

Hot Tips for Carers

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When your relative enters Acute Services

Make sure that the staff know that you are the main carer and they have your name and phone number on record.

Make a note of who is the Named Nurse - this person will work closely with your relative: and the doctor – the staff may call them the RMO - the Responsible Medical Officer.

Make sure you are given a leaflet which explains basic ward information, contact numbers, visiting times and rules.

When you feel up for it, in the first week, ask for an appointment with the RMO. This will give you a chance to share information and ask questions, but don't expect the staff to tell you personal stuff about your relative.

The staff may say that your relative has told them not to talk to you. Don't take this too personally – it is not unusual when people are mentally distressed for them to become very suspicious and especially about those closest.

This won't stop you being told general things about how the ward functions but be prepared to be persistent - explain that you are anxious and need to be reassured.

Many wards have a nurse who has the job of helping carers. Ask if there is a Carer Lead or Carers' Champion. This person will be able to give you extra help, information about carers meetings. Ask for a 'Carers Pack' which will give lots of general information including how to find help outside the ward.

Carers Support Workers work in the community though some visit the wards as well. Ask the staff for contact details. This person will meet you and introduce you to other ways of getting information and help. They work one to one and organise groups and activities for carers.

Carers are entitled by law to a Carer's Assessment of what they need in connection with the mental health care of relative or friend. This can link to other benefits including finance. Ask the staff or Carers' Support Worker to make the arrangements for you to have a Carers' Assessment. It will involve a conversation with a worker and help you both to get a clearer picture of your caring responsibilities. It is then easier to see what help is needed.

Ward Meetings and leave

Don't pass up the opportunity to share in ward meetings though not necessarily each time.

If the staff talk about '*letting your relative have some leave off the ward*', do make sure that your views are heard especially if their home is with you and they intend to eventually return.

Don't cancel important plans - your own needs are very important - insist on being informed in good time to allow proper arrangements to be made.

Feedback

After leave from the ward, find a way to feed your experiences - including any questions and problems - back to the staff. Check for the most appropriate time to do this so that you can involve either your relative's Named Nurse or the Ward Carer Lead.

Discharge

If your relative is being discharged to your home, you must be involved when the Discharge / Care Plan is being drawn up. The meeting should be clear about what community services are needed to keep your relative well. It should agree what signs may point to a developing relapse and the actions to be taken, contact details and keep the phone number carefully.

Future Planning

It is important for staff and yourself to encourage your relative to agree to make an Advance Statement and sign it. This will set out a series of actions agreed to when they were well which they wish to be followed. Copies should be kept by several parts of the service and a copy kept by yourself. If your relative becomes very confused you may be the first person to realise potential problems and it will be far easier to activate the Statement and to take early action.

Finally

It is very important that you try to keep your own life – especially when you first become involved in someone's care.

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.

CONFIDENCES and CONVERSATIONS

Sometimes by the time ones 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?