

Sharing information with family and carers



Information is important

This leaflet is about how we share your information, and the benefits of sharing it with your family and carers. Your personal information is needed to provide the right care and treatment. We also hold information that may not be so sensitive, such as dates of appointments.

We keep your personal information securely. We will protect your right to privacy, whilst sharing the right information with the right people. When staff do share confidential information they should:

- only disclose the minimum that is necessary for the purpose;
- share only with those people who need to have it;
- make sure it's accurate and up to date;
- make sure it's shared in a timely fashion; and
- make sure it's shared safely and securely.

This booklet is only a general guide, so please take advice if you are concerned about any of the issues raised. This booklet is about how we share information with carers – if carers have any concerns about how we record information about them, please talk to a member of staff.

Sharing information – what's the problem?

Families and carers often say that they didn't have the information they need to be able to help, because staff won't share important information.

I have been caring for someone with bipolar disorder for around 8 years. At the beginning I had no knowledge of the illness and no one from the Community Mental Health Team was forthcoming

*with information. I had to learn all about the illness by trial and error. During this time there were many instances where I made his illness worse, although I thought I was doing things for the best, my lack of knowledge antagonised the situation. There have been many hospital admissions and had I been aware of the illness and early warning signs some of these may have been prevented.
(‘Please Remember Ben’)*

Sharing information is a key part of how we provide better, more effective services that are co-ordinated around the needs of the person. It is important for early intervention and preventive work, for safeguarding and promoting welfare, and for wider public safety.

Sharing information with families and carers about someone’s health and the services being provided can be very straightforward, or can be a very sensitive issue. It depends on:

- How you feel about it
- How other people feel about it
- What the information is
- If it’s personal or general information
- The situation
- Your health

Deciding what information to share?

Before making a decision about whether to share information with families and carers about health or services, there are some things to think about. Will sharing the information:

- Help someone else to understand what’s happening and support you better?

- Help make the services work better – we know that when carers and family have provided information in the past, this has helped us to provide better care
- Mean you can talk to someone about how you feel and they will understand what the problem is?

'It would be good if care co-ordinators, carers and service-users could get together for 'problem-solving' meetings. A specific problem is identified, discussed and possible means for improvement agreed between all parties' (Please Remember Ben)

Who is a Carer?

In this guide, carers are anyone who provides regular support for someone with a health problem who is a friend, relative, spouse or partner. This sort of carer is not someone who is employed by any agency.

My son now lives independently. He has been treated in two different areas, these have been so different in the way they treat patients and their carers. One encourages carers to attend the ward rounds and all outpatients' clinics along WITH the patient. All the staff are very friendly and forthcoming with any new information they have. The psychiatrist listens to both the carer and the patient and the CPNs have a friendly and very supportive manner. You feel that everyone is working together as a team including my son and ourselves. Unfortunately my son has had to receive treatment from another area now, one which cuts out the carer and doesn't let them know when appointments are made. This results in appointments being missed because he forgets and there's another 3-6 months to wait for another one. I, his carer am not invited even when I have asked if I could be. (Please Remember Ben)

Information sharing agreement

To help you to be clear about what information you'd like to be shared with your friends and relatives (both routinely and if you're too ill to be able to make a decision), think about:

- Who you'd like to have information
- What information you'd like them to have, and when
- What circumstances you'd like it shared in

The form attached is a way of being clear about this. There are two copies, and we'd be really grateful if you'd let your health professional have one so that we can log your preferences and make sure we act on them.

Remember:

- It's your choice what information is shared
- You can change your mind
- Not all information is confidential information – if we tell your carer you have been admitted to hospital, for example, we do not have to tell them why, or your diagnosis, but it may help just that they know you are in hospital
- Consent to share information doesn't have to be in writing, but it really helps if it is, and we can then record it in your notes. We would ask you to sign the attached form, and we will also record our discussions about sharing information in your record.

Help and advice

There are organisations that can advise you about sharing information and confidentiality:

- **Your Information Your Rights** A leaflet explaining about how and why we keep personal information. Derbyshire Healthcare NHS Foundation Trust
- **Carers and Confidentiality in Mental Health: Issues involved in information sharing** Leaflet. Partners in Care/ Royal College of Psychiatrists www.rcpsych.ac.uk/healthadvice/partnersincarescampaign/carersandconfidentiality.aspx
- **Confidentiality** Rethink Mental Illness website www.rethink.org/living-with-mental-illness/rights-restrictions/confidentiality
- **Confidentiality and Data Protection – legal briefing** Mind www.mind.org.uk/information-support/legal-rights/confidentiality-and-data-protection/
- **Citizens Advice Bureau** www.citizensadvice.org.uk/

Advocacy – someone to speak for you

- **Peaks and Dales Advocacy** Advocacy in the High Peak and Derbyshire Dales for older people, people with mental health problems, and people with a learning disability Telephone 01298 79539 e-mail: padaf@btconnect.com www.peaksanddalesadvocacy.org.uk/
- **Derbyshire Carers Association** Advocacy for carers www.derbyshirecarers.co.uk/
- **Derbyshire Mind** Advocacy for people with mental health problems Telephone: 01332623732 E-mail: advocacy@derbyshiremind.co.uk www.derbyshiremind.org.uk/

- **Derbyshire Advocacy Services** Advocacy for people with a learning disability www.derbyshireadvocacy.org.uk/



Contact us

If you would like further copies of this booklet, please contact the CPA and Core Care Standards Service:



The Lodge, Walton Hospital
Whitecotes Lane
Chesterfield, S40 3HW



01246 515974



corecarestandards@derbyshcft.nhs.uk

Our Core Care Principle on Information: *We will keep information safe and share it when needed, and you will have the right Information at the right time.* Find out more about our standards and about information sharing at:

www.corecarestandards.co.uk

'Please Remember Ben' is published by Derbyshire mental health carers and is intended to inform professionals involved in the care of people with mental health problems. 'Please remember Ben' can also be found at: www.corecarestandards.co.uk

Derbyshire Healthcare has signed up to the **Triangle of Care membership scheme**, which sets standards that:

1. Carers, and the essential role they play, are identified at first contact or as soon as possible thereafter.
2. Staff are 'carer aware' and trained in carer engagement strategies.
3. A range of carer support services is available.
4. Defined post(s) responsible for carers are in place.
5. Policy and practice protocols regarding confidentiality and sharing information are in place.
6. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.



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