

<b>Confidentiality Policy Practice Guidance Note</b>		
<b>Carer's Charter - Common sense approach to sharing information with carers - V04</b>		
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## 1 Introduction

- 1.1 Within the process of the providing high quality care packages to people who use services provided by Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (the Trust/CNTW) there is a recognition that in many cases, carers are providing valued and vitally important care and support, sometimes on a full-time basis. There is also an understanding that carers often feel 'cut-off' from, and 'ill-

informed' about, the care of people close to them, even though they may be providing a significant level of care.

- 1.2 The Trust see people who are carers as '**partners in care**', and not just as a resource.

## 2 Aim

- 2.1 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 examine the issues and set out what users of services, families and carers might reasonably expect and provide guidance for staff on best practice in this area.

- 2.2 **The Trust is committed to working in partnership with people who use its services and with their families and carers. It recognises that providing effective treatment relies on a three-way partnership between service users, their families and carers, and professionals. We believe that it is part of the role of professionals to promote clear communication between service users and carers, working together towards recovery.**

## 3 Definition

- 3.1 We have used the term families and carers in its broadest sense to denote the most relevant people in the service user's life and social network; this includes children and young carers. It is important to clarify with the service user who they see in this role by asking who they see regularly and who provides them with support. This, of course, may change over time.

- **Why share information?**

- Sharing information enables carers to provide care and support more effectively, which benefits the patient/service user and promotes recovery
- Carers are better able to maintain their own wellbeing as they are relieved of the anxiety about doing the wrong thing through not knowing and therefore this prevents carers fearing the worst
- In addition sharing information helps professional's gain greater understanding of the patient/service user and the support available.

## 4 Consent to Share information

- 4.1 **It is necessary for the service user to give consent for information about his or her treatment to be shared with family, friends or carers. A lack of consent does not prevent staff listening to carers' concerns and/or providing them with general guidance and assistance.**

- 4.2 There are, however, exceptions to when confidentiality may be broken which largely relate to issues of public safety, including child protection (Department of

Health, 2003). **When others are deemed to be at risk, staff have a duty to inform them.**

4.3 The Trust Caldicott Guardian is a source of reference for issues where staff have concerns about information sharing when explicit consent has not been given.

4.4 **Staff must acknowledge that in practice they cannot provide service users with safe and effective care in the absence of relevant information about his or her condition and history. Seeking information from others for the purposes of care planning does not pose a threat to the service user's confidentiality.**

#### 4.5 **Principles and solutions**

- Staff should discuss information-sharing with service users at the initial meeting and also at regular intervals. They should agree what can be shared, with whom, in what circumstances
- If the service user consents to the sharing of confidential information, then this can be done in accordance with the principals above
- If the service user does not consent to the sharing of confidential information, then general information about conditions and treatments can be shared with carers
- Carers should expect in all cases to be able to speak to staff about supporting their loved ones, get general information and support in doing so and have their confidentiality rights respected in the same way

4.6 **A carer should be able to expect the following principles in their relationship with the care team:**

- Full recognition and understanding of their contribution
- Support to meet their needs as a carer
- Information to assist their understanding of the service users health needs and its presentation
- Involvement as a partner in carer needs

## 5 **Carers needs**

5.1 Carers may also have different needs, views and expectations to service users and should therefore be considered separately, in their own right, rather than being an addition to the service user's assessment and care plan.

5.2 Care Coordinators and named nurses (within inpatient care) will be expected to listen to and take into account the views of carers in relation to the cared for person, including such issues as the current position of the caring relationship and whether this can be maintained. It is also important to offer carers appropriate means of assessing their own needs within what is often a demanding caring role.

### 5.3 Carers should be able to:

- Ask for more information if they need it
- Ask for more support if they or the person they care for needs it
- Be clear about how information about themselves, the carers, is handled and shared
- Ask for an initial discussion and later review about information-sharing with professionals
- Exercise their right to a separate carer's assessment
- Recognise the rights of the person they care for
- Understand the professionals need to protect privacy and the rights of the service user
- Respect the professionals time, they will have a large caseload. If there are conflicts over time, consider setting up a system to manage communications
- Try to keep cool when speaking to professionals

## 6 To share or not to share

- 6.1 In the majority of situations, service users will agree to involving and informing the carer in all areas of their contact with services. Trust staff will positively emphasise to the service user the benefits of open communication with carers, outlining the positives that can be added to the care package by everybody involved in their care being fully involved in working together.
- 6.2 Where a service user chooses not to share information regarding his/her condition, on most occasions, they have every right to expect their wishes are upheld regarding confidentiality.
- 6.3 Any specific issues service users do not wish to be discussed or disclosed with their carer must be clearly documented.
- 6.4 In practice, there is a marked distinction to be made between general information, such as requests regarding the client's general wellbeing, routines of the unit or service where care is being provided from and information that can be seen as 'confidential' such as details regarding the client's current mental health.
- 6.5 When a member of staff is in discussion with a carer they should:
- Establish the past/current caring relationship
  - Clarify what the carer/significant other already knows about the clients' situation/mental health difficulties
  - Actively listen to the carer/significant others requests and respond accordingly

## 7 General information that can be given

- 7.1 Carers should be offered and/or given, by the named nurse/care coordinator general information concerning:

- Mental health problems, treatments; including information leaflets
- Medication (dosages, side effects, what to be aware of)
- Information re care processes, routines
- Signposting to and/or offered help to access organisations that can provide further information and support
- Contact details of the named nurse/care coordinator on the unit/community team to enable consistent support and reassurance, not only during periods of crisis
- Time and opportunity to share information re their unique knowledge of the service user and that this is recognised as an important and valued part of the assessment process

7.2 This information should be discussed with the carer/significant other and also offered as printed information where appropriate.

7.3 Even where consent to share information has not been given, staff can still provide information about symptoms and what to look for and how to respond to these. If the carer should request information about a particular illness that they suspect the service user may be suffering from, staff can give information including relevant leaflets without fear of breaching confidentiality.

## 8 Information that is deemed to be confidential

8.1 Where a service user has expressed a wish for confidential information not to be shared, this, in the majority of cases, will be adhered to.

8.2 Where staff are unsure re disclosure the following information provides a useful guide.

8.3 If the individual is **unable** to give permission to share information due to an assessed lack of capacity at that point in time, the implications of the Mental Capacity Act will need to be considered. Confidential information that is considered essential for the carer to be aware of, such as risk issues and any ongoing care information can be agreed to be shared following a Multi-Disciplinary Team (MDT) decision taking into consideration the views of the carers/significant others as to the likely wishes of the service user and if it is in the service users best interests to do so. Where there is a current advance statement/decision that has been made by the service user this should be used to guide practice if possible.

8.4 If the service user is **unwilling** to share confidential information and has been assessed as having capacity to make such a decision, disclosure can only occur following an MDT decision that a breach of confidentiality is necessary due to risk to self or others.

8.5 Families and carers also have the right to expect that information that they provide will not be shared with other people without their consent. However, staff will need to explain that the exceptions for when confidentiality may be broken apply to them, just as they do for the service user.

## **9 Advance Decisions and Statements**

- 9.1 **An advance decision/statement made by someone can be overridden at any time by the author. Staff should confirm with the client that the information still reflects their current wishes for how care should be delivered (this may include parameters around confidentiality).**
- 9.2 The carer will be made aware of these systems and the timescales that this decision making process will take.

## **10 When information cannot be shared**

- 10.1 Where carers' requests for confidential information cannot be met, staff must inform the carer of the process, be clear that their requests will be discussed with the MDT and the reasons for withholding information that is deemed to be confidential will be explained in full. Continued support to the carer from the staff involved with the service user's care will be ongoing.

## **11 Recording carer's information**

- 11.1 Information shared by carers should also be entered into the service user's case notes. This information will be classed as 'third party' information and carers can, in fact, ask for this information to remain confidential at the point of entry. Carers should be informed that if a service user requests to see their notes under the Data Protection Act 2018, this information will only be revealed if the carer consents or if it is possible to disclose the information without revealing the identity of the third party. Staff can also restrict access to information if it may cause serious harm to the physical and/or mental wellbeing of the service user or any other person. A clear statement of consent/dissent from the carer should be recorded in the case notes on each occasion the carer provides information.

## **12 Risk management**

- Carers should not be expected to provide care and/or manage risks without have sufficient information and support to do
- Details of decisions about information sharing should be recorded in the service user's electronic record, to enable all staff to relate to family and carers from an informed position
- Where service users do not wish information to be shared, families and/or carers still have a right to be heard by staff and to input their views into the care planning process

## **13 How we can help carers**

- 13.1 Staff need to acknowledge that family members and carers are generally doing the best they can in difficult circumstances. They may be experiencing considerable stress, and therefore be less able than usual to communicate carefully and clearly; staff need to take care therefore to make sure they are understood. Many carers and family members have little or no prior experience of mental health services and may be uncertain as to how to respond to their

relative. They would be helped by the routine availability of information such as the following:

- Information on the way the service works
- Information on relevant mental health issues
- Information on their rights to a carer's assessment
- Information on support available for carers
- Who to contact to share information
- Who to contact in the event of a crisis

### 13.2. **Staff should:**

- Value carers as partners in care
- Recognise the contribution to care made by carers and provide the necessary information and support so they can care effectively
- Recognise that carers are experts in the support they provide and their knowledge of the people they care for. Involving carers in the training and selection of staff and the commissioning of services leads to better outcomes
- Be proactive in addressing the topic of information- sharing as early as possible
  - Identify carers at the initial consultation
  - Include carers in the care plan
  - Raise the issue of information-sharing with the service user and get agreement on what information can be shared, with whom, when and under what circumstances
- Be approachable so that carers feel comfortable to ask for information
- Appreciate that carers' sometimes have fraught experiences and are coping in difficult circumstances and offer appropriate understanding and support
- Be flexible in offering lines of communication to carers
- Consider options for flexible, personalised support
- Offer carers a separate assessment and sufficient information and time to decide what would be most helpful
- Sign-carers to support organisations and groups
- Respect carers' own privacy and rights to confidentiality

### 14 **In line with the Carers Charter, the following approaches are now being implemented by the Trust:**

- **Leaflets** on confidentiality and information sharing will be given to service users and carers and discussed at the earliest stage, usually during assessments and then at review

- Staff will help patients to distinguish between sensitive and personal issues (for example, about their sexuality), which are to remain confidential and more general information about the illness, which can be shared
- Issues regarding confidentiality will be recorded in the patient's notes so that all staff are aware of any changes in the patient's attitude regarding confidentiality
- The use of, 'Advance Decisions and Statements' will be encouraged. These allow patients to plan their care when they are well, explaining what they would like to happen if they become unwell
- Staff will help service users to understand the benefits of sharing appropriate information with their carer
- The Care Coordinator will provide carers with the support and help needed on issues relating to information sharing and confidentiality
- Carers must be encouraged to ask questions. Time must be made available to answer questions
- Professionals will involve carers in treatment plans and in major decisions about the patient

## **Good Practice Checklist**

The following checklist has been taken from the 'Carers and Confidentiality in Mental Health' leaflet produced by the Partners in Care campaign and published by the Royal College of Psychiatrists. It is designed to assist staff to work closer with carers within the boundaries of current legislation and to help carers understand their rights.

### **Carers are given general factual information, both verbal and written about:**

- The mental health diagnosis
- What behaviour is likely to occur and how to manage it
- Medication – benefits and possible side-effects
- Local in-patient and community services
- Care Coordination (CC)
- Local and national support groups

### **Carers are helped to understand:**

- The present situation
- Any confidentiality restrictions requested by the patient
- The patient's treatment plan and its aims
- Any written care plan, crisis plan or recovery programme
- The role of each professional involved in the patient's care
- How to access help, including out-of-hours services

### **Carers are given:**

- The opportunity to see a professional on their own
- The right to their own confidentiality when talking to a professional
- Encouragement to feel a valued member of the care team
- Confidence to voice their views and any concerns they may have
- Emotional and practical support
- An assessment of their own needs with their own written care plan (i.e. if the patient has a serious mental illness or learning disability).

# **Commonsense approach to sharing information with family, friends and carers**

## **A guide for staff**

## Introduction

Within the process of the providing high quality care packages to people who use services provided by Cumbria Northumberland Tyne and Wear NHS Foundation Trust there is a recognition that in many cases, carers are providing valued and vitally important care and support, sometimes on a full-time basis. There is also an understanding that carers often feel 'cut-off' from, and 'ill-informed' about, the care of people close to them, even though they may be providing a significant level of care.

We have used the term families and carers in its broadest sense to denote the most relevant people in the service user's life and social network, this includes children and young carers. It is important to clarify with the service user who they see in this role by asking who they see regularly and who provides them with support. This, of course, may change over time.

Cumbria, Northumberland Tyne and Wear NHS Foundation Trust and its partners, in providing mental health and learning disability services, see people who are carers as '**partners in care**', and not just as a resource.

## Carer's needs

Carers may also have different needs, views and expectations to service users and should therefore be considered separately, in their own right, rather than being an addition to the service user's assessment and care plan.

Care coordinators/named nurses (within inpatient care) will be expected to listen to and take into account the views of carers in relation to the cared for person, including such issues as the current position of the caring relationship and whether this can be maintained. It is also important to offer carers appropriate means of assessing their own needs within what is often a demanding caring role.

## What carers should expect

A carer should be able to expect the following principles in their relationship with the care team:

- Full recognition and understanding of their contribution
- Support to meet their needs as a carer
- Information to assist their understanding of the clients mental health presentation
- Involvement as a partner in care.

## 1. What information can be shared and with who

In the majority of situations, service users will agree to involving and informing the carer in all areas of their contact with services. CNTW staff will positively emphasise to the service user the benefits of open communication with carers, outlining the positives that can be added to the care package by everybody involved in their care being fully involved in working together.

Where a person using mental health services chooses not to share information regarding his/her condition, on most occasions, they have every right to expect the upholding of their wishes regarding confidentiality.

Any specific issues service users do not wish to be discussed or disclosed with their carer must be clearly documented.

In practice, there is a marked distinction to be made between general information, such as requests regarding the client's general wellbeing, routines of the unit or service where care is being provided from and information that can be seen as 'confidential' such as details regarding the client's current mental health.

When a member of staff is in discussion with a carer /supporter /significant other they should:

- Establish the past/current caring relationship
- Clarify what the carer/significant other already knows about the clients' situation/mental health difficulties
- Actively listen to the carer/significant others requests and respond accordingly. Listening to carers does not breach confidentiality. Service users cannot prevent carers talking to staff to pass on information or to receive support and advice

## 2. General Information:

Carers should be given/offered by the named nurse/care co-ordinator:

- General information concerning:

- Mental health problems
- Medication (dosages, side effects, what to be aware of)
- Information re care processes, routines
- Signposting to and/or offered help to access organisations that can provide further information and support
- Contact details of the named nurse/care co-ordinator on the unit/community team to enable consistent support and reassurance, not only during periods of crisis

- Time and opportunity to share information re their unique knowledge of the service user and that this is recognised as an important and valued part of the assessment process

This information should be discussed with the carer/significant other and also offered as printed information where appropriate.

### **3. Information That Is Deemed To Be Confidential**

Where a service user has expressed a wish for confidential information not to be shared, this, in the majority of cases, will be adhered to.

If the individual is **unable** to give permission to share information due to an assessed lack of capacity at that point in time, the implications of the Mental Capacity Act will need to be considered. Confidential information that is considered essential for the carer to be aware of, such as risk issues and any ongoing care information can be agreed to be shared following a Multidisciplinary Team (MDT) decision taking into consideration the views of the carers/significant others as to the likely wishes of the service user and if it is in the service users best interests to do so. Where there is a current advance statement/decision that has been made by the service user this should be used to guide practice if possible.

If the service user is **unwilling** to share confidential information and has been assessed as having capacity to make such a decision, disclosure can only occur following an MDT decision that a breach of confidentiality is necessary due to risk to self or others.

### **4. Advanced statement**

An advance decision/statement made by someone can be overridden at any time by the author. Staff should confirm with the client that the information still reflects their current wishes for how care should be delivered (this may include parameters around confidentiality).

The carer will be made aware of these systems and the timescales that this decision making process will take.

### **5. Where request for information cannot be met**

Where carer's requests for confidential information cannot be met, staff must inform the carer of the process, be clear that their requests will be discussed with the MDT and the reasons for withholding information that is deemed to be confidential will be explained in full. Continued support to the carer from the staff involved with the service user's care will be ongoing.

## 6. Information shared by carers

Information shared by carers should also be entered into the service user's case notes. This information will be classed as 'third party' information and carers can, in fact, ask for this information to remain confidential at the point of entry. Carers should be informed that if a service user requests to see their notes under the Data Protection Act 2018, this information will only be revealed if the carer consents or if it is possible to disclose the information without revealing the identity of the third party. Staff can also restrict access to information if it may cause serious harm to the physical and/or mental [wellbeing](#) of the service user or any other person. A clear statement of consent/dissent from the carer should be recorded in the case notes on each occasion the carer provides information.

## 7. Good Practice Checklist

The following checklist has been taken from the 'Carers and Confidentiality in Mental Health' leaflet produced by the Partners in Care campaign and published by the Royal College of Psychiatrists. It is designed to assist staff to work closer with carers within the boundaries of current legislation and to help carers understand their rights.

### **Carers are given general factual information, both verbal and written about:**

- The mental health diagnosis
- What behaviour is likely to occur and how to manage it
- Medication – benefits and possible side-effects
- Local in-patient and community services
- The Care Coordination (CPA)
- Local and national support groups

### **Carers are helped to understand:**

- The present situation
- Any confidentiality restrictions requested by the patient
- The patient's treatment plan and its aims
- Any written care plan, crisis plan or recovery programme
- The role of each professional involved in the patient's care
- How to access help, including out-of-hours services

### **Carers are given:**

- The opportunity to see a professional on their own
- The right to their own confidentiality when talking to a professional
- Encouragement to feel a valued member of the care team
- Confidence to voice their views and any concerns they may have

- Emotional and practical support
- An assessment of their own needs with their own written care plan (i.e. if the patient has a serious mental illness or learning disability).