

## Confidentiality

Difficulties arising from 'confidentiality' have been a constant source of concern to NSF(Scotland) over many years and have caused harm and distress to many families affected by schizophrenia and allied illnesses.

While we acknowledge a lot of good practice in the psychiatric system regarding 'confidentiality' and 'communication with carers', we know that this good practice is not universal. Two surveys by this organisation, one on 'Communication with Carers' (1) and one on the 'Review of the Mental Health Act'(2) which included service users' and carers' views on present mental health services, confirmed this as a serious issue.

This paper seeks to outline the views of the Fellowship based on these surveys. Fuller reports of these surveys are available from our National Office.

### Understanding 'Confidentiality'

The general rule on 'confidentiality' is that *'information obtained for one purpose may not be given to a third party or used for different purposes without the consent of the client'*(3) NSF(Scotland) respects 'confidentiality' and emphasises the following points

- we do not expect private confidences from service users to staff to be passed on to carers
- we know that there is sometimes deep and lasting antagonism between the service user and the family/carer and there may be no point in involving this carer (except where there is risk of violence)
- information given by carers to staff should be used carefully as the relationship between carer and service user may be damaged if information is passed on.

### Professional Guidance on Confidentiality

The General Medical Council(4) requires doctors to *'respect patients' dignity and privacy'* and *'to respect and protect confidential information.'* Nevertheless, *'problems may arise if you consider that a patient is incapable of giving consent'.*

The Mental Welfare Commission(5) addresses this point where the patient is simply not fit to decide about informing his/her carer. The MWC (5) states that *'a decision has to be made in the best interests of the patient bearing in mind the decision which they might have been likely to make had they been able to make one'.*

Further they state that *'Staff should, of course, make the effort to go to the patient and ask for permission to share information where this is requested by carers and should not put up an automatic barrier on the basis of confidentiality.'*

The Scottish Home and Health Department Code of Practice(6) considers the *'need to know'* concept. *'Information about the health and welfare of a patient ..... should only be disclosed in connection with the purposes of health care and social welfare to those who would be unable to provide effective treatment and care without that information.'*

Nursing Guidelines(7) make the point that *'in the exercise of professional accountability, assistance should be given to others in the care team, including informal carers, to contribute safely.'*

### **Who are Carers?**

Carers may be relatives, partners or friends i.e. anyone who has had to change their lifestyle in order to care for and/or take responsibility for another who is experiencing mental health problems. Carers do not necessarily live with the person who is ill.

A carer can provide day-to-day support to the person who is ill, can give the background and history of the illness; help in the rehabilitation of the service user; monitor the progress of the service user and encourage the service user to accept the treatment.

When service users have leave from hospital for a few hours or a weekend, they mostly spend time with their carers and when discharged they either go home or visit frequently.

Carers therefore give substantial support and do so regardless of how much support the service user has from professional staff or how little information carers have been given.

### **Why should psychiatric staff communicate with carers?**

The psychiatric staff obviously has a first duty to the service user and it is desirable that the staff member and the service user have a relationship of trust. However it is also obvious from the previous paragraph that carers can have considerable influence on the outcome of the illness both in the short and long term and their need for information cannot be ignored.

NSF(Scotland) believes it is wrong for staff to send home someone, who has had close professional care for many weeks from experts in mental illness, to the family carer who understands nothing about it.

Compare the situation of a carer of someone with a mental illness to that of a carer of an individual with a physical illness when the carers would be much more likely to be given information and support to care for their relative in or out of hospital.

The CRAG Good Practice Statement for Schizophrenia(8) recommends that *'Therapists should encourage patients to take relatives into their confidence where these relatives are involved in their care'*

and Szmukler points out that *'The clinician can persevere in seeking the patient's consent'* (9)

### **What is the problem for psychiatric staff?**

Given the advice above, carers ask whether there is ever any justification for withholding information from carers. The policy of using confidentiality as a reason for not talking to carers may be justified in some instances.

- a. If the relationship between service user and carer is deeply antagonistic, there is no point in trying to involve the carer if s/he is not going to be part of the support network
- b. The therapeutic relationship between the psychiatric staff and service user may be damaged by the therapist appearing to betray the user's confidence.
- c. If there is only time for the psychiatric staff to ask the service user the question about giving information to the carer and no time to discuss the issue or persuade the user, then the user's wish must be honoured. In these circumstances, priority should be given to making enough time. Lack of time is not enough reason in the longer term.

### What is the problem for carers?

The NSF(Scotland) survey(1) found that among carers who got no information from professional staff, 40% were given 'confidentiality' as the reason. Sometimes carers were asked to give background information to staff but this was one-way communication only. In other cases, there was no information exchange at all.

The consequences of not getting information were found in the NSF(Scotland) survey (1) to be

- feelings of hopelessness, fear, guilt and isolation leaving carers demoralised and unable to cope. With hindsight, carers later realised how much their early reactions may have hurt the person who was ill
- family conflict about what to do in difficult situations, the anger from this spilling over on to the user
- expectations of the service user's ability being completely unrealistic, such as ability to lead a 'normal' life, to return to college or work
- hostility between carers and users because of misunderstandings and blaming each other, resulting in breakdown of relationships
- carers losing confidence in the professional staff's ability, possibly passing on this lack of confidence to the service user
- not being able to monitor the progress of the illness, the treatment and signs of relapse.

It appeared to carers that some staff say 'No' to talking to carers on the grounds of confidentiality and do not, in fact take time to ask the person who is ill.

Carers feel strongly that if staff in residential/supported accommodation require information to help support the person who is ill, so do carers fulfilling the same role at home. The family member or informal carer, may be in frequent if not daily contact with the user providing, as one carer put it, *'love, companionship, stability and activity'*.

### Eight recommendations

1. The right of a carer who is supporting someone suffering from severe mental illness to have ongoing contact and advice from a member of staff with experience in the management of severe mental illness should be recognised and respected.
2. All carers should be involved if at all possible. This requires a positive approach to carers with staff inviting carers to a meeting and giving them a chance to ask further questions.
3. Even when there is no definite diagnosis, information could be given including some idea of the nature of the illness and the treatment and the reasons why no definite diagnosis can be made. If staff seek out carers and treat them with courtesy and consideration, carers may be much more able to accept that some questions cannot yet be answered.
4. Service users should be given the chance to nominate their principal carer. Also, when their condition is stabilised, they should be able to say how much future involvement they wish from that carer and this should be recorded in an advance statement This will make it more likely that they will be content for that carer to have information. Where there appears to be antagonism between carer and user, staff should investigate to find if this is recent or deep-seated and long- lasting.
5. Explanation of the meaning of 'confidentiality' must be given to the carer when the service user does not wish carers to be informed. This could be accompanied by the reassurance that when the service user's condition has improved, staff will ask him/her again and will encourage the service user to confide in the carer. A carer who is denied information, could be given information that is not confidential, possibly by a member of the team not involved in hearing personal confidences from the service user, possibly a social worker. Examples of non-confidential information are
  - the patient is being treated with drugs to help to control the symptoms (which the carer already knows about) and there is a need to continue medication

- the hospital may have to try several drugs before they find the right one for the individual and this may take time.
  - tips on how to cope with situations and confrontations at home, could be given by say, the key nurse to carers when the patient first goes home to visit
6. A carer who is denied information, could be pointed towards another carer or organisation such as NSF(Scotland) to give them general information and support. 'Self-help groups run by other organisations and groups run as evening classes all take the giving of information away from the relationship between patient and doctor and thus relieve the burden of confidentiality.'(10) Carers should be offered information courses, run either by hospitals or voluntary organisations whether or not the issue of confidentiality has been raised.
  7. The user should be persuaded over time of the benefits of talking to carers. Therefore the need for carers to be given some information at the time of discharge should be explained to them in the same way as the information needs of community staff are explained.
  8. At the very least, if the service user is to have any contact with the carer, the latter must have telephone contact numbers for discussing problems and for emergencies. Other information for the carer can be negotiated with the service user such as information on treatment, including medication and side-effects; information on the nature of the illness including the prognosis to give carers a chance to find out more for themselves and to come to terms with all the implications; information on benefits, housing and other services or the name of someone who can help.

## References

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