

‘Do your local MH Services listen to carers’

Princess Royal Trust for Carers

**National Conference
at Birmingham**

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**Alan Worthington
Carer, NMHDP Acute Programme.**

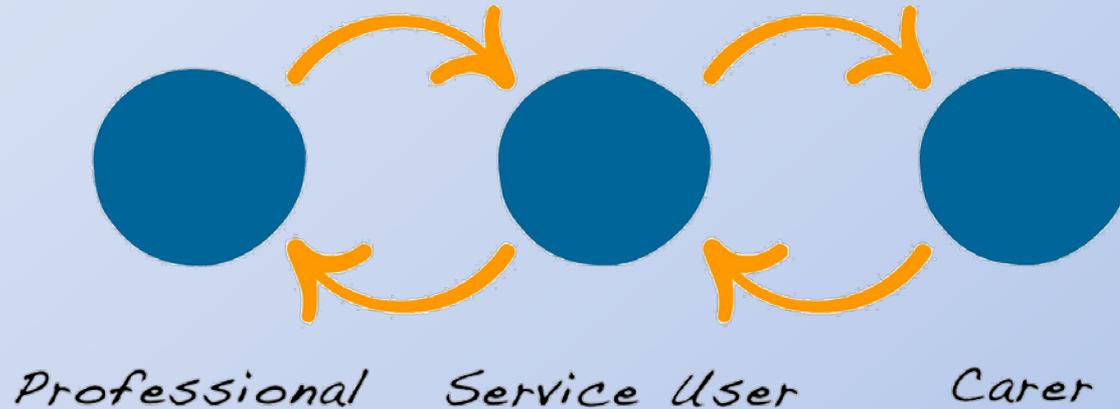
“The Carers needs are as great as the patient’s needs”.
(Hospice movement)

**“They didn’t know who I was, they told me nothing
and I wasn’t expecting him when he was sent
home”.** ***(Carer)***

“Why involve the carers?”

**They are already involved - and are likely to continue
to be involved after the professional has moved
on”.** ***(Consultant psychiatrist)***

A common model of professional involvement with carers.



Some of the consequences that carers report :-

- The 'care relationship' is not recognised.
- Carer not given key information.
- Carer not involved when important plans were being made.
- The carer's emotional or health needs not recognised.

- “I want to know what is going on” - *information.*
- “Am I responsible in some way” - *reassurance.*
- “What is going to happen to us in future” - *hope.*
- “How can I manage his/her behaviour” - *skills.*
- “I need to off load one to one or with a group”
- *find support .*

Other possible consequences - stereotyping !

- **‘The angry carer’ -**
- **‘The problem carer’ -**
- **‘Over involved carer’ -**
- **‘The difficult carer’ -**

Why listen to carers?

1. If there is a lack of sharing:-

- Carers are unlikely to know what services are available.
- They are unlikely to know how to provide effective support and have coping strategies.
- They are unlikely to have knowledge of treatments and be able to distinguish signs of illness from side effects.
- Without help, their own health may deteriorate and they become unable to continue to care.

Why listen to carers ?

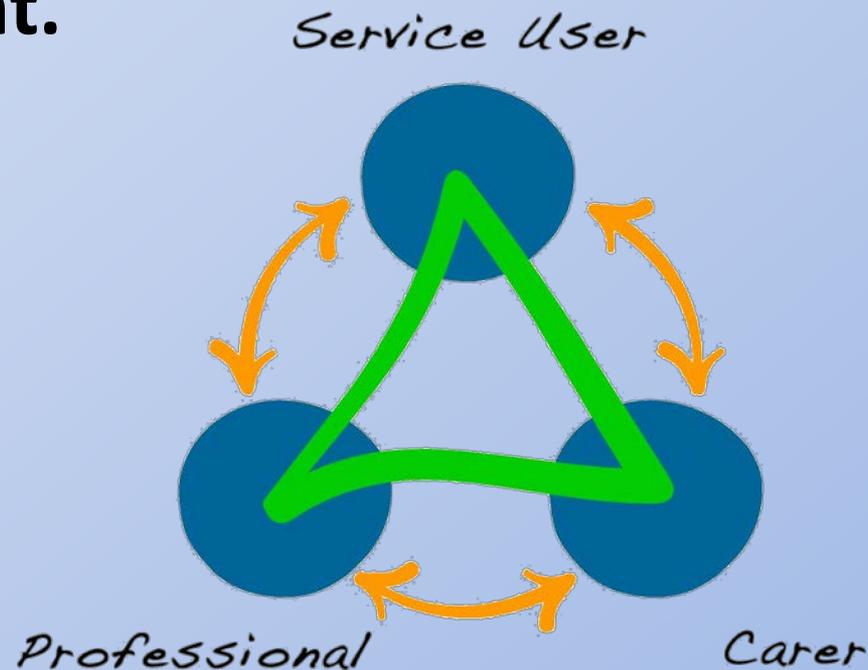
2. Some benefits of sharing -

- It helps to create a common strategy - which everyone understands.
- A good diagnosis and treatment depends on knowing the background and history in which the carer is likely to have been involved.
- Carers knew the person when they were well and are aware of their abilities and vulnerabilities and so may have insights about what may help recovery.
- Carers are likely to be aware of the early signs of relapse.
- Carers are likely to be around in the future and have a long term view and commitment.

An Ideal Situation for Carers

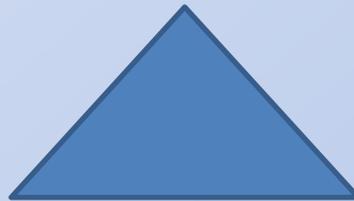
The idea of a triangle has been proposed by many carers who want to be an active partner within the care team.

This gives a more collaborative model of involvement.



Carers wishes for:-

Confidences to be
respected



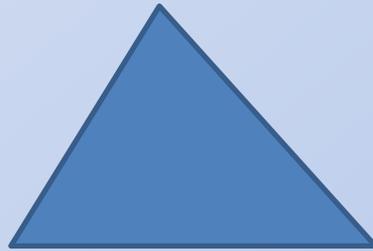
B T O

(Best therapeutic outcomes)

Best relationship
with service user
and clinician

Service User wishes for

Confidences to be
respected



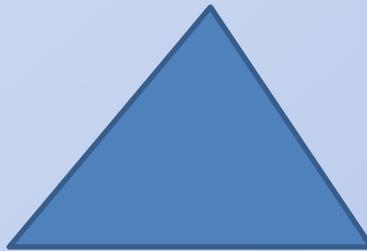
B T O

(Best therapeutic outcomes)

Relationship
with family & friends
and clinician

Clinician wants to

Adhere to their
Professional Code



B T O

(Best therapeutic outcomes)

Keep relationship
with patient

The Principles Underlying 'Confidentiality'.

- “Prevents disclosure of any information provided or discovered in the course of the professional relationship, to a third party without consent”.

However

“The user does not have the right to prohibit the professional from engaging with the carer, or providing information, advice, and support or from talking to the carer about the user, provided that no confidential information is divulged.

- “The user has no right to prohibit the professional from receiving information from the carer”.
- “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”.
- “Confidential information may be disclosed with the user’s consent, express or implied, regarding specific information and /or to specific individuals”. G. Machin 2004

Triangle of Care

Key Element 3 Information Sharing

‘Service uses policy and practice protocols for’

A “Guidelines for sharing information with carers”.

B “An Information Release Form and Protocol”.

C “An Advance Statement Form and Protocol”.

3 B “An Information Release Form and Protocol”.

Simple version.

- What information?
- What level of disclosure?
- To whom?

Example of Good practice “A Carer Clinic”.

(As reported by the Consultant Psychiatrist based at a PICU in Bucks).

- ***The Carers’ Clinic is timetabled on one morning each week.***
- ***Carers are invited to ring the secretary for an appointment.***
- ***Consultant offers each carer individual time at the Carers’ Clinic.***
- ***Meanwhile, the patient is asked how much information can be shared, either:-***
 - a) total disclosure.***
 - b) partial (is there specific info. not to be disclosed).***
 - c) “no disclosure” therefore the carer given general information and support only.***
- ***This allows conversations then take place between carer and doctor involving information shared on the basis of the patient’s consent.***
- ***Note In a), b), and c) the carer can pass on information.***

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 who support carers, I suggest that you talk to them.**
- **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 Help-lines 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?

Attacking Carer Stereotypes 2

- **‘The angry carer’** - there may be good reasons for this reaction and through better engagement and over time the carer may be less angry.
- **‘The problem carer’** – becomes part of the solutions.
- **‘Over involved carer’** – get confidence in the system and let go.
- **‘The difficult carer’** - becomes a collaborator for better services.

Triangle of Care

