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## **FOCUS GROUP ON A VOICE OF CARERS OF PEOPLE WITH A MENTAL ILLNESS.**

September 2014

HUG held a meeting of it's Thursday think in group on the subject of Carers and a Carers voice. In total seven people participated in the discussions. Following this the notes were passed to the HUG advisory group and adapted according to their comments.

Many of the people present had experience both of mental illness and of being a carer, we made the point that having an illness or impairment is common when in a caring role and that we can switch from acting as carers to being cared for at different points in our lives.

While we were very happy to offer our views on a Carers Collective Voice we felt that this was just a contribution to a discussion that should ultimately be decided by Carers themselves.

### **THOUGHTS ON CARERS**

The word CARER – we thought that despite some worry over the word CARER distracting from peoples roles as friends, partners or relatives that it was a suitable one to use although there is still a lot of confusion between unpaid, informal carers and those whose profession or job is to care.

### **SOME REFLECTIONS ON HAVING CARERS:**

We discussed our experiences of being cared for and being carers and reflected on the stress that can go with being a carer, and also the stress that we can feel when we know someone is caring for us.

We felt that carers are often unheard and that there are many different roles and ways of caring, from having a supportive emotional role to providing 24 hour 'nursing care'.

*"I like to be independent but I rely on my friends and family for many things."*

*"I find it hard when my son is seen as my carer – because my son knew I was getting ill before I did – because of my actions I ended up in A and E and he*

*had to go through hoops to get someone to listen to him; He had to go to the police."*

*"When I am like that and am lost and confused, people become carers around me, like my neighbours and the people in my community."*

*"When he is being my carer, it makes me remember when he was a boy – it is very hard to think of him in that role and what he had to deal with as a child – it can be very emotional. – I gave him responsibility way beyond his years – he still acts as a carer because he was my first born."*

*"I said I was her carer but it didn't make any difference."*

*"I was her only child and we lived together – it all seemed quite simple."*

*"There is a big difference between physical nursing care and dealing with someone's emotional needs."*

*"I still feel that I have a 'duty' to care for my mum now she is less capable."*

*"It's Pay back time for what they gave us."*

*"The stress can be too much we can stop being able to do it and have to deal with own mental illness."*

## **WHAT IS A CARER.**

We felt the main definition of a Carer is that they have a part to play in our emotional or physical wellbeing and that we are important to them.

A carer is: **"Someone who cares about you."**

*"If someone really cares about you they will do something, if only just listen to you."*

*"Someone like my neighbour who is a friendly ear. It doesn't have to be practical things"*

*"An important role is to try to ensure that where they cannot care directly, that there is professional care around – to act as an advocate."*

*"We need peace of mind as carers to know there are professionals doing their job properly."*

*"I can be too dependent on professionals –sometimes I think they should ask my advice as a carer more."*

*"Someone who is there for you in the middle of the night when you are in crisis."*

*"They do not need to be doing anything – my dad was my carer and his main role was to visit me and to abandon his prejudice; he was concerned about my welfare."*

*"Sometimes we are not carers and think we are -we feel we are caring for each other but in the end realise one person has more of a caring role than another."*

## **CONFIDENTIALITY:**

A Carer should be given information about us and involved in our care if we agree that they should be or have said in an advance statement how we want them to be involved in our care. If we have capacity and do not wish a person to know about our care or to be involved in our care then this should be respected.

There are exceptions to this:

- If they live with us, they will have basic information needs that should be provided whether we like this or not.
- If we are unable to make informed judgements about their involvement, perhaps because we are psychotic, and have made no statement about involvement when we had capacity, then there should be an assumption of a right to some involvement and information provision about our condition and care.
- At the very least our carers should be told if we have said we don't want them to be given information about us.

## **A CARERS VOICE**

We agree that there needs to be a collective voice for carers.

### **SHOULD THERE BE A VOICE FOR CARERS OF PEOPLE WITH MENTAL HEALTH PROBLEMS OR SHOULD IT BE PART OF A WIDER CARER VOICE?**

Most of us think there should be a specific voice for Carers of people with Mental Health Problems; the issues are completely different for different disability groups and should be respected.

We feel that often a carers' voice is about speaking out about the different ways in which the people they care for are treated, inevitably these issues will vary across different groups.

However a different perspective was given by saying that the issues that many carers themselves face are often similar and are often to do with stress, emotional wellbeing and their own mental health problems, as well as in being heard and over issues like finance.

If a carers' voice were to only look at the impact of caring on a carers own lives, there might be more of a need for a Carers voice that crossed disability/illness groups.

Ultimately we believe it is for Carers themselves to decide how they develop their collective voice.

## **DEVELOPING A CARERS VOICE**

We need to have a definition of a CARER and we need a definition of mental ill health/mental health problems.

This might need to be broad enough to include neighbours and our community as well as people close to us who have a considerable caring role.

It would need to look at whether dementia, and a variety of other disorders are also included, such as addictions.

There is a need to develop a data base of Carers who want to have a voice.

This and the carers voice should be developed by working in partnership with other organisations, especially Carers Support organisations.

- A Carers Voice should be separate to Service provision, including Carers support but could have a relationship with such organisations
- The Carers Voice should be separate to a Service Users Voice even though both groups will have common issues and will engage in common activities and may support each other.
- The Carers Voice should be developed in much the same way that the mental health service user voice has developed. The way HUG and VOX have developed may both be of some assistance in this; a key to development is to enable face to face contact between Carers.
- There should be local and regional groups, supported ideally by a development worker, linked into a National Voice which will also need to be resourced.
- There is some argument that as Carers support is so limited that this is a higher priority than a collective voice for carers.
- We discussed whether having a single National Carers Voice would be better than having regional groups but concluded that we need both a Regional and Local voice as well as a National Voice.
- We couldn't decide whether a regional voice should operate independently of a National organisation or a be a part of the National Organisation.