

Extract from Openmind 150, March/ April 2008

Coping with coming off

Since the publication of Mind's research into people's experiences of coming off psychiatric drugs,* a number of groups have been set up to try to meet the report's recommendations. Guy Holmes, Marese Hudson, the Living with Psychiatric Medication group and Rufus May describe three of these

Thinking about Medication group

The Thinking about Medication group, a 12-week course that 14 people attended in spring 2006 in Shropshire, was facilitated by clinical psychologist Guy Holmes (guy.holmes@nhs.net) and Marese Hudson, an ex-service user who has successfully come off medication.

In the first two sessions participants identified their individual aims, which were pooled and became group aims. The format typically consisted of an hour-long question-and-answer session with invited speakers, including local psychiatrists, a pharmacist, a drug misuse expert, a practitioner of alternative therapies, the director of the local department of psychological therapies and a community mental health nurse. This was followed by a break and then a further informal hour for sharing experiences and ideas in general group discussion.

By and large the group ran smoothly and seemed a very ordinary thing to be doing. But occasionally the unease that can accompany the idea of 'mad people not taking their medication' appeared to surface. For example, finding a venue for the group was difficult.

No one said they were unhappy having people not taking their medication on their premises, but a lot of potential venues turned us down before finally we were able to rent a room in an arts and community centre.

Support from local psychiatrists and other mental health practitioners gave the group a legitimacy that was helpful when people questioned what we were doing.

Following the course, some participants wanted to carry on meeting to offer and receive mutual support in a less structured support group environment, while continuing to reduce their medication with the aim of coming off eventually. This Out of the Box group met fortnightly for a further nine months. As during the Thinking About Medication course, participants followed a step-by-step reduction plan and used the advice summarised in Coming off medication by Guy Holmes and Marese Hudson. [2]

Living with Psychiatric Medication group

Network for Change – a voluntary sector organisation that promotes and supports user-led groups and activities – invited one of the Thinking About Medication group's participants and Guy Holmes to give a talk and question-and-answer session. The Living with Psychiatric Medication group³ has now been running in Leicester since 2006. Grant Paton and Alison Smith from Network for Change, and Suzanne Elliott (suzanne.elliott@leicspart.nhs.uk), a local clinical psychologist, help organise and plan the meetings. The group is open to new members, including workers or carers.

The structure is similar to that of the Shropshire course, with a speaker being invited to each session. Determination to be guided by the aims set out by group members at the

outset has meant that the remit has remained broad and is not exclusively about 'coming off'.

Both the Shropshire and Leicester groups generated similar aims, including to:

- increase knowledge of the effects of medications, including adverse effects and impacts of long-term use
- explore the complexities of distinguishing between 'symptoms' of mental health problems, adverse drug effects and withdrawal reactions to reductions in dose/coming off
- help to make informed decisions about coming off and to do it in a way that minimises withdrawal effects
- obtain and provide mutual support and tap the expertise of others in the group
 - explore alternatives to psychiatric drugs
 - get group members' opinions and experiences heard by prescribers
 - create environments that provide hope.

Participants have wanted the group sessions to find a balance between being structured and flexible, and crucially to provide a forum for open debate where differences of opinion are welcomed and respected (this is what appears to be lacking in many mental health environments). Evaluations of these groups revealed that most group participants had experienced severe difficulties in trying to come off medication in the past but retained a wish to come off at some time. There was a high level of satisfaction with the groups.

Many participants reduced their dose, some came off completely, while others came off one type of drug but remained on another. Some members returned to medication (or their original dosage level) after a period struggling with the process of trying to reduce or come off a drug. Participants valued the mutual support and opportunities to learn from each other; the chance to quiz experts outside the confines of clinical consultations; the wide range of reading materials provided; and the facilitation by people who do not have vested interests in them taking or not taking medication.

Group members felt strongly that their experiences should have a wider impact. With this in mind, there have been consultations with people from different areas about coming off medication and the setting up of groups; presentations at national conferences; attempts to publish articles and booklets about the groups; plans to organise a national meeting about psychiatric medication; and plans to lobby drug companies for tablets to be available in doses that assist slow withdrawal.

Coming off Psychiatric Medication group

A third self-help group, inspired by the 1997 Cambridge conference *Coping with Coming Off Medication*, now runs in Hebden Bridge, West Yorkshire, facilitated by psychologist Rufus May (rufus@rufusmay.freeserve.co.uk) and others from the local alternative mental health collective, Evolving Minds.

The group, which is co-operatively run and open to anyone, meets in the evening once a week in a cosy meeting room with purple silks on the ceiling, reclaimed wooden seating and

floors with lots of cushions. It has adopted the philosophy that if people want to come off psychiatric medication successfully they will need to develop new ways to manage difficult thoughts and feelings, and are likely to require additional levels of social support.

Fifteen people currently attend, and at least nine have volunteered to offer skills and services to individuals seeking support with reducing or coming off their medication. These skills include counselling, medical/pharmacological knowledge, massage, mindfulness, Bush flower remedies, reflexology, reiki, Indian head massage, Qi Gong, drama games and relaxation techniques.

In the first half of each session members take turns to lead on relevant educational topics and discuss practical aspects of the group's development. The second half is devoted to emotional support for group members. The group has recently set up a website that offers information about psychiatric drugs, how they are thought to work, the withdrawal process, and a collection of personal accounts of people's attempts to come off (www.comingoff.com).

* Read, J. (2005) *Coping with coming off: Mind's research into the experiences of people trying to come off psychiatric drugs*. London: Mind Publications, 15-19 Broadway, London E15 4BQ; 0844 448 4448; publications@mind.org.uk www.mind.org.uk/osb £2 plus 10 per cent postage and packing. The recommendations include that there should be services to support people coming off psychiatric drugs; dialogue between all interest groups concerned with taking or prescribing neuroleptics and mood stabilisers; and research into people's experiences of trying to come off psychiatric drugs.

1. Find out more about this group, including materials used, the flyer to advertise the group and an evaluation of participants' experiences, at www.shropsych.org/guyholmes.htm
2. Holmes, G. and Hudson, M. (2003) 'Coming off medication', *Openmind* 123.
3. Living with Psychiatric Medication group, c/o Network for Change, 150-152 London Road, Leicester LE2 1ND. info@networkhousing.org.uk