

**Opinion piece: the case for establishing a minimal medication alternative for psychosis
and schizophrenia**

Ruth E Cooper,^{1,2,3} John P Mason,^{4,6} Tim Calton,⁵ John Richardson,⁶ Joanna Moncrieff^{4,7}

1. *Newham Centre for Mental Health, Unit for Social and Community Psychiatry, Queen Mary University of London, E13 8SP, UK.*
2. *East London NHS Foundation Trust, Newham Centre for Mental Health, E13 8SP, UK.*
3. *University of Greenwich, Faculty of Education, Health and Human Sciences, SE10 9LS, UK.*
4. *Research & Development Department, Goodmayes Hospital, North East London NHS Foundation Trust, Essex, IG3 8XJ, UK*
5. *Lincolnshire Partnership NHS Foundation Trust, St George's, Lincoln, Lincs, LN1 1FS.*
6. *The International Society for Psychological and Social Approaches to Psychosis (ISPS), UK.*
7. *Division of Psychiatry, University College London, Gower Street, London, WC1E 6BS, UK.*

Correspondence to:

Dr Ruth Cooper, University of Greenwich, Faculty of Education, Health and Human Sciences, SE10 9LS, UK, email: r.e.cooper@greenwich.ac.uk.

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Abstract

The development of severe mental health conditions is strongly linked to our environments, particularly experiences of trauma and adversity. However treatments for severe mental health conditions are often primarily biomedical, centred around medication. In the case of schizophrenia and psychosis, this is antipsychotic medication. Although antipsychotics have been found to reduce symptoms and risk of relapse, some patients derive little benefit from these drugs, and they can lead to severe adverse effects. Subsequently a high proportion of people do not want to take antipsychotics and request an alternative. Yet in the UK and in many countries there are currently no guidelines for stopping antipsychotics or formal treatment alternatives, despite such alternatives being available in some countries. For example, in Norway and Vermont (USA), in response to pressure from service user organisations, governments have mandated the establishment of ‘minimal medication’ services. We examine whether everyone with a psychotic condition needs long-term antipsychotic treatment and evidence for alternative models of care. We recommend that healthcare providers should be encouraged to develop a psychosocial treatment package for people with psychosis or schizophrenia that provides a realistic possibility of minimising antipsychotic exposure.

Keywords: psychosis, schizophrenia, minimal medication, psychosocial treatments, antipsychotic reduction or discontinuation, alternative treatments

In 1979 the World Health Organisation (WHO) reported the surprising finding that people with schizophrenia may have better outcomes in some low and middle income than high income countries, despite those in low and middle income countries having less access to health services and medication (*World Health Organisation, 1979*). The results were subsequently replicated (Jablensky et al., 1992). Although debated (Cohen et al, 2008), these studies signal how societal-level problems may underpin potentially poorer outcomes of psychosis and schizophrenia in high income countries, which may be associated with a focus on treating the individual, with medication the primary treatment, rather than social and community-based support. The authors of the WHO studies commented “*The sobering experience of high rates of chronic disability and dependency associated with schizophrenia in high-income countries, despite access to costly biomedical treatment, suggests that something essential to recovery is missing in the social fabric*” (Jablensky & Sartorius, 2008). Like the WHO studies, we suggest the need for a renewed focus on psychosocial approaches to treatment.

Treatment for schizophrenia and psychosis

The primary treatment for people with a psychotic condition is antipsychotic (neuroleptic¹), medication, commonly taken for many years. The most recent UK audit found 98% of people diagnosed with schizophrenia were prescribed antipsychotics (*The Royal College of Psychiatrists, 2018*). Many people find antipsychotics to be helpful in alleviating the acute symptoms of psychosis and reducing relapse rates (Ceraso et al., 2020).

But antipsychotics do not help everyone. Rates of non-response are estimated at 38% (Samara et al., 2018), with an overall number needed to treat of 6 (for second-generation antipsychotics), which means that out of 6 people treated with antipsychotics, 1 person will have a significantly beneficial outcome (Leucht et al., 2009). Long-term benefits are even less certain, because evidence is limited by the antipsychotic discontinuation design of studies which may lead to withdrawal-related adverse effects, and short durations of follow-up (Moncrieff, 2015). Moreover, antipsychotics are associated with an increased risk of serious medical complications including significant weight gain, diabetes, heart disease, movement disorders and structural changes in the brain including brain volume reduction

¹ We use ‘antipsychotic’ instead of ‘neuroleptic’, We recognise the issue with ‘antipsychotic’ as it implies that they are modifying an underlying pathology. However we use this term as it is the most recognisable.

(Fusar-Poli et al., 2013). These physical health conditions are distressing and also have a significant economic impact on the healthcare system (Jerrell, et al. 2012). Alongside this antipsychotics can cause sedation, lethargy, emotional flattening and sexual dysfunction which can adversely impact on quality of life. The development of psychosis is linked to psycho-social factors such as discrimination, trauma, poverty, and isolation, therefore many people do not endorse primarily biomedical explanations and treatments for their condition (Read, et al. 2020).

Consequently, many people do not want to take antipsychotics and may request reduction or discontinuation of these drugs and ask for an alternative, or they may reduce/stop them of their own accord (see Box 1 for the service user perspective). Estimates from reviews suggest 29-41% of people do not take antipsychotics as prescribed (Lacro et al., 2002; Nosé et al., 2003), although studies vary, and some show even higher levels of discontinuation or deviation from prescribed treatment (Lieberman et al., 2005; Mullins et al., 2008). Other reasons as to why people decide to stop antipsychotics include the negative effects outweighing the positive, problems with the clinician relationship including experiences of coercion and inadequate information provision about the adverse effects of antipsychotics and that people feel better and no longer want to take medication (Roe et al., 2009; Salomon et al., 2014; Carmela et al., 2013).

Shared-decision making is promoted by the NICE Guidelines (The National Institute for Health and Care Excellence), which are used internationally, as both an ethical and legal requirement (NICE, 2014). Alongside this, the Mental Capacity Act states that every adult has the right to make their own decision if they have the capacity to do so, even if others view that decision to be unwise (Ahmed et al., 2007). The majority of service users, including inpatients, retain treatment related decisional capacity and are therefore legally entitled to decline antipsychotics (unless subject to involuntary treatment under the Mental Health Act) (Okai et al., 2007). Given the adverse effects of antipsychotics, ineffectiveness for some people, and further reasons for stopping described above, requests to stop or not take these drugs should be seen as a legitimate preference not, as some clinicians may assume, as 'lack of insight' (Jaeger et al., 2019; Moncrieff et al., 2020).

However, despite the high proportion of people who do not want to take antipsychotics, in the UK and in many countries there are no official national guidelines for the treatment of

psychotic conditions without antipsychotics, or for the reduction and discontinuation of these drugs (Cooper et al., 2020). Clinicians are often reluctant to reduce or stop antipsychotics due to lack of guidelines, concerns about relapse, and service-level barriers, such as pressure to rapidly discharge and lack of resources to support reduction (Cooper et al., 2019; Moncrieff et al., 2020). With no formal alternative approaches, for some people treatment ‘choice’ can often be reduced to which antipsychotic they want to take and people have reported that they do not feel involved in medication decisions, often feel coerced, and would like to have more choice over their treatment including more support with reducing/stopping these drugs (Larsen-Barr & Seymour, 2021; Morant et al., 2016; Morrison et al., 2012; Read & Sacia, 2020; Roe et al., 2009). As a result people will often stop antipsychotics abruptly, without clinical support, which may be more likely to lead to adverse outcomes (Horowitz et al., 2021).

The service user and carer community have called for alternatives to antipsychotics and greater support for coming off these drugs, and have tried to fill this unmet need by establishing their own guidance and peer support groups for reducing and stopping psychotropic medications (Framer, 2021; Oedegaard et al., 2020; Read & Sacia, 2020; RRASMQ/ÉRASME, 2014; Smith, 2019). This includes, *‘The Harm Reduction Guide to coming off Psychiatric Drugs’*, which has been translated into 17 languages (The Icarus Project and Freedom Center, 2012) and the online site the ‘Inner Compass Initiative’ which links to *‘The Withdrawal Project’*, which in 2020 had 215,000 visits from 122 countries (personal communication). The need for greater caution in the long-term use of antipsychotics (Moncrieff, 2015; Murray et al., 2016) and a formal treatment option that attempts to avoid or minimise the use of antipsychotics (Morrison et al., 2012) has been called for by clinicians, and is recognised by NICE who have requested research into psychosocial interventions for people who choose not to take antipsychotics, stating: *“The development of alternative treatment strategies is important for the high proportion of people with psychosis and schizophrenia who choose not to take antipsychotic medication, or discontinue it because of adverse effects or lack of efficacy”* (NICE, 2014).

Do antipsychotics benefit everyone with a psychotic condition?

Antipsychotic treatment is based on evidence that this treatment reduces psychotic symptoms and risk of relapse overall (Leucht et al., 2013, 2012). There is no evidence for claims that

antipsychotics inhibit an underlying process of neurodegeneration (Zipursky et al., 2013) and there is debate about whether they work by targeting any other underlying pathological process (McCutcheon et al., 2020; Moncrieff, 2011). In fact prolonged antipsychotic treatment has been found to be one of the causal factors for progressive brain changes that have been found in some people with schizophrenia (Fusar-Poli et al., 2013). The characteristic mental and behavioural alterations produced by antipsychotics via their modification of typical brain functioning (which include cognitive slowing, emotional blunting and behavioural ‘deactivation,’) may plausibly account for their therapeutic action (Breggin, 2007; Healy, 1989; Moncrieff et al., 2009), as suggested by the original pioneers of these drugs in the 1950s and 60s (Deniker, 1960).

Although randomised controlled trials show increased rates of relapse following antipsychotic discontinuation over the short-term, not everyone relapses, and relapse does not necessarily indicate a poor long-term outcome. Furthermore some service users may not prioritise symptom reduction and relapse avoidance to the same extent as services/clinicians (Larsen-Barr & Seymour, 2021). The process of reducing or stopping antipsychotics may itself increase the risk of relapse above that of any concurrent mental health condition due to antipsychotic-withdrawal related effects. However this increased risk may diminish over time and may be minimized by gradual tapering (Chouinard & Chouinard, 2008; Horowitz et al., 2021; Récalt & Cohen, 2019). Indeed, one long-term follow-up suggested that people randomised to maintenance antipsychotic treatment had poorer functional outcomes over the long-term than those allocated to a flexible reduction and discontinuation strategy, and that rates of relapse, although initially higher in the reduction/discontinuation group, converged over time (Wunderink et al., 2013). This is consistent with several cohort studies that show poorer long-term outcomes among those who use continuous antipsychotic treatment compared with those who do not (Harrow et al., 2012; Harrow et al., 2021; Moilanen et al., 2013; Morgan et al., 2014; Wils et al., 2017). Although there is counter evidence. For example a 10-year follow up of a randomised trial of antipsychotic discontinuation versus maintenance treatment found a poorer clinical outcome in the discontinuation compared to maintenance group (Hui et al., 2018). There is an ongoing debate as to whether antipsychotics may increase or decrease overall mortality in people with schizophrenia, which is high compared to the general population (Ralph & Espinet, 2018; Taipale et al., 2018).

There is evidence that some people with psychosis or schizophrenia can be treated with psychosocial strategies with ‘minimal’ antipsychotics or with no antipsychotics (‘minimal medication treatments’), with potentially equivalent outcomes (e.g. for symptoms and functioning) to those receiving antipsychotics as usual and no evidence of greater harm (Calton et al., 2008; Cooper et al., 2019; Francey et al., 2020). Aside from the evidence on outcomes, many people with psychosis and schizophrenia and their carers throughout the world are calling for services and support to help them avoid antipsychotic medication, or to reduce and stop it once they have started (Oedegaard et al., 2020; Read & Sacia, 2020; Smith, 2019).

Research on minimal medication approaches

A series of radical treatments were delivered in different countries from the 1950s-1980s perhaps best exemplified by the residential treatment programme Soteria House pioneered in the US and Switzerland, which allowed people to go through an episode of psychosis with high levels of support with the aim to find meaning in the subjective experience of psychosis (Bola & Mosher, 2003), the therapeutic communities at Kingsley Hall and Villa 21 in the UK, and, in Finland the family and social network approach to care, Need-Adapted Treatment, subsequently developed as Open Dialogue (Seikkula et al., 2011). More recently CBT has been trialled (Morrison et al., 2018; Morrison et al., 2014, 2020) Such treatments have minimised antipsychotic use by either not prescribing these drugs or using a minimal medication strategy, including postponing antipsychotic prescription for up to 6 weeks and prescribing short-term benzodiazepines instead when necessary. This has generally resulted in significantly lower antipsychotic prescription rates compared to usual care.

Evidence on the potential effectiveness of such minimal medication treatments has been summarised in two systematic reviews (Calton et al., 2008; Cooper et al., 2020). These reviews included nine psychosocial treatments, in 2,250 people with psychosis or schizophrenia, in both inpatient and outpatient settings. Results showed that the majority of treatments, in comparison to an antipsychotic as usual control group, were at least as effective in reducing symptoms and improving functioning, with this being achieved with significantly less use of antipsychotics than usual care, with no evidence of greater harm in the minimally medicated groups. The more promising approaches were Soteria House; Need Adapted Treatment – (which has developed into Open Dialogue), CBT, and various psychosocial treatment packages, e.g. an inpatient milieu providing occupational and recreational

therapies, ward meetings, hydrotherapy, and social case work. However the results of these reviews, although promising, are tempered by the significant lack of high quality recent research, with only the CBT trials conducted recently, small sample sizes, and potential selection bias, with higher risk service users sometimes excluded.

Since these reviews, a trial in Australia, provided an intensive psychosocial treatment package to people with first episode psychosis (n=90) who were classed as 'low risk', and randomised them to receive antipsychotics or placebo (Francey et al., 2020). The package consists of care-coordination, CBT, psychoeducation, family intervention, and close monitoring. Results after the 6 month intervention period indicated no difference in outcomes, including symptoms and functioning, between the placebo and the antipsychotic groups. At the 1 and 2 year follow ups, again no difference in outcomes between the placebo and antipsychotic groups were found, although strict statistical criteria for non-inferiority of the placebo group were not met and the authors concluded that longer-term outcomes were less clear. Results are also tempered by the high drop-out rate of participants in both groups. Despite this the study gives preliminary evidence that an intensive psychosocial treatment package, similar to what may be already available in early intervention services, could be a potential alternative to antipsychotics for some. A larger trial of this treatment package is certainly warranted.

Current minimal medication services

Alternative 'minimal medication' treatments are available in regions where governments, in response to pressure from service user organisations, have mandated the availability of services that offer an alternative to standard medication-based treatments. In Norway, from 2015, 56 beds across 14 hospital units have been established for 'drug-free' treatment, with outpatient care also offered (Bjørngen et al., 2018). One example is the Drug-Free Treatment Unit, University Hospital, North Norway (Box 2). In the US state of Vermont a Soteria House has been opened (Box 2). Formal evaluation of these services has not yet been conducted however, in North Norway, in the first year of opening the Drug-Free Treatment Unit, 32 people were admitted and 16 of those did not use antipsychotics during their stay (Hald, 2019). In Vermont, there is limited data, but reports from the Soteria staff are that many people do not take antipsychotics during their stay, or they utilize the support that is available to reduce their medication (personal communication, 2020).

How could a minimal medication alternative be offered?

We need to consider what psychosocial treatments would be useful for people who are not taking or trying to stop antipsychotics. Existing or previously used minimal medication approaches include elements that are already integral to beneficial treatments for people with psychosis including emotional and practical support, talking therapies and psychoeducation. Less common aspects of these psychosocial interventions include ‘being with’ people who are actively psychotic, in a non-intrusive manner, practical, social, and creative activities such as exercise, art and animal therapy, and peer support from people with lived experience (Cooper, et al. 2020). Another important aspect may be the framing of psychosis as a meaningful experience to accept and work with and through, rather than an illness to aggressively stop (Mosher & Bola, 2004). The Hearing Voices Network, particularly their peer support groups and ‘Talking with Voices’ treatment utilise this sort of approach (Dillon & Hornstein, 2013). These approaches may help some people integrate the experience into their sense of themselves and their lives and to exert some control over symptoms. Families and the wider social network may be concerned about relapse, and their involvement and support will be important. Emphasis should be placed on improving the quality of relationships. Involvement could include attending appointments and information sessions and discussing relapse and how to manage this. Some service users may need to distance themselves from those who become too distressed and residential treatments such as Soteria House (Box 2) could provide space for this (Larsen-Barr & Seymour, 2021). Short-term use of sedatives, such as benzodiazepines, is common across the psychosocial minimal medication approaches and may replicate some of the therapeutic effects of antipsychotics (e.g. helping sleep/relaxation) (Mosher & Bola, 2004). However the possibility of tolerance and dependence is high and guidance suggests that sedatives should be used for no longer than 1 month (NICE, 2021).

Management of risk and relapse are important considerations. Close liaison with other services is essential, and the development of relapse prevention and crisis plans, the provision of close monitoring and early intervention during a deterioration and family involvement are likely to mitigate risks. Services may wish to consider excluding people with known high risks of causing harm to themselves or others.

‘Deprescribing’ guidance on how best to reduce antipsychotics will be needed. Recent guidance suggests a slow and gradual reduction, over months or years, with slower reductions

at lower doses. This should give time for underlying neuroadaptions (due to taking antipsychotics) to resolve, therefore minimising the risks of withdrawal symptoms and relapse (see: Horowitz et al., 2021). Tapering strips could be used to reduce, although these are only available in certain countries (Groot & van Os, 2020). People may require more intensive monitoring and support during the reduction and for a time after they have stopped (Horowitz et al., 2021; Larsen-Barr & Seymour, 2021). For some people reducing to the lowest possible dose may be more plausible than stopping, and some may find intermittent antipsychotic use during symptom exacerbations to be helpful. Education about possible withdrawal effects of antipsychotics, such as insomnia, could help people to distinguish withdrawal symptoms from relapse. Management of anxiety through therapy, self-management strategies and short-term medication (e.g. benzodiazepines) is likely to be important, and some people will need support to become re-accustomed to emotions which were previously suppressed by antipsychotics.

Conclusion

Evidence from treatments that are centred around psychosocial strategies and aim to avoid or minimise the use of antipsychotics is consistent with interpretations of the WHO studies that suggest that a supportive community approach may enable people to have good outcomes while minimising the need for antipsychotic treatment, and its associated complications. Yet, regardless of the evidence on outcomes, many service users and carers are calling for alternative treatment facilities that would enable them to avoid or minimise exposure to antipsychotics. We have outlined some of the approaches that current services could adopt to enable them to cater to those who wish to avoid, reduce or discontinue antipsychotics more effectively. Further research is needed into the extent to which established psychosocial interventions, such as CBT and family intervention, can enable people to avoid, reduce or discontinue antipsychotic medication and what benefits might accrue from the addition of the more targeted elements described above. We have an opportunity now to listen and respond to service users and, as in Norway and Vermont, governments could encourage the provision and further research of minimal medication services to provide people with genuine choice about their treatment. Further discussion, in consultation with service users, of the key elements such a service should include is needed.

Box 1

Personal experience: John Richardson

The first ‘mental health treatment’ I received was being pinned down and injected against my will. This came after being handcuffed and dragged into a psychiatric hospital; because I was trying to save the world from a secretly impending doom. However, the world’s initial response to me was far more apocalyptic than anything I was imagining.

My introduction to medication was it being used as a weapon. In hospital I had no choice but to take it. ‘Compliance’ was king, a word synonymous with obedience. That rings true to me still to this day because so often I’ve felt a submission involved alongside medication. As though I’m giving power to something and giving up a piece of myself.

The ideas and the stories that come in tandem with antipsychotics all have an impact, perhaps just as much as the chemical compounds. One doctor once told me I’d “need to be on this medication for the rest of my life”, or I would “have another psychotic episode”. That’s the script we are asked to swallow and one we need to shake. It is simply unjust to disembodiment the context of our experiences in this way.

Medication can help, of course. It’s disingenuous to blanketly dismiss its potential for utility. Sometimes it’s been a choice I’ve had to make in order to navigate the world around me. What is critical to me, a fundamental aspiration I hope we can all share, is that it becomes a choice.

Box 2: Minimal medication services

The Drug-Free Treatment Unit, University Hospital, North Norway: This unit provides in and out-patient services for people with severe mental health conditions (primarily psychosis, schizophrenia or bipolar) who want to reduce and discontinue medications, such as antipsychotics, or who do not want to take medication. Ward staffing includes people with lived experience, nurses, psychologists, and psychiatrists. Treatment is centred around psychosocial approaches with the aim of helping people to manage without medication. Treatments include: art and music therapy, indoor and outdoor exercise, group and individual psychological therapy, animal therapy, recovery workshops, psychoeducation, network meetings (with families, social networks and professionals) to help support the service user, and social activities, such as hiking trips. Specialised support is provided to help people reduce/discontinue their medication and there is no involuntary treatment.

Soteria House, Vermont: based on the original Soteria houses (Bola & Mosher, 2003), this is a residential alternative to hospital for people experiencing an acute first or second episode of psychosis. The house is mainly staffed by people with lived experience, and staff and residents share responsibility for the daily running of the house. Psychiatric consultations and medication are optional and support is available for medication reduction and discontinuation. One of the main principles is to ‘be with’ the resident while they are going through an acute episode, with the view that psychosis can be a temporary and meaningful experience to work through, rather than a chronic illness. The house also offers: creative expression (art, music, writing), engaging with nature, exercise, meditation and relaxation, increased understanding of hearing voices, sleep hygiene, network meetings with family and friends, and the reframing of crisis as an opportunity. There is no involuntary treatment.

(see: <https://www.pathwaysvermont.org/what-we-do/our-programs/soteria-house/>).

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