recognises that for many, providing effective services relies on a three-way partnership between people who experience mental health problems, their families and carers, and professional staff. It believes that its staff have a clear responsibility to be proactive in establishing constructive and supportive working relationships with all carers who play a significant part in the lives of service users.

Definition of carer

We use the term ‘**carers**’ in its broadest sense to include the most significant people in the life of the service user, including children and young carers. It is important to clarify with the service user who they see in this role.

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

Why share information?

- Agreement at an early date between service users, their families and carers, and staff over information sharing can prevent problems from occurring later on.
- Carers are more likely to know the well person and recognise subtle changes at an early stage. The information they provide can often prove crucial in planning care.
- Carers are unlikely to be familiar with medications and unable to differentiate between side-effects and the return of ill-health; and careful education is needed.
- Carers may benefit from education and encouragement to learn what effective support might be and what services may be available.
- Support for the whole family is essential.

- Families and carers are usually very aware of the social context and history. With guidance, this knowledge is probably the greatest contribution they can make toward recovery.
- Fear about breaching patient confidentiality has frequently created a barrier to effective involvement of carers in mental health care (DoH – Rethink 2006)

Good communication

Wherever possible communication with carers will be timely and free of professional jargon or use of abbreviations. In many circumstances, face to face communication will be preferred.

Consent to share

Although it is necessary for the service user to give consent about his or her treatment to be shared with their carers, **general information can still be given without breaching confidentiality**. However, “the service user has no right to prohibit the professional from engaging with the carer, from providing general information advice and support, or from talking to the carer about the service user, providing that no confidential information is divulged.” In addition, “the service user has no right to prohibit the professional from receiving information from the carer” It is important to bear in mind that “the professional is 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)

The following should guide best practice:

- Staff should seek service user’s views on sharing information at the earliest opportunity. This will normally be during initial assessment or admission.
- This is the time when it is most likely the service user will refuse permission. They may be very unwell, feel betrayed by their carers, or be very angry about the carer’s participation in the process of assessment or possible detention.
- There needs to be a clear understanding that the issue will need to be re-visited when things have calmed down. Regular review of the situation is essential.
- If permission to share information is refused at this point this must not mean that staff feel unable to give general information about mental illness and treatment options, or to discuss the carer’s concerns or fears, or to signpost them to carer’s support services. For a start, 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 individual case.
- When dealing with confidential information provided by carers the same principle of confidentiality still applies. When receiving information from a carer, staff must establish the carer’s expectation as to who the information can be shared with.
- Where the service user withholds consent or may have lost their mental capacity and cannot express their wishes clearly, personal information will only be shared on a strictly **‘need to know’** basis. It is essential that an explanation is given as to how and why the action to overrule their wish is for their benefit.

Staff must be mindful of the way cultural difference and attitude may impact on the role of carers and their understanding about confidentiality. Both service user and carer might have differing expectations. Where there is a diversity of values or understanding, staff, carers and service users will benefit from a discussion about the principle of confidentiality.

Staff need to be open and informative especially where autonomy and freedom of choice may not be universally held 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 irrespective of culture, religion, social status, disability, sexuality or gender.

People vary about what they regard as sensitive and confidential. An example of best practice is where *“A psychiatrist with 30 years experience describes how she will always see the patient on their own, then the carer alone (with the patient's consent) and finally both together. In this way, she gets the maximum information from both the patient and the carer, learns what the sensitive and confidential areas are from them both and, what they are willing to share.”*

(Royal College of Psychiatrists 2004 p5),

Even when the patient continues to withhold consent, carers must be given sufficient knowledge to enable them to provide effective care. They are also given the opportunity to discuss any difficulties they are experiencing in their caring role and help to try and resolve these. The provision of general information about mental illness, emotional and practical support for carers does not breach confidentiality. (DoH SDO Briefing Paper 2006)

Themes for conversations between staff and carers

When a service user has stated their wish for confidential information not to be disclosed to their carer, the following responses may be suitable.

A member of staff might say to a carer:

- What sort of things do you want to know? I can speak about this but not that.
- I can't talk to you, but if you wish, I can ask one of my colleagues to do so.
- 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 so.
- I could contact your Carers' Support Worker if you wish, and ask him/her to talk to you.

A carer might say to a member of staff:

- I don't want to know about confidential stuff. 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?
- I appreciate that you have been asked not to talk to me, so can you suggest one of your colleagues who I could approach with my questions?
- Can you suggest any leaflets, books or Helplines to help me find more information?
- Could you help me by explaining a few things that I have read about but don't fully understand?

Case Study 1

James lived with his parents. He was an excellent apprentice up to his 19th birthday, following which he started to fall behind with his college course-work.

He failed to get up to go to work and stopped attending the Technology College. He cut himself off from his friends and spent more and more time isolated in his bedroom. He also thought “every one

Case study

Jean was adamant that she did not want her family to be told anything about her involvement with the mental health services. When her Community Psychiatric Nurse took the time to establish the reasons for this attitude, Jean revealed that she was concerned lest 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 to negotiate with her what information she was comfortable with being shared with her family.

This case study provides good example of how honesty, sensitivity to, and respect for Jean's concern quickly enables improved communication between all parties, thus minimising any need for secrecy or collusion. In this way the family can be kept in the loop without undermining Jean's wish.

Advance statements

Where someone has already experienced acute illness then the use of '*advance statements*', which include the service user's wishes regarding information sharing with family and carers can be used. When discussing advance statements emphasis should be placed on the importance of information sharing to providing effective care. When sharing is refused the issue needs to be

explored to find out whether, for example, this applies to all information or just some sensitive areas. This issue will need to be revisited at intervals to reflect the service user's health status and changing care delivery.

Whenever possible relatives and carers should be involved in decisions surrounding care and treatment particularly when an individual has a lack of capacity for consent. It is advisable that relatives and carers named in an advance statement are consulted by the individual to make sure that they are willing to act in such a capacity. Named individuals should be encouraged to sign up to the document and their signatures clearly dated.

Case study ③

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

The **Statement** included a description of how things typically developed when a crisis struck, such as the usual presence of Mary Ann's make-up suddenly taking on a strikingly lurid appearance, a sure early warning sign that her mental health was starting to deteriorate.

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

Mary Ann signed several copies of this document and asked that her Consultant, Care Co-ordinator and the ward manager each keep a copy in her medical files.

Good Practice Points raised by the Advance Statement case study

- **Pro-active planning – issues discussed between service user, staff and carer when things are going well and service user feels most sure of how her wishes and needs can best be met at times when her own judgement may be affected by her illness.**
- **Early warning signs are identified.**
- **Clear instructions are provided - do's and don'ts.**
- **Several copies of the *Statement* are placed in different files to ensure its availability even during out-of-hours admission times.**
- **It makes clear who should activate the *Statement* in the event of future crisis.**

Where service users clearly express their right to withhold consent to share any information with carers, in the absence of an advance statement, staff should refer to the guide below.

Service user exercises their right to withhold consent to information sharing

Assess mental capacity of service user

Assess context of care:
Try to understand service user's reasons:
e.g. who is the carer?
What is their relationship?
Why don't they want their carer to know?

Assess risk to service user, carer or others of not sharing information

Where capacity is lacking

Explore issue of consent with service user and carer together (wherever possible)
Identify areas of information they feel comfortable sharing

Discuss with service user what information the carer may 'need to know' where they have substantial involvement in the care plan

Decision to break Confidentiality must be based on:
- Risk
- Law
- e.g. Court order

Explore alternative ways of sharing – i.e. Possibilities that are acceptable to the service user – e.g. share with another closely involved person

Discuss with service user the consequences of not sharing information on a 'need to know' basis

Explore issue of consent i.e. help service user identify which aspects of their information they feel comfortable sharing

After discussion with team use professional judgement to balance service user and carer needs

Where necessary

If a decision is made to break a service user's confidentiality this must be:
- discussed with colleagues
- documented in notes
- and the service user informed (except where to do so would increase risk)

Supportively explain to carers why information can't be shared

Offer alternative support to carers
- signpost to carers group
- give general information
- offer carers assessment
- give information on training

Regularly review with service user the issue of consent in light of circumstances

These guidelines emphasise that in all decisions about confidentiality, allowance must be made for professional assessment and discretion. This applies not only with regard to the service user's situation, but also the context of care, the carer's circumstances and the consequences of providing or withholding information.

Similarly where language difficulties inhibit clear communication, all effort should be made to clarify individual needs, if necessary seeking the assistance of an interpreter or staff member who may have knowledge or experience of specific cultural norms.

Where service users are engaging with mental health care for the first time these issues require additional attention. Otherwise the following advice from a service user represents best practice: -

"I think it should be written down when the client is well, stable, and somewhere prominent the things they want done when they're ill and things they don't want done. Come the time when they're ill it's too late to start collecting consent"
Service user

Balancing the confidentiality needs of carers with those of the service user

The Carer's (Equal Opportunities) Act 2004 provides legal support to ensuring that carers who devote much time and resource to someone else's needs, also receive consideration for their own.

In striving to maintain a balance, 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 and respect in relation to matters that may directly impact upon the service user.

Carers recognise the need for this balance, but may have legitimate reasons for retaining some privacy and confidentiality in matters that may impact upon those they care for. e.g. Where a carer may hold the householder responsibilities to the home in which the service user normally lives, they may wish not to share details of financial burden or tenancy agreements.

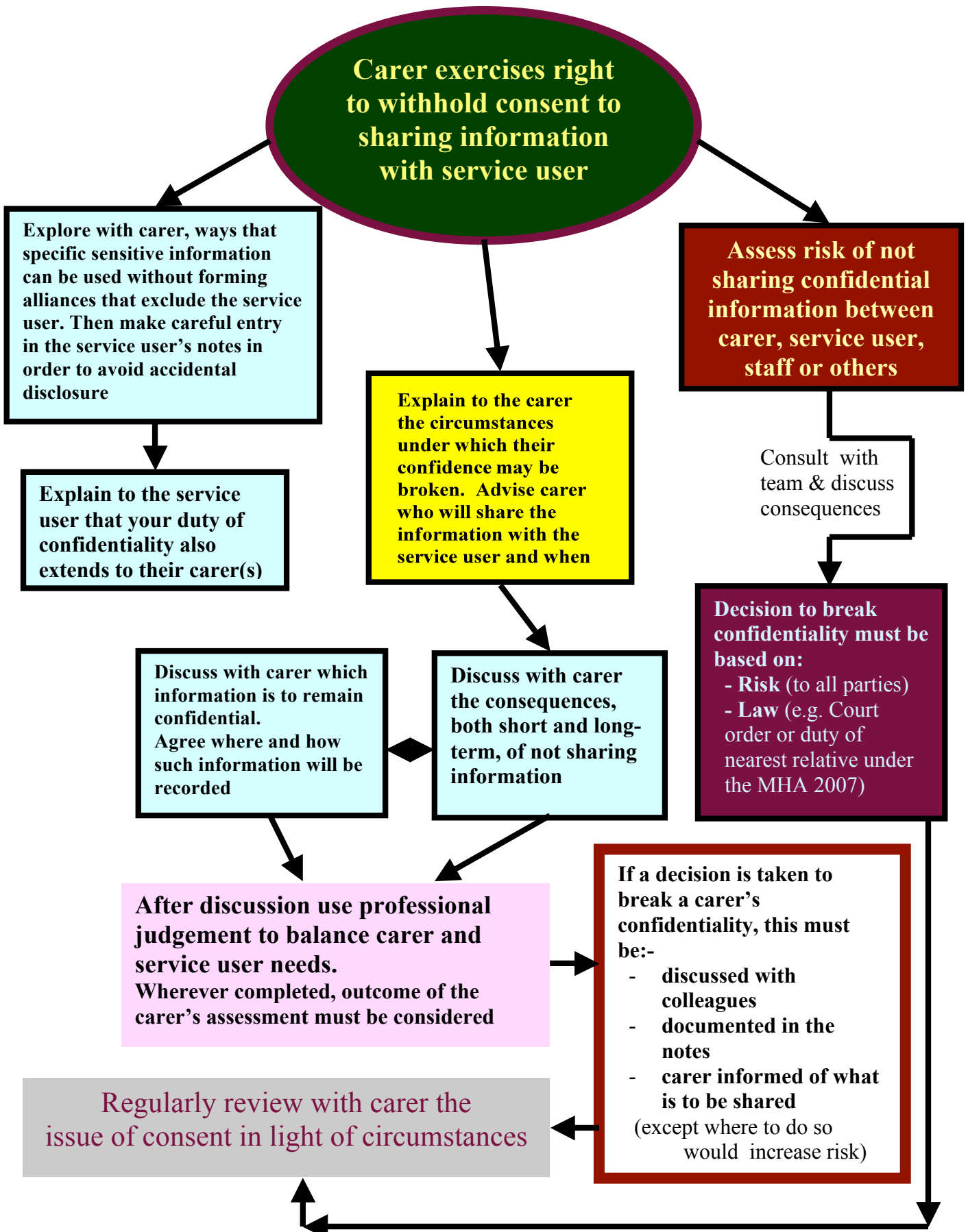
Similarly, carers' own health matters, which may be deemed important to share with the team for practical reasons, but not with the service user, may require careful consideration.

Understandably, staff may have many reservations about being party to confidential information, as they fear being asked direct questions by the service user, causing them to avoid or even lie about certain matters. Or they fear accidentally disclosing something that they had forgotten had been shared in confidence. For these reasons, openness and joint discussion between all parties are usually best. But where legitimate situations dictate, staff must consider the following:

- **How and where information confidential to the carer is to be recorded and held**
- **How information about past or recent history of the service user, given in confidence, can be utilised**

In such circumstances, it is left to staff to use professional judgement to the best of their ability, to promote and uphold the needs, rights and wishes of service users, whilst also exercising their responsibility toward the carer, whose role is so often crucial to the plan of care and longer term recovery.

Where information is given in confidence to staff by carers, they may also exercise their right to withhold consent to the sharing of that information with the person they care for, or service user. In such circumstances staff should refer to the chart below.



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, the staff from all services, statutory, voluntary and independent, and the service users themselves.

These guidelines provide advice and direction for all involved, but 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 managing what can often be delicate communications, staff must consider the carer's, as well as the service user's own health needs, cultural expectations, willingness and capability, when recognising the vital contribution that so many make, often for long periods, with little respite and sometimes little sense of reward.

These guidelines are not presented as do's and don'ts. Rather they offer sound advice for many complex situations that are unique to the care and support of people with serious mental health problems.

References

Carers (Equal Opportunities) Act (2004) HMSO

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Machin G (2004) *Carers and Confidentiality – Law and Good Practice*
Paper presented to Carers' Council Conference held at
Edwinstowe on 23rd April 2004

Royal College of Psychiatrists (2004) *Carers and confidentiality in mental health – Issues involved in information sharing*
www.partnersincare.co.uk download campaign materials – Carers and Confidentiality leaflet

This document has been compiled by a working party of experienced carers, mental health and social care staff. Drawing from the above resources, advice from the National Institute for Mental Health in England and having engaged with service users in a variety of forums this draft is now ready for further consultation prior to ratification by the Devon Partnership Trust as a guideline to accompany the Trust's Confidentiality Policy. It is to be used as both a reference document and educational resource to support future training. July 2007