

**'A Life of Your Own'
Report from the Carers' Forum for
Carers of People with Mental Illness**

14th June 2010



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Contents

Page 3	Introduction and Executive Summary
Page 4	How can access to mental health services be improved for you as a carer?
Page 5	How do you know when you are not coping?
Page 7	What do you need for yourself?
Page 9	Evaluation of the Event

Introduction

The Mental Health Carers' Forum was held in Carers' Week as a joint event between the Carers' Centre Bath and North East Somerset and Rethink. Key note speakers were Andrea Morland, Joint Mental Health Commissioner Adult Health, Social Care and Housing Partnership - Bath and North East Somerset and Mariella Dexter, Foundation Trust Programme Director, Avon and Wiltshire Mental Health Partnership NHS Trust.

Carers were asked to give their views on three areas. Gaining the views on each area was facilitated by professionals from the Carers' Centre, Rethink, Bath and North East Somerset Council, NHS Bath and North East Somerset and Avon and Wiltshire Mental Health Partnership and notes were taken of the carers views.

Executive Summary

The main views of the carers were:

- Professionals should listen to the carer.
- G.P's need to be more understanding.
- Need for an emergency service.
- More support needed for carers including counselling, and an advice line.
- Need for simplification of the systems and clear lines of accountability.
- Need for local services.
- Need for breaks and support to take a break.
- High quality information needed.

1. How can access to mental health services be improved for you as a carer?

- When the cared for person is discharged what happens if you need to fast-track the person back into services?
- Bank Holidays are a classic example - you can guarantee there'll be an incident but there's never anyone available to support.
- My husband has been ill all our married life. His medication was suddenly changed recently - he'd been suffering terrible nightmares. The Dr. rang at 6 o'clock on Friday morning to tell him he'd been taking too many valium - his medication was stopped immediately. My husband panicked and just went to pieces! He has told me if you leave me I'll kill myself.
- Issues of confidentiality - when the person you care for is well everything's fine and you're left to get on with it but when there's a crisis confidentiality can be a real barrier
- GP's - I get more help and understanding from the Dr's Receptionist than the GP.
- Your physical health is more obvious - it gets treated quicker than mental ill health the effect of my husband's illness on me and the rest of my family.
- I need someone to *understand*. I've been going to the same surgery for years but the Dr. doesn't seem to realise - I just can't get my husband to go to the surgery or the Walk-In Centre.
- What suits one diagnosis doesn't always suit another.
- The Carer Support Worker only comes in for an hour a week so he only gets a snapshot - doesn't see the 'real person'. He doesn't realise that being taken off for an outing causes him more anxiety than good.
- Develop a sense of trust between health professionals and carer - listen to carers' views
- There needs to be more understanding - nowadays you expect people to be more accepting of mental illness but when you mention it the reaction is 'shock-horror'
- 'It's all about my partner, there is no support for me'.
- Carer feels pressure to support her partner in performing all day-to-day tasks and fears the repercussions if she does not take on so much.
- It would be useful to understand more about the medication her partner is on and any possible alternatives.
- Carer feels she would benefit from help planning for emergencies.
- The GP doesn't take into account Knowing how to access the service, instead of wasting time.
- Users are at one end of the service and funders are at the other end, what happens in between? Bureaucracy, language they are all barriers. Barriers need to be removed. We need to understand how services are delivered and the roles of each service. As carers we don't know where to go or who does what?
- You lose accessibility and accountability if you can't see who is responsible.
- A simple, printed, explanatory leaflet would be useful.
- It's such a complicated process; nobody has explained the mechanics of it to us.
- I have had problems because my son's GP and my GP don't co-ordinate together and the psychiatrist won't listen. Things can get desperate, especially at weekends.
- The crisis team is not really 24 hour. I had information from them... who to call in an emergency, but all I got was an answer phone, or so far anyway. There seems to be a lack of co-ordination.
- You can't wake a psychiatrist between 11-5 unless the ill person is on red-alert. Sometimes they are just climbing the walls, once I ended up giving my mum someone else's medication to calm her down as I couldn't get any help at all.
- There is nowhere to go. A&E is not any help, they don't know about mental health.
- I have gone around to different people trying to get help, but I have never had a diagnosis from anyone about my son, the only support I have had was from Rethink. Services only responded by changing medication and increasing/decreasing the amount of

medication my son was on. He is now trying to come off the drugs on his own and despite all the problems of withdrawal, he is at last beginning to improve.

- There is a lack of accountability and responsibility when things go wrong; we don't know who to go to, to get things back on track.
- Rethink have been helpful, but it feels as if nobody else is listening to us.
- Everything, all the useful services seem to be closing down.
- We need an advice line that goes through to someone who understands and provides you with advice and things to try for the next 4 hours (should be available throughout the night) for example: how do I prevent this person harming themselves or someone else. Part of the help available should be the offer of someone to come out if it is required-a kind of triage process that assesses the situation and listens to the carer and provides help 24 hours a day 7 days a week. The process of support MUST be available in a variety of forms including a home visit and practical solutions when required.
- We need more locally based services. No good having assessments from people based outside B&NES, especially for people with challenging behaviour.
- My mother drank alcohol and had mental health problems. I couldn't get help with the mental health problems because of the alcohol and I was left in Limbo.
- Police Station is not a good place of safety to take people.
- I think people are pigeon holed. If you don't fit into a pigeon-hole, you don't get anywhere.
- Better framework for service delivery. There is often duplication. We want to know what each person does and how it is all made clear, so everyone has their part to play
- Clarity will help to focus services and avoid duplication.
- Confidentiality - I never know what he says to the GP or the Psychiatrist
- Single point of access?
- Continuity of care required. Lack of continuity amongst what AWP/other services have to offer after illness e.g.: back to work etc...
- Surely what people spend their personal budgets on is an indication of what services people find helpful?

Prompt: What are the routes to effective engagement long term with carers, without it being a chore?

- Childcare.
- Focus groups, not questionnaires.
- 1-1 individual consultation by appointment.
- It took a while to get there, not always clear where to get help from, because of where one lives.
- Tried different medications, tried monitoring medication - didn't work. Needed help. Was then sectioned. Nobody asked how we were after the event. Bath hospital was very good.
- Would have helped to have been spoken to after my son was "taken away" Have received information and support from CPN and Rethink.
- Found it hard to engage with support at first "is it my fault?" "What could I have done differently?"
- Felt well provided for by GP, visits from mental health team and appointments with psychiatrist.
- Years ago, not taken seriously, doctors didn't seem interested, eventually found a "good" doctor who was more proactive.
- Persistence of carer supported wife.
- Maybe when people are well they could put a "statement" in place about what could/should happen.
- After referral from RICE prompt helpful response from CMHT with regular visits from the team - they will communicate with carer, helps to cope better.

- It's much worse for the carer.

Prompt: Factors that help:

- Faith.
- Playing the piano.
- Gardening.
- Support- someone to talk to who you know.
- More support following discharge - things are not in place before discharge.
- Lack of information, lack of consistency of staff.
- Lack of couple counselling, individual counselling.
- Feel "on the edge".
- Some carers feel worse than when user is getting better as they have more time to themselves and distress they have been holding in comes out.
- Feeling that "mothers" are expected to manage.
- Planning in to the future. Carers worry about being unable to care in the future.
- Confidentiality issues.
- More information needed, confusion about the systems and services and how they fit together.
- After discharge from CMHT - who checks on people? Need for mentors.
- Concerns about people isolated in their own accommodation and closure of supported accommodation.
- Need to train and inform community to be able to support users living within them.
- Awareness raising for the public.

2. How do you know when you are not coping?

- When you haven't got the energy to ask for help.
- You have to work around it - I've learned by looking at her what sort of a day it's going to be.
- No-one seems to understand - you're on your own with it. It can feel so lonely - I can be in a room full of people yet still feeling alone.
- It's having to deal with all the day-to-day things - all on your own - it's a lot of pressure.
- I've had to be both mother and father to my daughter; she worries about me and also about her dad - I worry about the affect on *her* and on the rest of the family - he worries about me!
- I don't have a social life - that's why 'Give Us A Break' and 'Two's Company' outings are so good because they take both service users and carers.
- I sometimes think I'm doing too much - I wonder what would happen if I couldn't do it
- I've got the Community Mental Health Team coming to see *me*. I don't really like him, but he's my dad and he's in trouble. In order to get some help I need to be extreme - I told them I was at the point of suicide and killing my dad, before they finally agreed to send someone in. I've had enough now... what I'd like would be for someone to come in three days a week to give me a break - some relief.
- But then you feel guilty!
- The cared-for person won't always accept carers coming in.
- It's easy to become self-pitying because it drains you.
- I get one doctor, then another and you have to explain everything again from scratch - you become a wash-out - exhausted - you haven't got the energy.
- It's not always easy to recognise the first signs of stress building up - it can hit you suddenly.
- Then you begin to learn to spot the early signs - recognise that things are getting on top of you - I go out for a walk for 10 minutes to try to calm down. I'd like a support group - use of a room at the Carers' Centre in the evenings.
- Sometimes we take on too much. You have to learn to know how much you *can* do yourself and then you have to say I'm sorry but I just can't do that any more!
- I almost feel as if I'm being judged if I ask for help.
- If I go to the Dr's inside I'm churning - I feel I'm a traitor.
- Today at this event everyone can relate to what you're going through.
- Some doctors' attitude and manner can be really abrupt - it's so wonderful to get a response that's warm & friendly.
- If you ask for help it's a genuine cry for help - you're not 'crying wolf'!
- Too many GP's don't have enough knowledge of mental ill health.
- GP is my first point of contact, but he is always busy. Carers Centre/ Rethink listen.
- Some GP's are involved and responsive but there is no consistency amongst GP's.
- My GP is a nice man, but he doesn't know about mental health, he just pats me on the back.
- Sometimes I ring Rethink they always listen, or I ring Samaritans, they listen, it's better than nothing.
- Others have similar problems, but I don't like to keep calling on them as they have their own problems.
- Carers' health is suffering: has problem with her knee and is feeling depressed.
- Feels she has 'lost motivation' and 'given up', partly due to the lack of communication between her and her partner.
- Carer feels that she is always put in second place to her partner, always supporting him in detriment to living her own life. He 'puts me down' and 'I don't have the confidence any more to stand up for myself'.

Prompt: How many have had a break from their caring role?

- Not for 5 years, apart from carer events.
- Breaks make a big difference as to whether we can continue to care.
- Rethink arrange breaks and events which help.
- There is a knock on effect on our own health, it makes me anxious, sleep deprivation etc... is difficult to manage, family support is important.
- I lost significant work opportunities. I took early retirement in the end because I couldn't get where I wanted to. It would have meant working away from home and I couldn't do that. If there had been more options to get a better care/work balance it would have been better. We spent 4-5 years trying to get access to services for our son and we didn't get anywhere.
- There is talk about getting people back in to work after mental health problems, but there is no help. It is not possible.
- My children are young - they might do something little and I find myself taking out my stress on them, so I have to back off from my caring role.
- Family time sessions through the early intervention team is very valuable And helped us a lot. I think that family therapy should be available to everyone, not just through Early Intervention. This model should be available to all families.
- One knock-on effect is that I can't have anyone over to my house because I never know what he will be like. It is very isolating, but I try to go out quite a bit. I maintain friendships if I can.
- Physical health deteriorates.
- Worry about what you are saying.
- Become very drained.
- Sleep is disrupted.
- Cancel outings.
- When things are ok I can get on with my life. Have learnt to "let go" having had discussions with Rethink.
- No social life-only with partner- "always with him" feel I have lost friendships, hard to express my feelings to my family.
- No social life - carers feel totally relied upon.
- Never able to relax.
- Arguments.
- Feel as if there is a wall in front of me - I don't know which way to go.
- Want to escape- "run away".
- Tired, not sleeping well.

3. What do you need for yourself?

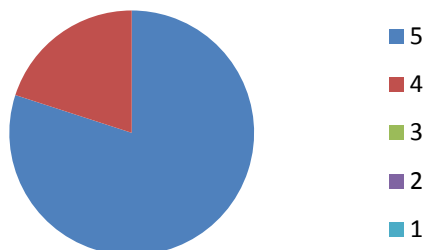
- An Emergency Planning service - with one number to ring - at times like Bank Holidays when no-one's around.
- The person needs to be in 'the system' - with records, knowing who they are, what the needs are etc.
- Need to work round the confidentiality issue - 'Consent To Contact' form could be helpful - service-user agrees to list of agencies who can be contacted in a crisis.
- Particularly important for those people who have nobody to care for them
- Consistency and continuity of Care Services are really important:
- some care agencies care worker can come at any time between 8.00am and 11.00am.
- it may never be the same care-worker coming in twice.
- in some cases care-workers are coming in at 6.30pm in the evening to put the person to bed.
- some care agencies are just in it for the money.
- How much check does the LA make on quality of care agencies?
- Family relationships/ marriages do suffer.
- Talking Therapy for carers - for themselves - it's not always about the service user. Need someone to listen to me, how I'm feeling.
- Difficulty dealing with issues of 'selfishness'.
- It can be difficult to talk when your emotions are pulling you in different directions - it can make you ill.
- I feel guilt - betrayal - in talking about my relationship negatively.
- Anger, fear, guilt - the most common negative emotions experienced.
- More professional help needed from properly trained staff in mental health.
- Better communication skills from professional E.g. good command of spoken English, being treated as a human being - good 'bedside manner'.
- Need to build trust in relationship between carer and psychiatrist and mental health team.
- GP's to be trained to have more knowledge about mental health issues.
- 'I want someone to talk to who will listen and understand'.
- Carer feels that she needs to 'build confidence' as she is scared to speak in a group and she doesn't feel that she knows how to ask for anything for herself.
- Sometimes we need to change to make things different.
- Carers Centre (Care Network) and Rethink need more money to do more of the same.
- It's always too busy, I could do with finding something for myself.
- I lose confidence when I stop caring. Things that are available are not always available when I am free, as I have children as well. My time at work tends to be my time away.
- My son is in residential care in Bristol and I can't get help with transport to visit my son because he is in residential care. I have mobility problems and can't get help to visit him. We need to see each other.
- My mother used to have someone from Sedgemoor to visit her but then she was told she would have to pay. The support stopped. CPN visits stopped as well and now CPN only visits by request, there is no regular contact otherwise. I worry, because the visits used to help me, when she had that extra support.
- I feel I am treated as a second class citizen due to my children's disability, by social services. I feel people think I am a bad wife as my husband left because he couldn't cope with 3 children who have disabilities.
- More opportunities to be able to talk away from person they care for, to talk about what is going on.
- Helps to get out and about.

- Need some “real respite” a break away from my caring role, but cant always leave the person.
- Befriending.
- Not always fun doing things by yourself.
- Introduce someone to the person cared for in an appropriate way.
- 1-1 to unwind/ in a safe place.
- Information/benefits info.
- Age concern are good.
- Acceptance.
- More provision for 1-1 for carers to off load to someone.
- Better, accessible respite care e.g.: for a weekend or a week.
- Easy access to a range of services available.
- Respite is important.
- A consistent contact who is knowledgeable about our specific situation.
- Mentor so that it’s not always a “red alert”.
- Someone supporting user to inspire them - provide hope.
- Fairy wand - High quality, individual support for the people cared for, telephone helpline for users to contact a mentor.

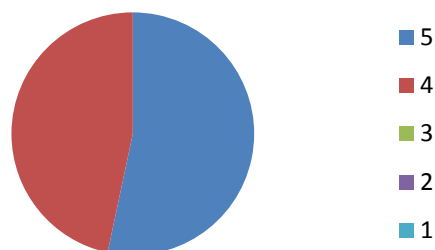
Evaluation of the Event

17 carers attended 15 carers completed evaluation sheet
(For each statement 1 indicated the lowest rating and 5 the highest)

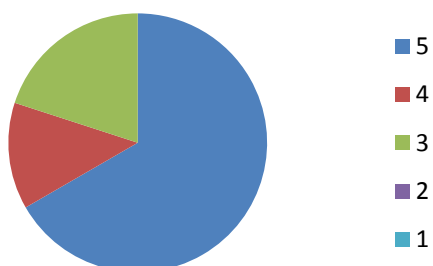
The day offered what I came for



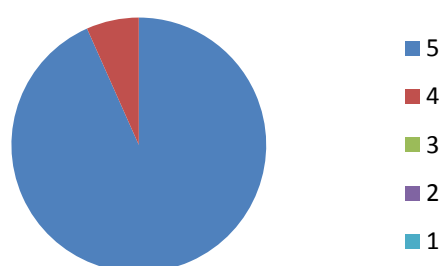
The information stand were useful



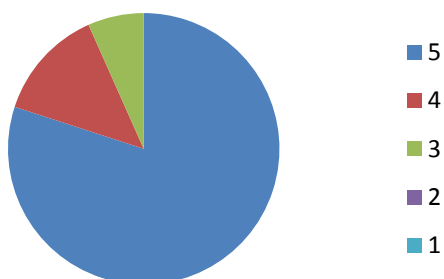
The speakers were clear and understandable



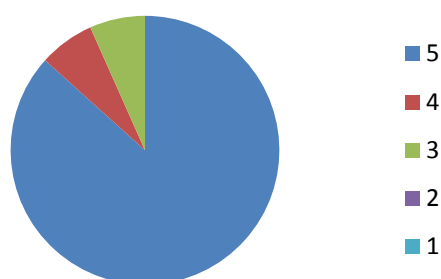
The venue was appropriate



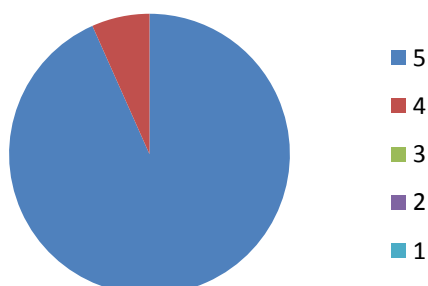
The small-group discussion were interesting



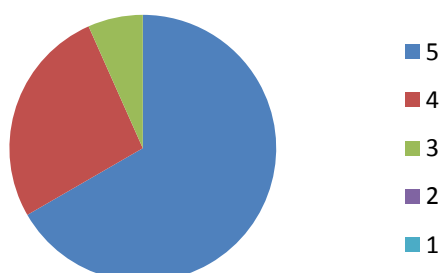
The size of the group felt right



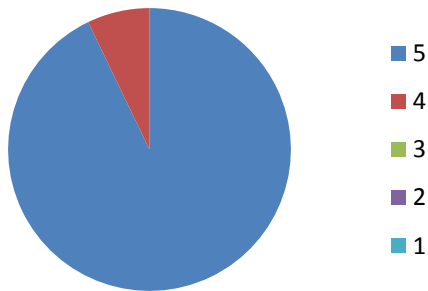
The structure of the day was well planned



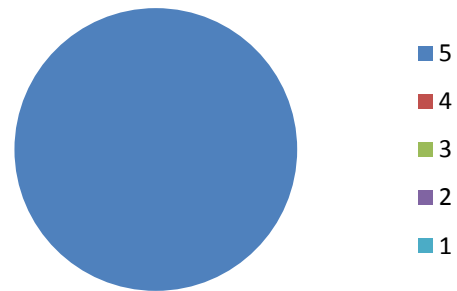
The well-being activities were enjoyable



The pace of the day
felt right



I would be interested in
further events



Further comments:

- An excellent day, lots of information to give and receive and lovely venue and food.
- A great day – forward! Thank you.
- Thank you all for a most enjoyable and relaxing day. Listening to other carers and sharing views was most valuable.
- I don't very often give all 5's but it was an excellent event!
- A very interesting day. The group discussions were very interesting, hearing other people's views and problems. Lunch was superb! Life- coaching: I am going to follow it up as he was very interesting and left me feeling confident.
- Thank you all for such an enjoyable day in beautiful surroundings in the company of lovely people – and for your commitment and care.