DOPAMINE AGONIST WITHDRAWAL SCHEDULE

If you develop augmentation or Impulse Control Disorder on dopamine agonists (DAs), you will need to withdraw from the medication.
There are several ways to do this and you will need your doctor to support you throughout, as the withdrawal can be extremely difficult and traumatic, involving constant, severe RLS and little to no sleep.
You should plan ahead and arrange time off work and socialising for the two to three weeks after the last dose of dopamine agonist. Ask in advance for the support and help of family and friends, particularly during the nights.
Experts say it can be more difficult than withdrawal from heroin or crystal meth.
It is essential that you arrange morning, fasting, full panel iron blood tests, as raising serum ferritin above 100ug/L, preferably 200ug/L can help settle augmentation and reduce withdrawal symptoms.

Slow Withdrawal
Most RLS experts recommend a very slow, tapered withdrawal. If you have been on high doses of DAs for several years, the top US experts (Drs Buchfuhrer, Berkowski, Winkelman and Ondo) recommend a slow withdrawal over at least 6 months.
Fast Withdrawal
However, Dr Earley at Johns Hopkins University in Baltimore, recommends a 3 week withdrawal because he believes the process is torturous whether you reduce over 6 months or 3 weeks, and it is better to get it over with more quickly. You should discuss this with your doctor. If you are otherwise fit and healthy, a faster withdrawal may be preferable. If you are older and have any other health or mobility issues, a slower withdrawal will be more suitable.

What to expect
At every dose reduction, your RLS symptoms will become more severe and you will get little sleep until your body adjusts to the lower dose. The RLS will become very intense and will involve violent jerks. It will cause feelings of being extremely ‘wound up’ and anxious. Ideally, your doctor should prescribe a low dose opioid (tramadol 50mg, codeine 30mg, oxycodone/ oxycontin 10mg) to help settle the withdrawal symptoms.
When you stop the last dose of DA, you will experience at least a month of severe withdrawal symptoms. The first 5 days will be the worst. You will get little to no sleep and you will need to move around constantly.The RLS will be very severe and will involve violent body jerks. Exhaustion can cause falls so, ideally, you should arrange for someone to be with you, especially at night, for at least the first 5 days. During this stage you should sleep or rest whenever you can. The symptoms gradually improve each day over the next few weeks, and you will start to get 3 or 4 hour’s broken sleep by Day 14. With each passing day, you will get a little more sleep, and the severity of your RLS will decrease. Ensure you clear your diary and take time off work for this stage of the withdrawal process.

Your dopamine receptors can take months, or longer, to settle down and recover. Withdrawal can cause severe physical and mental withdrawal symptoms and DAWS (Dopamine Agonist Withdrawal Syndrome) can affect up to 19% of patients.[1]

Tapering Schedule

Ropinirole
First switch extended release Ropinirole for the equivalent dose of normal release Ropinirole, then reduce by 0.25mg every 2 weeks. Ask for a supply of 0.25mg pills.
Pramipexole
First switch extended release pramipexole for the equivalent dose of normal release pramipexole and reduce by half a 0.088mg pill every 2 weeks. Ask for a supply of 0.088mg pills.

Rotigitone/Neupro Patch
First switch to the equivalent dose of normal release Ropinirole pills, then follow the reduction schedule for Ropinirole. Alternatively, use 1mg patches and cut into quarters and reduce by a quarter patch every 2 weeks.

At any stage in the reduction process, you can slow down even further if the withdrawal symptoms are too unbearable. A low dose opioid, such as codeine, tramadol, oxycodone, can help to settle the increased symptoms at each reduction. As stated below, buprenorphine or methadone can make the withdrawal far less brutal, and in some cases can eliminate ALL withdrawal symptoms.

Replacement Medication
Most RLS experts recommend that you start a replacement medication while you are reducing your DA, as the withdrawal will be too torturous otherwise. Dr Earley is one of the only RLS experts who recommends a withdrawal without any medication. He believes that a 2 week washout period after stopping a DA is required to assess the baseline RLS. This is extremely difficult and RLS-UK would not advise this method as the withdrawal would be brutal. However, there are cases where patients have been able to taper off DAs and not start replacement medication, especially if they have responded positively to intravenous iron infusion.

The usual replacement medications to take during DA withdrawal are pregabalin or gabapentin or a low dose opioid.

Gabapentinoids

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[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9335375/#:~:text=Symptoms%20include%20panic%20attacks%2C%20depression,chronically%20(months%20or%20years).

Pregabalin and gabapentin are prescribed ‘off licence’ for RLS. They take 3 to 4 weeks to reach full effectiveness, so it is best to start them around 4 weeks before you drop the last dose of DA. They will NOT usually override the intense withdrawal symptoms so do not expect them to help during withdrawal or until around 3 weeks after the last dose of DA.

Opioids

Low dose opioids can be very effective in controlling RLS, but can be difficult to obtain because of unfounded fears of addiction or tolerance. The Massachussets Hospital Opioid Registry[2], set up by Dr John Winkelman, is showing that addiction does not occur unless there is a history of abuse, and if patients are properly screened and monitored. Unlike when opioids are used to control pain, tolerance (the need to take higher doses to achieve the same effect) does not generally happen and the Register shows that patients stay on the same low dose for years. The main opioids used to treat RLS are Targinact (Oxycontin and naloxone), Oxycodone, Oxycontin, tramadol or codeine. Targinact is licensed for RLS in the UK and is usually taken twice a day. However, Oxycontin has a short half life and can often cause mini opioid withdrawals.The main symptom of opioid withdrawal is RLS. Many people report that Oxycontin does not cover their RLS symptoms and that they experience RLS breakthroughs. But, as with all medications used for RLS, everyone reacts differently.

Methadone and buprenorphine are highly effective for refractory RLS because they have a long half life. Patients have reported on the RLS-UK help forum that using methadone or buprenorphine while withdrawing from a DA can completely eliminate DA withdrawal symptoms. Both methadone and buprenorphine are difficult to obtain in the UK because there have been no UK trials for RLS and most doctors are unfamiliar with prescribing them for RLS. Buprenorphine is ‘red listed’ in many UK areas and can only be prescribed and monitored by a specialist. There have been reports that even when a specialist recommends Methadone or buprenorphine, some GPs refuse to continue the prescription.

[2] https://www.massgeneral.org/rls-registry