

Common sense confidentiality

A guide for carers, family and friends



Who is a carer?

Carers are people who provide help and (unpaid) support to a family member, friend or neighbour who would otherwise not be able to manage. We use the term 'carer' in its broadest sense to include the most significant people

in the life of the service user/patient, including spouses, parents and young carers. It is also important to note that the carer is not always the "nearest relative". Some carers may not think of themselves as carers.

Why is it important to share information with carers?

At CNWL, we believe that those who provide clinical services should work in partnership with carers and family members as well as the patient.

As a carer, you provide important information that can help our staff to have a better understanding of the needs of the service user or patient. Communicating effectively with carers can also help avoid unnecessary hospital admissions and help prevent serious incidents.

Not only this, but involving you as the carer can help you maintain your health and wellbeing and result in better health and outcomes for the person you care for.

Effective care and better clinical outcomes rely on this three-way partnership between people in our services, their families and carers and our staff. Working together this way is known as the triangle of care.

References: Carers and confidentiality in mental health, May 2010 – Royal College of Psychiatrists (www.rcpsych.ac.uk/about/campaigns/partnersincarecampaign/carersandconfidentiality.aspx)

Commonsense Confidentiality Information leaflet, January 2019 – Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust (<https://www.cntw.nhs.uk/resource-library/commonsenseconfidentiality-a-guide-for-carers-family-and-friends>)

Common Sense Confidentiality, June 2018 – Tees, Esk and Wear Valleys NHS Foundation Trust (www.teew.nhs.uk/services/common-sense-confidentiality)

Common sense Confidentiality: A guide for employees, carers and service users accessing adult health services, March 2019 – Cambridgeshire and Peterborough NHS Foundation Trust (www.cpft.nhs.uk/carers/confidentiality.htm)



Getting consent to share information

Sometimes there can be difficulties in relation to confidentiality and sharing information. When a patient wants to keep personal information private to themselves, then these wishes must be respected by staff.

It is essential that you as a carer are informed of this.

As an area of good practice staff will:

- Discuss with the patient/service user what particular information they wish to keep private.
- Explain to the patient/service user the importance and value of sharing information with those who care for them.

- Explain to you at an early stage what information can be shared, and if information cannot be shared explain the reasons for this.
- Share this leaflet with you and answer any queries you make have on this topic.
- Ensure that you receive as much information as possible to help you in your caring role.

Issues around confidentiality should not be used as a reason for not listening to you or for not discussing fully with patients the need for you to receive information so that you can continue to support them.



Types of information

The nature of the information shared can vary according to circumstances, and there are three identified types of information.

General Information:

This includes information about conditions in the public domain such as leaflets, published materials and websites, side effects of medication, legislation including the Mental Health Act, welfare, rights for service users and rights for carers, discharge information if this directly impacts the carer, contact information for local and national services and their availability, any confidentiality restrictions requested by the patient, and how to access help, including out of hours service contact details in the event of a crisis.

Personal Information:

This relates to specific information about the person you are caring for, for example the diagnosis, medication and its effects, the care plan, discharge care planning and contingency planning.

Sensitive Personal Information:

This includes information of a highly personal nature, details of previous sexual or emotional abuse, sexual

activity, breaches of the law and the service users' views about family members.

Providing you with general information about an illness or offering emotional and practical support does not breach confidentiality. Staff should also check with you what information you already know, such as diagnosis and treatments, as any information you are already aware of is not to be treated as confidential.



Carers are also entitled to confidentiality

It is important to note that the same principle of confidentiality applies to information given by carers, family and friends. You should be given the opportunity to discuss any difficulties you are experiencing in your caring role, and staff must clarify with you who the information can be shared with. In certain cases, you may not wish for any information disclosed by you to be shared with the service user/patient, and it is within your rights for staff to respect this.

Why is consent important?

All staff working in health services are bound by law and professional codes of conduct to a duty of confidentiality to their patients and to carers. A breach of confidence can lead to the professional facing disciplinary measures and legal proceedings, including being sued or dismissed.

When can confidentiality be broken?

Any decision to break confidentiality must always be made in the best interest of the service user/patient and to achieve the best possible outcome for them. It is essential that staff explain to you how and why the decision to breach consent is in the patient's best interest.

Where the service user withholds consent or lacks capacity and cannot express their wishes clearly, 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.

Similarly, a carer's confidentiality can only be broken in exceptional circumstances such as risk to their own or others' health and wellbeing, public interest or for legal reasons.

Good practice checklist:

The checklist overleaf has been adapted from the "Carers and Confidentiality in Mental Health" leaflets produced by the Partners in Care campaign and published by the Royal College of Psychiatrists.

It is designed to assist staff to work more closely with carers within the boundaries of current legislation and to help carers understand their rights.

Although written with mental health services in mind, the principles of this are transferable to any health setting.





Good practice checklist

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

- A diagnosis
- What symptoms/behaviour may occur in people with this diagnosis, and how to support the person
- Medication – benefits and possible side effects
- Local health services available
- What different care and treatment might be used for people with this diagnosis or health issue
- Local and national support groups

Carers are helped to understand (subject to the patient agreeing):

- The present situation
- Any confidentiality restrictions requested by the patient
- The patient's treatment plan and its aims
- Any written care plan, emergency care/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
- Assessment of their own needs with their own written care/support plan





Case study

Andrew 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.

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 was 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 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 continue to be engaged with the professionals in his care.



Signposting and support

Carer Resource Packs for each borough and area within the Trust have been put together by the central Patient and Carer Involvement Team
www.cnwl.nhs.uk/patients-and-carers/information-carers/support-carers

Information on how and where to get a carers' assessment
www.cnwl.nhs.uk/patients-and-carers/information-carers/carers-assessments

The CNWL Recovery and Wellbeing College is a good place to signpost carers for courses on wellbeing, developing skills and gaining understanding on different conditions
www.cnwl.nhs.uk/patients-and-carers/recovery-and-wellbeing-college

How can I get involved?

To find out more and to register, visit our webpage
www.cnwl.nhs.uk/patients-and-carers/patient-and-carer-involvement
or contact our team at
involvement.cnwl@nhs.net

