

Helping people to come off neuroleptics and other psychiatric drugs

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Summary: *This article invites clinical psychologists to think about how they might help people who are considering coming off psychiatric drugs*

MIND have recently had a conference and published some excellent research on ‘Coping with Coming Off’, exploring people’s experiences of withdrawing from psychiatric drugs (see Read, 2005). The literature on coming off psychiatric medication is not comprehensive, especially for drugs other than minor tranquillizers, but there have been a couple of excellent books in the past couple of years, notably Lehmann (2005) and Breggin and Cohen (1999). MIND’s research (Read, 2005) involved qualitative and quantitative data through the use of questionnaires and interviews with 204 people who had attempted to come off their medication. Some findings include: the most common reasons for wanting to come off were a dislike of the adverse effects and not wanting to be on drugs long-term; over half of the sample had difficulties in coming off; many withdrawal reactions mirrored psychiatric symptoms/disorders; people who had been on medication for less than 6 months had less difficulties in coming off than people who had been taking drugs for a long period. Some findings were quite surprising e.g. there was no evidence that doctors could predict successfully who could successfully come off their drugs – people who came off against medical advice were just as likely to succeed as

those whose doctors agreed should withdraw; Psychiatrists and General Practitioners were identified as the least helpful people in terms of assisting people to withdraw (less than 50% of people found them helpful compared to over 85% of the participants had found counsellors/psychotherapists, a support group, complementary therapists and other service users helpful). Recommendations from the report include: people need access to more information on drugs and withdrawal effects; require access to alternatives to medication; need to be seen as credible people and listened to and treated with respect when talking about their drugs and wishes to come off; for there to be less emphasis on control and coercion; services with adequately trained people are needed to support people through the process of coming off their medication.

Psychologists were not named by participants in the research as being helpful or not helpful. The report and raw data indicates that people in this sample did not talk to psychologists about coming off drugs. At a time when the DCP is lobbying for psychologists to have formal powers under a new mental health act as clinical supervisors and some members of the profession are keen for psychologists to have prescription privileges, it seems surprising that we were not included in the list of helpful/unhelpful people. It has made me curious as to how psychologists respond to people who mention their medication, who exhibit signs of adverse effects of drugs, or who say they want to stop taking psychiatric drugs. This article describes some of the ways I respond to these situations and is written as an encouragement to others to take up a role that the MIND research project invites – perhaps psychologists might be useful to people who want to come off their psychiatric drugs? The article is slanted towards people on neuroleptics

(a.k.a. major tranquillizers, anti-psychotics) as when people say they want to come off anti-depressants it is often viewed as a choice whereas people report different responses when they say they want to come off neuroleptics, notably fear, talk of relapse and danger, dismissal of the idea, and compliance ‘therapy’. Interestingly, the MIND research indicated people had greater problems coming off SSRI anti-depressants than neuroleptics.

I work in a community mental health team that focuses on seeing people who have been admitted to psychiatric hospital, are at risk of admission through risk of suicide or have what are deemed to be ‘severe and enduring mental health problems’. People referred to me are sent an information leaflet detailing what it would be like to meet me and explaining some things about clinical psychology. They can then opt-in by requesting an appointment at a convenient time. Of relevance is the section of the leaflet entitled ‘What might lead to a person seeking help from a Clinical Psychologist?’: Alongside statements such as “Distress relating to the hearing of voices” there are statements such as “Feelings of having been hurt by previous psychiatric treatment” and “A wish to come off psychiatric medication”. Elsewhere there are statements such as “you will not be forced to do anything against your will...Clinical Psychologists do not prescribe medication...I am happy to talk about the pros and cons of any treatment or therapy that you have had in the past or may be thinking of in the future.” In other words, a door is marked as open for people to talk about medication amongst other things that the person might think is relevant.

The vast majority of people I see are taking psychiatric medication. Some people on drugs do not want to discuss medication issues with me. Others start exploring the roots of their difficulties and we enter into discussions about the possibilities of adverse effects of medication underlying their difficulties (e.g. indifference, lack of feelings, lethargy, agitation, impulses to self-harm, restlessness, shaking, inability to get an erection or have an orgasm). Sometimes the conversation leads to an exploration with me about reducing or coming off medication, sometimes not (people decide to take up the conversation with their prescriber). Another group of people specifically come wanting to think through issues relating to medication and other experiences of the mental health system and wish to consult me about coming off their drugs. I had no training at undergraduate or post-graduate level in psychopharmacology – everything I have learned has been picked up through talking with psychiatrists, service users, friends and family members who have taken psychiatric drugs, and through reading the literature. At one level it seems weird that I am now seen by some as an ‘expert’ in this field.

For the bulk of the people I see conversations about medication dovetail with exploration of alternatives to medication in terms of coping with difficult feelings or states of being and exploration of the roots of a person’s breakdowns/problems. My experience is that for some people this is hampered by the medication (e.g. the effects of neuroleptics hinder recognition, acceptance and expression of emotions that a person’s historical account indicates may have been troubling in their past, are less troubling now due to the dampening down effect of the drugs, but might need to be accessed if the person is going to learn to respond to life challenges differently). Others appear to be able to engage in

the psychotherapeutic process despite the drugs or might even be assisted by the drugs. However, it has always been strange to me that most psychologists would not see psychotherapy with someone who had smoked a joint or had several pints before the session as being potentially useful but we see people who have recently taken equally strong mind and mood altering drugs; how much of the sessions are remembered, or remembered once the person is not on drugs is another unknown.

Although I have previously audited some outcomes of my work and related it to (amongst other factors) medication (e.g. Holmes, 2003), I have not done a precise audit of outcomes of all people who have come off neuroleptic and other medication. Looking back over my caseload over the last 10 years indicates that most people who have met with me have stayed on their drugs, although many reduced their dose. Those that have come off fall into roughly three equal groups: people who have not re-entered our service so to my best knowledge have not ‘relapsed’; people who had difficulties coming off and returned to medication quite quickly (albeit sometimes on a lower dose); and people who had a period of stability of at least 6 months but then had a breakdown which led them to go back on medication. This latter group includes people who subsequently stayed on their medication and people who subsequently came off their medication again; some of these people have gone from using medication continually to using it ‘cleverly’ in David Healey’s terminology – using it as and when needed to ward off a breakdown, for example by enabling sleep after a period of sleeplessness or to calm a bombardment of thoughts and feelings. It must be noted that the above is a summary of my impressions having gone through a list of all of the people I have seen over the past 10 years and

clearly is not a methodologically sound piece of research - it is liable to all the biases inherent in professional opinion based on memory of individuals.

As an adjunct to helping people think about medication I often use a process based on Fig.1.

Coming off medication...

Good things/advantages

e.g. I won't feel zombied

I'll feel more confident if I lose weight

It will confirm I'm better

I can drive

Bad things/disadvantages

I might have another breakdown

My husband might get uptight

I'm worried how I might react

People might not agree with it

Staying on medication....

Good things/advantages

e.g. I won't risk withdrawal reactions

I'm quite stable- life's not too bad currently

They help me sleep and not get overwhelmed

No-one is hassling me to take drugs

Bad things/disadvantages

The side effects – weight gain, tremor

I don't feel alive or creative

I don't like doing things just because

people say it's good for me

Fig. 1:

Aid to help people think through pros and cons of coming off and staying on medication

Both service users and professionals who have used this have reported it as being helpful. It is best used in conversation, with people asked to ‘brainstorm’ things that are relevant to them in each of the four segments. It helps people to clarify their ambivalence about their medication and weigh up whether, overall, they want to come off or stay on their drugs. It also identifies areas that people can focus on e.g. check out the reality of other people’s potential reactions to them coming off their drugs; find alternatives to medication in terms of the benefits they feel they get from their drugs. People often want and need access to more information so they can make an informed choice about coming off; as well as consulting other professionals (eg nurses, doctors) and using the internet, there are many useful books - David Healey’s *Psychiatric Drugs Explained* has good sections on the benefits and adverse effects of psychiatric drugs, with the latest edition also having a chapter on withdrawal; it has been well-received by all people I have lent it to.

Some of the benefits of this process extend beyond the psychologist-service user domain. I have encouraged people to discuss the completed sheets with family members and this has led to shifts in attitudes and less anxiety in families about the issue. People have also been encouraged to take completed sheets to their outpatients appointments, or I have included them in reports and letters to prescribers. This has led to shifts in the doctor-patient relationship, to a relationship where people work collaboratively rather than in a culture of ineffective compliance and frustrations on both sides – people have gone from being viewed as lacking in insight to making a rational decision even if it goes against what the prescriber would recommend. Having a psychologist involved also assists the

Responsible Medical Officer – the ‘responsibility’ (often experienced as fear of being blamed) if a person ‘relapses’ is shared. Having a psychologist involved during the withdrawal period also shoulders some of the monitoring duties, which are burdensome and worrying to psychiatrists who can only offer short and infrequent out-patient appointments.

In terms of the concept of ‘risk’, the risks of staying on medication have to be balanced against the risks of coming off. Although the long term risks and adverse effects of taking medication reduce as people come off, some (such as tardive dyskinesia) can become more apparent and debilitating. Coming off medication is a risk, but then so are other potentially helpful and stressful things like getting a job, leaving home, starting an intimate relationship, etc. It is also important to recognise that going through the process outlined in Fig.1 is not a one-off, but an ongoing process – the relative weights of things on the lists vary over time.

I have previously published a number of *top tips* for people coming off medication, based on my experiences helping people and my co-authors’ personal experiences of successfully coming off psychiatric drugs (see Holmes and Hudson, 2003); these tips apply to neuroleptics as well as other classes of psychiatric drugs. It is not possible to list all of these here, but they include: taking a step-by-step approach, tapering dosage and going back up a step if withdrawal reactions are too overpowering; obtaining medication in doses that can be reduced slowly (e.g. 5mg scored tablets rather than 10mg tablets; converting to a liquid rather than tablet dose); having ‘breathers’ i.e. staying at a

particular dose level for an extended period if withdrawal reactions occur frequently to each stepped reduction; not automatically interpreting difficulties whilst coming off as 'relapse' (withdrawal reactions can mirror a wide range of psychiatric symptoms such as hallucinations, panic, and strange sensations such as an experience of electricity in the limbs and head); taking months or even years if people have been taking medication for a long period; getting as much support as possible but recognising some people might not support the decision to try and come off; planning it well and getting in as good physical health as is reasonably possible; utilising alternatives to medication; learning from people who have gone through the process; accessing support groups (see www.shropsych.org for a description of a *Thinking About Medication Group* we have set up to help people with the above issues).

Whilst participants in MIND's research did not mention psychologists, 53 people did state that counsellors/psychotherapists had been very helpful regarding coming off medication. Surely members of our profession have similar skills in helping people reflect on things and think through dilemmas, can provide and help people access alternatives to medication, and are in a relatively powerful position regarding advocacy for people who want to come off psychiatric drugs?

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References

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Those who have come off psychiatric drugs tend to want to help others do the same. Almost all of the people I've worked with over the years have expressed this. Coming off, we gain so much knowledge about what helps that we have to share with others. It becomes a calling. I'd love to hear your ideas about how we can support each other more in psychiatric drug withdrawal and how we can make that support more accessible, while retaining our integrity and staying healthy ourselves. I hope some of what I've learned and shared here can be useful to those coming off or supporting others in coming off psychiatric meds. The biggest thing I have learned and continue to learn is how much this is an unmet need for so many. Our page on support for coming off psychiatric drugs has information about other ways to find support. Remember: whether to continue or stop taking medication is your decision, and you have the right to change your mind. 5 tips for when you want to come off your medication. Have you got a support group nearby or other people in your life who can provide any help you may need? If you've tried to come off your medication before but have not been able to manage it, what factors might have played a part then? Can you avoid or minimise them when you try again? Whenever you decide to try coming off, it is best to withdraw slowly and safely. It might take a long time, or you might find that you become comfortable on a lower dose and decide not to come off completely. Success after drugging, or without drugging, is more common than success while drugging. Read the recovery stories of specific people who turned down drugs or tapered off drugs. Success stories are everywhere, though they are not nearly as codified and popularized as stories of drug use being the only or best way forward. Get a taste for the variety and highly personal nature of recovery from drug use and working through psychological difficulties. Think about what you yourself have found interesting, supportive, or otherwise useful. Even if this is strictly an academic question and you have never used antipsychotics, you can still build a greater understanding of the dynamics and Many people successfully come off psychiatric drugs, with or without guidance, while others find it very hard. Many continue on psychiatric drugs because the benefits are greater than the drawbacks. Many of us get help from psychiatric drugs, but might not understand how they really work or what the other options are. Some of us never found medications useful, or medications even made our problems worse, and we are ready to try living without them. Sometimes people are torn between the risks of. Coming Off Psychiatric Drugs: Successful Withdrawal from Neuroleptics, Antidepressants, Lithium, Carbamazepine and Tranquilizers. Peter Lehmann, ed. www.peter-lehmann-publishing.com.