Confidentiality and Sharing Information

All Trusts have a Document on a Policy on Confidentiality – one needs to look beyond this.

Guidelines are needed because:- these explain the rationale – the reasons for actions.

- they give illustrations of what if?
- they make clear what carers can and cannot expect.

Best Practice comes from Good Protocols - clearly laid down ways of doing things.

Without Guidelines and Good Protocols staff make individual judgements based on an interpretation of their Professional Code of Practice (PCP).

Main areas for Protocols on Sharing Information with / involving Carers.

1. On your relative being referred and entering the service. A record of your relationship and any siblings. (Carer can mean partner, key supporter).
2. Ward meetings. (Notice of these. How the carer can contribute).
3. Creating a Carer’s Care Plan.
4. When leave is considered and on returning from leave.
5. When discharge is planned. Plan if relapse occurs.
6. Creation of an Advanced Statement where kept and how it is activated.

Training

Staff value an “In my shoes” type of exposure to positives & negatives.

Staff need a shared culture of working with carers - ward staff and clinicians.

Training based on the Guidelines, Protocols and carers experiences.

Audit

(See T o C ‘Self Assessment Tool Criteria 3’ - page 23)

The current status against the Criteria 3.1- 3.9.
GUIDANCE FOR CARERS

When your relative becomes first involved and when they move between parts of the service, make sure that staff understand your relationship and record it. This is particularly important if your relative is unwell and refuses to consent to your involvement.

Get to know the named nurse and senior Ward Staff. Many wards have a Carers Link on each shift. They are a valuable contact if the named nurse of your relative is away.

Keep in touch with your relative even if you meet hostile rejection or no response. Remember they are ill but will recognise if you stay engaged.

Give feedback after trips from the ward. You may have gleaned insights which will help the staff.

After stays off the ward, report to staff (though not necessarily late at weekend - Monday is better). Encourage staff especially the named Nurse to use you to monitor progress, undesirable side effects and indicators of relapse.

At the time of Discharge make your views heard and recorded. You need to know what is in the ‘Contingency Plan’ in case of relapse or other problems. Keep any emergency contact details carefully.

Don’t forget there are several ways to pass on your views to the nurses and doctors. You might phone, email, fax or send a letter (***). Keep copies and if you can - a calendar of progress. This is useful especially if you record medication, important events and wellness.

Finally remember in extreme situations you can refuse to have your relative live at home with you. It can sometimes be best for both.

I A W   November 2010
CONFIDENCES and CONVERSATIONS

Sometimes by the time one’s relative enters Acute Services they can be very suspicious of some people. This can include their family and friends so they may say to staff you are not to talk to my carer. Legally this is something that the patient can demand.

They may be concerned that very personal stuff is passed on but this is something that the staff are most unlikely to do anyway.

Staff however want to keep good relationships with their patients and so are in a dilemma however the see the main duty is to the patient under their professional code.

It can help to establish what information the carer feels the need to share, to shield the named nurse from accusations and to respect the confidences of the carer.

The following are strategies to respect the needs of the 3 parties in this scenario.

Themes for conversations between staff and carers

When a service user has stated their wish that information should not be disclosed to their carer, the following responses may be helpful

A member of staff might say to a carer:

- What sort of things do you want to know? I can speak about this but not that.
- I can’t talk to you, but there are people appointed to support carers, I can refer you.
- I can’t talk about your relative but we can talk about general aspects. For example, we might talk about why people might have strange ideas or behaviours.
- I could refer you to a Carers’ Support Worker if you wish, and she/he will talk to you.

A carer might say to a member of staff:

- I don’t want to know about confidential stuff. What I need is help and advice to manage the situation – so that I don’t make things worse.
- I have heard doctors mention psychosis. Can you explain what this means? How do people deal with this as carers?
- I appreciate that you have been asked not to talk to me, so can you suggest some one I could approach with my questions?
- Can you suggest any leaflets, books or Helplines to help me find more information?
- Could you help me by explaining a few things that I have read about but don’t fully understand?