

CONFIDENTIALITY AND CARERS - GENERAL PRINCIPLES

DEFINITION OF A CARER

A Carer is someone who unpaid takes responsibility for the everyday living needs and/ or emotional well being of a friend, partner or family member who is disabled, frail or ill (mentally or physically). They will be involved with the service user on a regular basis. Carers enable service users to continue living in the community and they carry out these tasks without a wage. NB a Carer can be a child under the age of 18.

PRINCIPLE OF INFORMATION PROVISION TO CARERS

Carers as defined above are entitled to access basic information of relevance to their caring situation, which enables them to care safely for themselves, their family and the service user. Interpretation and translation services should be provided if needed.

PROFESSIONAL'S RESPONSIBILITY TO THE SERVICE USER / PATIENT AND CARER

The professional involved with the service user must as early as possible ask the service user whom they may talk to about their care. The professional has a responsibility to ensure the best care and safety of both the service user / patient and the person involved in caring for them.

Community Care Assessments

Department of Health policy is that professionals should involve carers in the assessment of need of the person they are looking after, followed by a separate carer's assessment if eligible. The Department of Health requires each local authority to report on the numbers of carers involved in these assessments as a performance indicator.

Information on Health Care

The National Carers Strategy (DH 1999) emphasises the need of carers for:

Good information on the health needs and treatment of the person they are caring for – especially on medication: when to take it, and recognising any side effects arising from it. They need information to allow them to deal with the symptoms of some illnesses and to recognise when they should urgently ask for professional help and where to get such help, especially when they are caring for someone with a mental health problem.

The NHS has always sought to maintain the confidentiality of information, which is given to clinicians in confidence. But in the majority of cases where a patient has a carer, the patient would be very happy for their carer to know as much as they do. The Government believes that general practitioners and other clinicians should proactively offer help and full information to their patients, and should **always** explicitly seek the patient's consent for information to be passed to their carer. (National Carers Strategy)

The Confidentiality: NHS Code of Practice (DH 2003) gives the following guidelines for sharing information with carers for 'Healthcare Purposes'

Carers often provide valuable healthcare and, subject to complying with the best practice outlined, every effort should be made to support and facilitate their work. Only information essential to a patient's care should be disclosed and patients should be made aware that this is the case. However, the explicit consent of a competent patient is needed before disclosing information to a carer. The best interests of a patient who is not competent to consent may warrant disclosure.

Explicit Consent is defined as articulated patient agreement. The terms are interchangeable and relate to a clear and voluntary indication of preference or choice, usually given orally or in writing and freely given in circumstances where the available options and the consequences have been made clear.

The requesting of consent is essential as if health professionals fail to ask for this, they cannot pass information about the person's illness or disability, or about their medication or symptoms to their carer. Health professionals must also recognise that patients have a right to change their mind on whether to give consent and they should review the decision regularly with the patient.

Confidentiality and children

Children are entitled to the same duty of confidence as adults, provided that, in the case of those under 16 years of age, they have the ability to understand the choices and their consequences relating to any treatment. Young people aged 16 or 17 are presumed to be competent for the purposes of consent to treatment and are therefore entitled to the same duty of confidentiality as adults. For children under 16, the key issue is the 'competence' of the child. If the child is competent then their consent is required to disclose and use information. Staff should encourage children to involve parents, particularly where significant decisions need to be made, but should respect the choice made. However, consent for treatment purposes may be given by parents even where a child objects.

Young Carers

Professionals and family members sometimes assume that carers under 18 should be "protected" from knowing more about their family member's condition without consulting them on this. The reality is often that they are very aware of the symptoms of the condition and suffer added distress through lack of understanding. Children's fears are often even worse than the reality. The Fraser Guidelines established that professionals should use their judgement about a young person's developmental stage and can supply young people with information relevant to this stage. However, Young Carers may need extra support to cope with and understand the implications of any diagnosis and it is important that any professionals involved in the care of the patient recognise this and ensure that they are supported by someone who knows them and has experience of working with young people. The Lewisham Young Carers Project can also help with this.

WHAT TO DO IF THE SERVICE USER / PATIENT DOES NOT GIVE PERMISSION TO SHARE INFORMATION WITH THE CARER

Discuss implications

If the service user is not willing for the carer to have access to key information that may, in the Professional's opinion, impact negatively on the life of the carer or service user, the issue of confidentiality must be discussed with the service user and carer together in the hope of coming to some mutually agreed solution. Any agreement made should be written on the record of the cared for person so that others who access this information in the future know the situation.

Mental Competence

The cared for person has the right to keep certain information confidential and if necessary change their mind about who has access to it. However, if this refusal or change of mind is in circumstances where the person is not completely mentally competent at the time, the Professional must ensure that by accepting and not challenging this refusal they are working in the best interest of the service user **AND** carer if they **DO NOT** share relevant information. The Mental Health National Service Framework (DH 1999) states that if the service user is incapacitated, information may be passed to the carer if it is in the service user's best interests. Decisions should be made on a case-by-case basis.

If the service user is not always or completely mentally competent due to the nature of their illness or disability then it may be that the Carer has Enduring Power of Attorney and is therefore legally entitled to act on behalf of the service user in financial or property matters. It may be relevant for the Professional to suggest that the service user and carer in situations take out an Enduring Power of Attorney where this may arise.

Under common law, staff are permitted to disclose personal information to prevent abuse or serious harm to others where they judge, on a case by case basis, that the public good that would be achieved by the disclosure outweighs both the obligation of confidentiality to the individual patient concerned and the broader public interest in the provision of a confidential service.

Information, which can be shared

If the service user is unwilling to let the Professional break confidentiality at all, a carer as defined above, should be given the following basic information:

- ◆ General basic information about the nature of the illness
- ◆ General basic information about how best to care for the person
- ◆ General basic information about how to cope with behaviours, including signs of potential deterioration/adverse drug reactions to look out for etc.
- ◆ How to manage any equipment and medication
- ◆ Moving and handling the service user safely
- ◆ Who the carer could speak to if there is a problem
- ◆ What to do in an emergency
- ◆ Where to get support for themselves
- ◆ How to and the importance of taking care of their own health needs whilst caring
- ◆ How to access a carers assessment of need

Young Carers

If a parent or guardian refuses to allow professionals to disclose information that is particular to himself or herself to another individual this has to be respected. However, it is the duty of professionals involved with the family to try and ensure that children and young people are not disadvantaged by the lack of disclosure. Professionals should encourage parents to be as open as possible with their child. Parents may need help with this and may need to be directed to appropriate sources of information, such as being given age appropriate literature, which they can then choose to share with their child. When carrying out any work with children, the law states that the best interests of the child remain paramount.

CARERS ASSESSMENTS

Under the Carers (Recognition & Services) Act 1995 and the Carers and Disabled Children Act 2000, carers who are providing substantial care are entitled to an assessment of their own needs even if the service user / patient refuses an assessment themselves. It does not require the agreement of the service users. During this process carers can give the professional their perception of the needs and difficulties faced by their cared for person as well as their own situation. Where there are problems with confidentiality this is a tool the professional can use to gain an insight into the problems faced by the carer and the carer can use it to inform the professional about the impact of caring on their day-to-day lives. Care plans may then be devised and / or adjusted to help to address difficulties faced by the carer and the carer may be eligible for services in their own right.

CONFIDENTIALITY IS A TWO WAY PROCESS

Confidentiality is also an important issue for carers. The same duty of confidentiality must be given to the carer. If a carer tells a professional something in confidence this must also be respected and explicit consent required to share this information unless it has legal or safety implications. If the issue raised does have these implications, the carer must be informed that the professional may not be able to keep the information confidential.