

Making sure siblings get information and support

A new online resource for brothers and sisters of people who have experienced a first episode of psychosis will help them gain information about mental illness and glean support and advice from others in the same position.

'Siblings can help promote the recovery of their brother or sister, but they need information about the best way to help, and may need support themselves,' says Jacqui Sin who is developing the resource with the support of funding from the National Institute for Health Research. A mental health nurse, Jacqui is currently working as a researcher in the Florence Nightingale School of Nursing and Midwifery at King's College London. 'The plan is to create a resource that will help siblings take care of their relative and take good care of themselves,' she says.

The online support package will be designed with the help of an expert advisory group: that group includes siblings as well as mental health professionals, parents and professionals who work in youth organisations. Once the resource is up and running, Jacqui will seek feedback through focus groups and also run a trial to judge how effective it is, and whether it makes a difference to siblings' own wellbeing and their ability to offer support to their brother or sister.

Jacqui and her colleagues have already carried out research to find out more about the experiences and support needs of siblings of people who have experienced psychosis for the first time. She interviewed 31 siblings aged 11 to 35 who all said they had been greatly affected by their brother or sister's experience of psychosis. 'They said they wanted information about their sibling's diagnosis, about how to cope practically with psychotic symptoms, about services and about how to help promote

recovery. They said advice on how to deal with hallucinations and delusional beliefs would be particularly helpful. Often mental health professionals talk to parents, but the rest of the family, especially a sibling, is ignored,' she said.

'Most of them also said their range of emotions in response to their brother's or sister's diagnosis affected their own wellbeing – worry, guilt about not being more supportive or taking up too much of their parents' time, stigma, loneliness, resentment, for example. The online resource we are developing could include discussion boards where siblings could get peer support and share information and experiences.'

The research is being carried out in collaboration with the charity Rethink Mental Illness, which has already launched an online Siblings Network (www.rethink.org/siblings). That site will be used initially to host the new resource that Jacqui is developing.

This project will run until 2014.

■ If your brother and sister has experienced a first episode of psychosis, if you're aged between 16 and 35 and live in London and would be interested in helping to shape the online resource, contact Jacqui Sin (jacqueline.sin@kcl.ac.uk).

She is looking for siblings to join a Reference Group being set up to oversee the study from January 2012 through to October 2014. Members of this Group will be asked to review and help develop ideas and materials.

*uploaded onto mentalhealthcare.org.uk 13/12/11
to be updated September 2012*