

My journey with RADAR LEAP

Research Antipsychotic Discontinuation and Reduction, Lived Experience adversary Panel

Can you tell me why you joined the RADAR LEAP?

I had a long history of enduring Schizophrenia and extensive involvement with all kinds of antipsychotic medications to get me healthy. From my service user's perspective, participating in research into antipsychotic reduction studies and joining a panel of experts by experience will broaden my knowledge. Importantly, RADAR LEAP, I hope, will be an emotional benefit for me as I am involved in rational thought discussions that boost my self-esteem. Yet, I know, much of my cognitions are damage by the schizophrenia disease, and I manage to stay focus.

Since being diagnosed, what has been your experience of medication use, support from psychiatrists and family, and your medication choices?

Medication use has never maintained remission, averted relapse or improved the quality of my life. When I have chronic psychotic symptoms of Schizophrenia, antipsychotic medication is critical in taking me out of my mind made up conceptional existence. It brings me back into this world's objective reality and knocking out some cognitive skills, and I experience negative symptoms with physical pain persisting.

The psychiatrists were very slow in treating my holistic self; they were excellent in giving me drugs to stop positive symptoms but did not focus on the negative traits and poor cognition that persisted. Thank goodness for family support; without a doubt, they helped in my speedy recovery. My mum and dad had such a love devotion and did all they could to see me better, but they died while I still had spells of re-hospitalisation because Schizophrenia had never gone away. So since the early years in 2000, day one of the approvals of Aripiprazole, it has become the clinician, mine and my family choice to knock back Schizophrenia. I have been continuously using variable doses effectively to stable the symptoms of Schizophrenia and when it flairs up unexpectedly.

What's been happening specifically in the last four years in terms of your antipsychotic medication use?

I had been tapering the high dose of 30mg antipsychotic medication. I aimed to allow my brain's chemical factory to produce and regulate the right amount of substance to keep a healthy balance ratio in my body and mind. I asked one of the RADAR study team how I could achieve my goal of total mental wellness? They advised I needed to know myself well to gauge the symptoms and placebo effects while withdrawing slowly off the medication. That gave me some confidence, and I did achieve my goal of discontinuing antipsychotic medicine on my own because my psychiatrist would not support me. I haven't expected it to be so hard to come off the medication. I thought reducing the drug slowly over a long time would be okay.

I successfully discontinued the med in 2018. However, it was severely arduous, real physically, because the withdrawal process gave all over body pains, particularly at lower doses, and robust tinnitus.

Nevertheless, I endured them to have a state of mind that became total mental wellness, taking no medication. After all, negative symptoms had diminished, and cogitation improved. Unfortunately, I relapsed nearly one year later when societal upheavals, environmental factors mixed with my genetic predisposition sensitised me and brought back active Schizophrenia, including psychosis. In 2019 a 30mg dose of antipsychotic was valid to have my madness becomes stable again, and in 2020

10mg of Aripiprazole has become the preventable dose. It holds off the illness as my general life stresses diminish, and my human body management system is not under severe or chronic stress. I know I need to keep pressures out of my life to stay well, which is not always easy, but I am committed to staying well, so that's what I have to do.

What have you learned from the group or study team about medication issues? Have you used this knowledge at all in your own life?

RADAR is a different kind of group I join. Those usually focus on people talking about getting over their problems. But RADAR's focus on medication is so interesting for me, 40 years on the stuff, which has not done me well most of the time. So, I feel privileged to have joined the group, and everyone understood what was going on in the psychiatric system, and it provided me with status and knowledge. Before, I was not accepted by my psychiatrist as someone knowledgeable about medication reduction and discontinuation. So, for four years, he would not listen to me. Being on the panel that collaborating recognised research led by university college London professors, other professionals, and talented service users have given me a new position with my psychiatrist and other clinicians.

I learnt how to use my voice to inference with the knowledge I gained about the severe adverse effects of taking antipsychotic medication. The group experiences and study team feedback on medication issues gave me the social power to challenge and change my high maintenance treatment dosage. For years I have been worried about developing severe adverse effects of taking antipsychotics, and I only asked psychiatrists to help me find the minimal effective dose. Still, none wanted to coordinate the care, and I had four years of going it alone. And finally, they listen now. They had vigorously defended the practice of keeping me on a high maintenance dose, and I was fighting the system to take a paradigm shift. As an ethnic Black male, I exercised my Right to have tailored treatment with antipsychotics for a while, and I was learning to empowered myself to cope with my reality. My evidence of taking costly biomedical therapy for years after years had no complete remission or unimpaired functioning or prevented re-hospitalisation. I feel lucky I have no severe adverse effect, and today the psychiatrist recognises I need to learn more coping skills based on a sound contemplative psychotherapy approach. We work together to obtain the minimum effective dose for the rest of my life and monitor my stress intolerances.

Has experience with RADAR had any effect on family/ friends or your relationship with them?

They are proud of me to be involved in such a pioneering research project that will form clinical guidelines for clinicians whose clients wish to reduce/ discontinue the use of an antipsychotic drug. They are okay with it as they see my journey to reduce my med is not to reach discontinuation again. I am contented and being with RADAR has been a learning curve for all of us.

LEAP feedback

How has your expertise evolved as a LEAP member over time?

I have evolved from having anticipatory anxieties, expecting withdrawal symptoms to be not paralysing. Still, having gained further expertise by the experience of how paralysing it can be, I am at a mindset now it's not much different from overcoming prescription drug dependency. Ditching antipsychotics is a lot tougher than I could have imagined, and I evolved to be in a "good place." I would still like to come entirely off medication – I have not given up on that goal because my madness was arguably psychological in origin and not caused by any disease or damage to the brain.

It becomes preventable when my reactions to adverse life events and psychological trauma use social approaches to learn more coping skills with a therapeutic approach based on sound contemplative psychotherapy.

How could we improve how expertise within the LEAP is best used in RADAR?

I have not any new ideas on the matter!

Messages for other people

If there is one thing you want to tell someone who has been struggling with medication, what would you like to say to them?

Before you decide to come off your medication, make sure you talk to your psychiatrist, a GP, your family, and a friend before making any changes to your prescription. It should be based on discussion, research, and planning.

What messages do you want to tell psychiatrists, social workers, and other practitioners about medication use or discontinuation?

Be more honest about getting hooked on a high maintenance dose of medication that current evidence shows is best tapered when the crisis has passed and the patient gains back their purpose, self-esteem, and self-worth. Change the over-prescribing of drugs and their use on patients for far too long to cure all social ills. Instead, use more extensive low dose pharmaceutical drug treatment and therapy, or have a discontinuation programme. It can work best when the patient is ready to take up their personal goal challenges.

Author Links: ucl.ac.uk/psychiatry/research