

## CARERS AND CONFIDENTIALITY – LAW AND GOOD PRACTICE

Graham Machin

A paper presented to the Carers' Council Conference on "Carers and Confidentiality in Mental Health" held at Edwinstowe on 23<sup>rd</sup> April 2004

---

### What carers need

The carers I have in mind in the title are people providing a significant level of care to one or more adults suffering from enduring mental illness. They may be parents, children, partners, brothers, sisters or friends. They may or may not live in the same household as the person for whom they care. That person may have periods of in-patient treatment, but is likely to spend most time "in the community".

Such carers find themselves in a three-cornered relationship, involving themselves, the person for whom they care, and a team drawn (mainly) from the statutory health and social services.

What do carers need from that team, in order to ensure the best possible care for the user with the least possible stress and strain for themselves? They need

- Recognition and respect
- Information, advice and encouragement
- To be involved in care planning (as they are inevitably involved in delivery)
- Effective access to the team, not only to seek advice, but to convey information

These needs are, at an official level, now widely recognised in plans and policies, and reflected in legislation. For instance

#### *Caring for Carers (Government report 1999)*<sup>1</sup>

*The Government values carers and will support them in their caring role. Too often in the past, bureaucratic restrictions have made it difficult to target help at carers themselves. But helping carers is one of the best ways of helping the people they are caring for. Help for carers cannot be seen in isolation from help for the person for whom they are caring. Providers of the range of services and benefits which exist to meet the needs of sick, disabled or frail elderly people must recognise that the patient or user of services and their carer are closely linked, and must not neglect the carer's existence and needs when they are looking at and meeting the needs of the patient or user.*  
(Chapter 1, para 7)

*Carers' needs are diverse. .... a number of common factors emerge from what carers themselves tell us: emotional support, relief from isolation, receipt of reliable and satisfactory services, information, and recognition of their role and contribution can all work well in supporting carers. (Chapter 2, para 33)*

*Carers need 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. (Chapter 4, para 15)*

*A commitment to Carers (leaflet produced for the Department of Health by the National Schizophrenia Fellowship – still current)<sup>2</sup>*

*What carers should expect from mental health services*

*Recognition and Understanding*

- *You should be recognised and listened to as a partner in providing care*
- .....
- *You should be able to work with staff who understand the effects of mental illness on you and your family*
- .....

*Support*

- *You should receive help and information when it first becomes evident that you are providing care for someone with a mental health problem*
- *You should have the chance to discuss your concerns about the person's illness and how it is affecting you*
- *You should receive prompt and positive responses to your requests for help*
- *You should be able to get immediate help in a crisis*
- .....

*Information*

- *You should be given an explanation of the mental health problem affecting the person you care for and be told where you can go to get more information*
- *You should be told what treatments the person is receiving, what other treatments are available, how they work and what the potential side-effects are*
- *You should be told how to recognise signs of a relapse*
- .....

*Confidentiality and information sharing*

.....

*Confidentiality should not be accepted as an excuse for not listening to you. You should be given sufficient information by mental health services, in a way you can readily understand, to help you provide care effectively.*

### **What carers experience**

Unfortunately, these needs are not consistently satisfied. The Carers' Council in Nottinghamshire has contact with many carers, some of whom complain that, for instance, their role is not recognised, they are starved of information and involvement in care planning, and that they do not have ready access to the professional care team.

These experiences are reflected more widely in the professional literature.

*Working with Serious Mental Illness (Ed by Gamble and Brennan – 2000)*<sup>3</sup>

*Carers of people with mental health problems were critical of how Social Services Departments and other agencies did not take their views and needs into account so that they would be left to manage very difficult situations on their own. (Chapter 11, p 179, quoting Favin 1998)*

*Historically, families have been as much burdened by the mental health system as by the illness. This may seem like a contentious statement but, as Ann Devison (1992) illustrates, all too often they are and have been perceived as part of the problem, if not the cause, of serious mental illness. The reality is that the treatment of serious mental illness would not be tenable without them. Community care would be exclusive, expensive and unfeasible (Noland 1996) In the main, it is dependant on the participation of families and informal carers as they represent the major resource and support network. This role has often been forced upon them with little or no preparation. Unlike professional carers, they do not make an active choice to be involved with serious mental illness. In our experience, families when offered intervention immediately question why 'they were never given this at the start?' (Chapter 11, pp 179-180)*

*Textbook of Community Psychiatry (Ed by Thornicroft and Szmuckler – 2001, Chapter 40 by Margaret Leggatt)*<sup>4</sup>

*'Confidentiality has become a 'shibboleth' masking a wide range of other issues where good practice methods need to be developed.'* (Furlong and Leggatt, 1996, p. 620).

.....

*Confidentiality is not absolute. There are situations where it is legal and ethical to breach confidentiality ..... Confidentiality is the right of the patient, not of the professional. Professionals often fail to ask patients whether or not they would like family members to be involved. Problems with maintaining confidentiality can be largely overcome if professionals develop a*

*commitment to ongoing involvement with family carers by establishing an equal partnership with them.*

*In the process of engaging with family carers, clarification is needed on what information can be divulged, and what information a consumer has a right to know can remain private. It is legally, ethically and morally possible to help family members without breaching confidentiality through divulging personal and private information that is unique to particular individuals.*

This last quotation is correct to maintain that these needs can be satisfied, and by the statutory services as presently organised, because they frequently are. Why then is delivery so patchy?

“Confidentiality” is a reason frequently given by professionals to excuse lack of engagement with carers. Often confidentiality is not the real reason, either because its scope is misunderstood (yes, by some professionals) or because it masks a lack of inclination or simply a lack of time and resources. Misuse of the term by professionals has understandably led to a similar misuse by carers. It has become a label to identify a range of problems centred on communication and liaison between carers and professionals, in seeking to fulfil their respective roles in supporting users.

In truth, confidentiality can never excuse a failure by the statutory care team to make genuine attempts to establish a healthy and supportive relationship with informal carers. At most, the principle of confidentiality may operate to limit the information, about the user, which the professionals can divulge.

### **The user’s right to confidentiality**

The right of a person not to have confidential information about him divulged, without his consent, is embodied in the Common Law. It is not restricted to medical situations.

A classic exposition of the general principle is provided in the speech of Lord Goff of Chieveley in the “Spycatcher” case:

*Attorney-General v Guardian Newspapers (No 2) [1990] Appeal Cases 109 at pp 281<sup>2</sup>:*

*I start with the broad general principle (which I do not intend in any way to be definitive) that a duty of confidence arises when confidential information comes to the knowledge of a person (the confidant) in circumstances where he has notice, or is held to have agreed, that the information is confidential, with the effect that it would be just in all the circumstances that he should be precluded from disclosing the information to others.*

Lord Goff went on to refer to three limiting principles. The first is that the principle of confidentiality only applies to information to the extent that it is confidential; that is, not already known. The second is that the principle does not apply to useless information or trivia. The third is, that the public interest that confidences should be preserved may be outweighed by some other public interest which favours disclosure.

Information of a personal and intimate nature certainly qualifies as confidential; and it is well established that the relationship of doctor and patient, or similar relationships between lay people and professionals, import the obligation of confidence. The general principle of confidentiality therefore undoubtedly applies as between a user of the mental health or supporting services, and the members of the service team.

Quite apart from the law, the principle of confidentiality is independently entrenched in medical ethics. The obvious starting point is the Hippocratic Oath:

*All that may come to my knowledge in the exercise of my profession or outside of my profession or in my daily commerce with men, which ought not to be spread abroad, I will keep secret and never reveal.*

Note the words I have underlined, which show that the obligation is not absolute, and are apt to accommodate the decisions about what information is confidential, the releasing effect of consent, and the existence of exceptional situations.

Very recently, the principle finds expression in –

*Confidentiality - NHS Code of Practice, (Department of Health, November 2003)*<sup>6</sup>

*A duty of confidence arises when one person discloses information to another (e.g. patient to clinician) in circumstances where it is reasonable to expect that the information will be held in confidence. It –*

- a. is a legal obligation that is derived from case law;*
- b. is a requirement established within professional codes of conduct; and*
- c. must be included within NHS employment contracts as a specific requirement linked to disciplinary procedures*

.....

*Figure 2*

*Patient information is generally held under legal and ethical obligations of confidentiality. Information provided in confidence should not be used or disclosed in a form that might identify a patient without his or her consent. There are a number of important exceptions to this rule, but it applies in most circumstances. (page 7)*

This last is erroneous in one respect, in that information does not have to be “disclosed” or “provided” in order to be protected; it may simply be observed or discovered by the confidant in circumstances attracting the duty of confidentiality.

The principle of confidentiality is also addressed in codes of conduct and guidance issued by professional bodies to which many in this audience owe allegiance.<sup>7</sup>

### **The limits of confidentiality**

Confidentiality is thus of central importance to clinical and professional practice. It is a good and necessary principle, which should be respected and protected. Nothing I say is intended to undermine or dilute it. But its scope is frequently misunderstood. In particular, in the present context, it is sometimes assumed to prevent a doctor/CPN/social worker from discussing the user or his illness with the carer at all (other than in exceptional circumstance – of which more in due course). It is therefore sometimes given as a reason, or an excuse, for the professional to refuse or neglect to engage constructively with the carer. Such an assumption is simply wrong.

The confidentiality principle, when it operates, has the effect of prohibiting the professional from disclosing to a third party, without the user's consent, information provided by the user, or discovered in the course of the professional relationship with him or her. The limits of its operation can be expressed in the following propositions:

- A     The user has no right to prohibit the professional from engaging with the carer, or from providing information advice and support, or from talking to the carer about the user, providing that no confidential information is divulged.**
- B     The user has no right to prohibit the professional from receiving information from the carer.**
- C     The professional is not prevented from talking to carers about facts they already know; a breach of confidentiality only occurs when confidential information is newly disclosed.**

This point is well expressed in the BMA document “Confidentiality & disclosure of health information”<sup>8</sup>, when defining “confidentiality” and “breach of confidentiality”:

*Patients have a right to expect that identifiable information about themselves provided or discovered in the course of their health care will not be shared with other people without their knowledge, and the disclosure of identifiable information without subject consent to someone who did not previously know it breaches confidentiality.*

.....

*Logically, confidentiality can only be breached when the recipient of the information learns something that was previously unknown to him or her. It is not a breach of confidentiality to discuss the medical implications of general information which is already known to the recipient. Where relatives, for example, are already aware of an individual's condition or diagnosis, an explanation of the possible options for that patient does not breach confidentiality, but revealing the person's views of those choices would do so.*

- D     Confidential information may be disclosed with the user's consent, which may be either express or implied and may be either specific to certain information, or certain types of information, or to certain people (for example, carers).**

The recent NHS Code of Practice<sup>9</sup> usefully defines implied consent as meaning “patient agreement that has been signalled by behaviour of an informed patient”.

“Although consent is often regarded as an exception to the obligation of confidence, in fact it is not. It is merely a recognition by the patient that the doctor is no longer under an obligation to keep the confidence – it defeats the *existence* of the obligation” This observation, from Kennedy and Grubb on Medical Law<sup>10</sup>, states a general principle. It does not apply only to a doctor-patient relationship.

These propositions, A to D, have nothing to do with exceptions to the confidentiality principle, when confidentiality may be overridden in the interest of the user himself or in the public interest, or under statutory authority. I will come to those later. Nor are they doubtful or controversial. They simply express the boundaries of confidentiality, and the releasing effect of consent.

It is therefore clear that confidentiality never prevents the establishment of a proper relationship between the services and carers, and it will only hamper or inhibit such a relationship when a user will not consent to disclosure which the professional team and/or the carers believe would be advantageous.

The fact that a professional may disclose information to carers does not mean that it must be disclosed (unless the user has so directed). In everyday reality users and carers may be reasonable or unreasonable, intelligent or obtuse, confused, stressed or distracted. What can or should be or must be disclosed or discussed, when, and to whom, is inevitably subject to a continuous professional judgment.

Nevertheless, the underlying duty of the professional is to be positive and constructive in dealings with both users and cares. The professional team should be proactive in seeking to establish a constructive and supportive relationship with a carer in the interest of both the user and the carer.

#### Caring for Carers<sup>11</sup>

*All organisations involved with caring must now focus not just on the client, patient or user – but must **include the carer** (from the Executive Summary).*

Further, when it would be in the interest of the user to permit the release of information to a carer (for instance, by their being involved in review meetings), and the user’s consent is necessary, the relevant professionals should do their best to obtain that consent.

#### Caring for Carers<sup>12</sup>

*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 (Chapter 4, para 16).*

I have so far been concerned to identify the considerable scope for a constructive relationship between carers and the statutory services, without there being any breach of a duty of confidence owed to the user. I have concentrated on this, because I believe that, for carers, the problems associated with “confidentiality” are due largely to misunderstanding in this area. Circumstances may nevertheless arise where a professional may breach a user’s confidence without acting unlawfully or unethically. These come next.

### **Lawful breach of confidence: statutory authority**

Parliament is sovereign, and may therefore override principles of confidentiality existing at common law or required by professional ethics.

There are a number of cases where specific statutory regimes apply, some of which go so far as to require disclosure. These sorts of provision are not aimed at mental health service users, but may affect them. For example, doctors who treat drug addicts are required to give their names, and other information about them, to the Home Office.

The statutory provisions which are actually intended to override confidentiality are therefore of limited impact so far as carers are concerned.

### **Lawful breach of confidence: disclosure in the public interest**

The law recognises that disclosure of confidential information is permitted where the public interest in disclosure outweighs the public interest in maintaining confidentiality. The courts have not attempted to spell out the precise scope of this exception, partly because of the need to preserve the ability of a professional (or sometimes of the court itself) to make a judgment balancing these interests in differing and often unforeseeable situations. But the main application of the exception is to protect people from serious harm.

A leading case is *W v Egdell*<sup>13</sup>, decided by the Court of Appeal in 1990. W was detained as a patient in a secure hospital, having been convicted of manslaughter after multiple violent killings. W applied to a mental health review tribunal for release from hospital, and his solicitors instructed Dr Egdell to prepare a psychiatric report for use in the application, hoping that it would be helpful. In fact, he reported to the effect that W remained highly dangerous and showed a persistent interest in explosives. W thereupon dropped his application, but Dr Egdell felt that the contents of his report should be made known to the medical director of the hospital, and to the Home Office. This would inevitably involve a breach of the confidence owed to W, who applied to the court for an injunction preventing its disclosure. The Court of Appeal refused to prevent disclosure of the report, holding that the public interest in protecting the public from violence took precedence over the public interest in ensuring the confidentiality of medical consultations.

The decision whether to disclose will normally be taken by one or more professionals in reliance on their own judgment. The reported cases suggest that they should be guided by these principles:

- (1) To justify disclosure the professional must reasonably believe that disclosure may avert or reduce a real risk of serious harm to individuals (including the user himself) or the public generally.
- (2) Disclosure must be directed to a person or authority with a legitimate interest in receiving the information; for example the police, or a person perceived to be at risk.
- (3) Disclosure should be limited to the extent judged necessary to nullify the risk.

This exception could clearly operate in ways affecting carers. For instance, should a user announce to a member of his professional care team that he intends to harm his carer, or to commit suicide, a warning in breach of confidentiality would clearly be justified.

*Confidentiality: Protecting and Providing Information (GMC 2000)*<sup>14</sup>

*Disclosure of personal information without consent may be justified where failure to do so may expose the patient or others to risk of death or serious harm. Where third parties are exposed to a risk so serious that it outweighs the patient's privacy interest, you should seek consent to disclosure where practicable. If it is not practicable, you should disclose information promptly to an appropriate person or authority. You should generally inform the patient before disclosing the information (para 36).*

**Lawful breach of confidence: for the benefit of a user incapable of consenting to disclosure**

Any user is normally entitled to refuse treatment, and to prevent the disclosure of confidential information, to which they have not consented. But some users, and especially those suffering from a mental illness, sometimes or always lack the physical or mental capacity to consent. What happens then?

This is a thorny issue, which has mainly been considered, by the courts and the caring professions, in relation to consent to treatment. In that connection it is also topical, in light of the possibility that the government will bring forward controversial legislation, which may extend the circumstances in which treatment may be imposed without consent.

But capacity to consent to the disclosure of confidential information, in the context of mental illness, is inevitably an issue of frequent occurrence, requiring decisions by professionals. And those decisions often concern the sharing of confidential information with carers.

The basic principles are clear. First, the initial assumption is that the user is capable of deciding for himself. The rules only change if the responsible professional judges that he is incapable of doing so.

Secondly, capacity must be assessed at the time of the decision in question, and be related to that decision. At any given time a user may be capable of taking some decisions, but not others.

Thirdly, capacity to decide requires that the user can understand and retain information relevant to the decision, and can rationally weigh the factors for and against a course of action, before deciding what to do. The reasons given for refusing to allow information sharing may even demonstrate a lack of capacity to make that selfsame decision, as where a user demands the exclusion of a carer for reasons which are clearly delusional.

Fourthly, the absence of capacity does not in itself dissolve the user's right to confidentiality. Disclosure still needs to be justified. It means that, should a professional holding confidential information wish to disclose it, for example to a carer, but the user is incapable of giving a valid consent, the professional will have to take the decision himself.

Fifthly, although disclosure when the user lacks the capacity to consent may be regarded as another instance of disclosure in the public interest; in my view it is in truth more accurately disclosure in the user's interest, when the user lacks the capacity to assess that interest for himself. The following professional guidance reflects both approaches. The GMC leans towards the first approach, as seen in the next extract:

*Confidentiality: Protecting and Providing Information (GMC 2000)*<sup>15</sup>

*In cases where you have considered all the available means of obtaining consent, but you are satisfied that it is not practicable to do so, or that patients are not competent to consent, or exceptionally, in cases where patients withhold consent, personal information may be disclosed in the public interest where the benefits to an individual or to society of the disclosure outweigh the public and the patient's interest in keeping the information confidential (para 18).*

*In all such cases you must weigh the possible harm (both to the patient, and the overall trust between doctors and patients) against the benefits which are likely to arise from the release of information (para 19).*

The following passages are from the BMA guidance on confidentiality, which clearly places the user's best interests at the centre of such decisions.

*Confidentiality and disclosure of health information (BMA 1999)*<sup>16</sup>

*Disclosure without consent in the subject's vital interests*

.....

*One of the most difficult dilemmas for health professionals concerns cases where the extent of the patient's mental capacity is in doubt. Relatives may report aberrant behaviour but if the patient refuses to cooperate in an assessment of his or her capacity, it is unclear to health professionals whether*

*they are justified or not in providing medical information which would enable another person to act in the patient's interests. The BMA's advice in such cases is that health professionals must assess the information which is available from the patient's record and from third parties. They should attempt to discuss with patients their needs and preferences and weigh up whether the patient appears to be making a valid refusal regarding the assessment or the sharing of information resulting from it.*

.....

*If a patient lacks the ability to understand, decisions must be based on the incapacitated person's best interests which should reflect the individual's current or previously expressed wishes and values. Disclosure of information about mentally incapacitated patients may be essential for their protection or well-being .....*

### **Confidentiality and team working: the “need to know”**

In this day and age health care relies on a team of professionals who need to record and share information about their patients in order to provide appropriate care. In the field of mental health, given “care in the community” and the Care Programme Approach, the professional support team is not confined to doctors and nurses, but includes social workers, physiotherapists, and potentially many others, often dispersed across several agencies.

In practice, confidential information is shared, often without reference to the user; but the Department of Health and the relevant professions have agonised over the justification of this practice. The challenge is to square practice with principle, without so discrediting principle that it cannot be applied in other situations. It has some relevance for carers, as will be seen

There are two contending rationales for team sharing of confidential information. The first is, that such sharing is based on the consent of the user. If this is the case, it follows that users are entitled to withhold or withdraw their consent to the passing of confidential information between members of their supportive professional team.

The other view is that the justification for sharing confidential information in “need to know” cases is the public interest. Users' needs can only be met by teams of professionals, who must necessarily record and share information, and the public interest in providing a service to all users justifies overriding an objection by any particular user.

This public interest justification is claimed to be more realistic and honest about what actually happens, but it implies a far wider disregard of a user's right to control the release of confidential information than is openly accepted.

This continuing debate has implications for carers, who are frequently a central and irreplaceable part of the team supporting the user. Why should information sharing be confined to the professional part of the team?

By and large, the regulatory bodies, in their guidance, re-affirm the need for consent to disclosure (except in the exceptional cases I have already discussed). In summary, they recognise the practical necessity to share confidential information within professional teams; treat that as based on the patient's implied consent; therefore recognise the right of a competent patient to withhold consent; seek to minimise patient objection by encouraging service staff to explain the need for information sharing to patients without drawing undue attention to their right to object; but advise that the patient's actual consent be sought before disclosing confidential information to non-professionals – including voluntary carers.<sup>17</sup>

In the NHS Code of Practice on Confidentiality<sup>18</sup> Disclosure Model B1 (page 26) applies where it is proposed to share confidential information in order to provide healthcare and the advice (at pages 39-40) about disclosure to the different groups of recipients relevant for present purposes, is in these terms:

**1) To NHS staff involved in the provision of healthcare**

*Where information has to be shared widely to provide healthcare, additional efforts to ensure that patients are effectively informed should be made.*

**2) To social workers or other non-NHS staff involved in the provision of healthcare**

*The test of what would satisfy the requirement to effectively inform ..... should be more demanding than where disclosure is limited to NHS staff as the breadth of the information disclosure is not as obvious to patients and their consent cannot be assumed. Disclosure may lead to confidential information being held outside the NHS in the records of partner organisations. Patients need to be made aware of this and partner organisations also need to be made aware that holding health records imposes particular duties and obligations.*

.....

**5) To carers without parental responsibility**

*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 may warrant disclosure.*

For myself, I entirely accept the practical necessity for sharing confidential information between professionals, but find the prevailing “implied consent” justification evasive and unconvincing.

I would prefer to see such sharing amongst professionals justified squarely on the basis of public interest, and therefore permissible in the case of users subject to professional care irrespective of consent, but subject to the limits of relevance and necessity.

However, I would leave disclosure to non-professionals, including carers, subject to consent, express or genuinely implied, for three reasons. First, it is important to protect the autonomy of competent users, which is already subject to erosion and possibly legislative attack. When a competent user forbids the release of confidential information to his carer, that may be hurtful to the carer and even harmful to the user, but it is the user's freely chosen course.

Secondly, in practice disclosure of sensitive information to family or friends is likely to be much more problematic for a user than disclosure within a professional team, and should normally be a matter of free choice rather than release as a matter of course.

Thirdly, almost all carers' problems attributed to "confidentiality" have nothing to do with the application of that principle, as properly understood, for reasons I have tried to explain. Improvement in the general experience of carers does not depend upon any dilution of the confidentiality principle.

#### **A carer's own right to confidentiality**

It is important to remember, because it is often forgotten, that the relationship between a carer, and a member of the user's professional care team, is itself one which attracts confidentiality; and so gives rise to a duty not to disclose confidential information about the carer without consent, or pursuant to an overriding public interest.

This is well expressed in the DoH/NSF leaflet<sup>19</sup> :

*You and the person you care for have the right to expect that information either of you provide for mental health services will not be shared with other people without your consent. This includes information provided by you as a carer not being shared with the person you care for and vice versa. This can only be over-ridden if justified through risk or if this is required by law.*

The Department of Health's Practitioner's Guide to Carers' Assessments (2001)<sup>20</sup> makes the same point, at paragraph 53:

*The carer may wish to discuss information they have not revealed to the person they care for. Such information can only be shared with the service-user with the carer's consent.*

Nevertheless, carers frequently complain that service providers report to the user indiscriminately what they have been told by the carer, often with predictably adverse consequences for relations between user and carer. This can occur despite the carer's request for his confidence to be respected.

Two distinct misconceptions may be involved. The first is the failure to recognise the carer's own right to confidentiality, leading to the unauthorised disclosure to the user of information confidential to the carer. Note that the comment: "Your carer told me that" is a disclosure of confidential information about the carer, if "that" is non-trivial information.

A second misconception is the belief that the user's right to confidentiality somehow operates to entitle him to know all that the carer has told the service provider about the user. This is not the case. Therefore, whilst information from the carer about the user is not in itself information confidential to the carer, the service provider is entitled to exercise a professional judgment whether, when, or to what extent that information should be revealed to the user.

When an individual professional learns confidential information about a carer, he has no right to share that information within the user's support team without the carer's consent.

Of course, carers frequently provide information to the user's professional care team with the intention or willingness that it should be disclosed and acted upon; there is then no problem, because consent releases the information for disclosure.

### **Data Protection Act 1998**

Much of the confidential information gathered by the statutory services about users is likely to be recorded in either electronic or papers records which are subject to the Data Protection Act. Health information is subject to special protection as "sensitive personal data". It can only be "processed" (a term that includes consulting and using the data) if a series of conditions are met. Everyone who uses the protected information must adhere to the data protection principles set out in Schedule 1 to the Act, which therefore provides a general governing framework for the use of information in healthcare, as in other situations.

The first data protection principle is:

*Personal data shall be processed fairly and lawfully and, in particular, shall not be processed unless-*

- (a) at least one of the conditions in Schedule 2 is met, and*
- (b) in the case of sensitive personal data, at least one of the conditions in Schedule 3 is also met.*

The requirement for data to be processed lawfully makes its use and dissemination subject to the general law on confidentiality, whilst the conditions in Schedules 2 and 3 are such that, in the field of health and social care by statutory services, they will almost always be met.

The remaining principles in Schedule 1 confine the gathering and use of data to authorised purposes, require that it shall be relevant and not excessive, be accurate and up-to date, and shall not be kept longer than is necessary. In addition, the person the subject of the information ("the data subject") is entitled to be informed of the

nature of the data held about him, the purposes for which they are held and used, and the classes of people to whom data may be disclosed. He is also entitled to have communicated to him any personal data held about him in an intelligible form.

Overall, whilst the requirements of the Act are highly material to the acquisition and use of information about users, by the statutory services, and whilst their operation requires and assumes that the obligations of confidentiality will be met, the Act does not override or modify those obligations.

### **Human Rights Act 1998**

This Act indirectly incorporated into English domestic law the great majority of the European Convention on Human Rights. The Act makes it unlawful for a public authority to act in a way which is incompatible with a Convention right, with the result that individuals can directly enforce their Convention rights against such authorities, which of course include the statutory health and social services.

The Convention right most relevant to confidentiality is Article 8, which provides:

*Right to respect for private and family life*

1. *Everyone has the right to respect for his private and family life, his home and his correspondence.*
2. *There shall be no interference by a public authority with the exercise of this right except such as in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.*

It is likely that in future the Courts will use the framework of Article 8 of the Convention to analyse whether exceptions to confidentiality are permissible. However, most if not all of the exceptions permitted by law and envisaged in professional guidance, would fall within the exceptions provided under Article 8(2) as being “in accordance with the law” and “necessary in a democratic society in the interests of .....public safety ..... the protection of health ... or for the protection of the rights and freedoms of others”. There have been no decisions, since the Act came into operation, suggesting that this will not be the case.

The Human Rights Act does not, therefore, require any fundamental re-appraisal of the principles of confidentiality as developed by the courts and as reflected in the requirements and standards of the bodies which regulate professional responsibility.

### **Final thoughts**

The most important fact I seek to establish is: **that in most cases confidentiality, properly understood, need not and should not impede constructive co-operation between a carer and the statutory mental health care team, for the benefit of both user and carer.**

This is because the scope of the confidentiality principle is not as wide as some believe (propositions A, B and C), it is moderated by user consent (proposition D), it can when necessary be overridden in the public interest, especially to avert the risk of serious harm to the user or others, or when the user lacks capacity but disclosure is in his best interest.

Carers themselves are entitled to have their confidences respected, according to the same principles as are applicable to users.

The public bodies who contribute staff to professional care teams should have in place clear policies and procedures relating to confidentiality, co-ordinated so as to operate where necessary across employment boundaries, regulating amongst other matters flows of information to and from carers.

Issues of confidentiality cannot be evaded – you can have good practice or bad practice, but not no practice.

---

<sup>1</sup> Government report “Caring for Carers” published 1/1/99

<sup>2</sup> A commitment to Carers (leaflet produced for the Department of Health by the National Schizophrenia Fellowship (now known as Rethink) in about 2000 – still current)

<sup>3</sup> Working with Serious Mental Illness – A Manual for Clinical Practice, Ed by Gamble and Brennan, 2000, published by Baillière Tindall in association with the Royal College of Nursing (extract attached)

<sup>4</sup> Textbook of Community Psychiatry, Ed by Thornicroft and Szmuckler, published by Oxford University Press, 2001 (extract attached)

<sup>5</sup> Attorney-General v Guardian Newspapers (No 2) [1990] AC 109 at 281

<sup>6</sup> Confidentiality – NHS Code of Practice, Department of Health, November 2003

<sup>7</sup> See General Medical Council “Good Medical Practice” (2001) and “Confidentiality: Protecting and Providing Information” (2000); British Medical Association “Confidentiality and disclosure of Health Information” (1999); Royal College of Psychiatrists “Good Psychiatric Practice: Confidentiality” (2000); Nursing and Midwifery Council “Code of Professional Conduct” (2002) and website Advice on Confidentiality; and British Association of Social Workers “Code of Ethics for Social Work” (2003)

<sup>8</sup> See note 7 above

<sup>9</sup> See note 6 above

<sup>10</sup> Kennedy and Grubb on Medical Law, Third Edition (2000), page 1084

<sup>11</sup> See note 1 above

<sup>12</sup> See note 1 above

<sup>13</sup> W v Egdell [1990] 1 All England Reports 835, CA

<sup>14</sup> See note 7 above

<sup>15</sup> See note 7 above

<sup>16</sup> See note 7 above

<sup>17</sup> See the NHS Code of Practice on Confidentiality (note 6 above) especially paras 12 to 17 and 38, disclosure model B1 on page 26 and the text relating to that model on pages 39-40, and the BMA guidance on Confidentiality (note 7 above) especially under “Implied consent: disclosure for purposes of care or treatment”

<sup>18</sup> See notes 6 and 17 above

<sup>19</sup> See note 2 above

<sup>20</sup> A Practitioner’s Guide to Carers’ Assessments under the Carers and Disabled Children Act 2000 (Department of Health - March 2001)