

Consumers' Guide to the Opioid Treatment Program: Exiting the OTP

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*Opening the Doors
on Opioid Treatment*



ACKNOWLEDGMENTS

'Consumer's Guide to the OTP: Exiting on the OTP'. 1st edition, 2019

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The OTP Consumer Guidelines series was produced by the NSW Users and AIDS Association (NUAA). NUAA is governed, staffed and led by people with lived experience of drug use. Since 1989, we have provided innovative harm reduction services, advancing the rights, health and dignity of people who use drugs illicitly in NSW. This includes supporting and advocating for people on the Opioid Treatment Program. This resource has been reviewed and approved by the NSW Ministry of Health (MoH). The MoH provides NUAA with the funding to do this work. Special thanks to all our wonderful peers who helped create this resource.

Distribution: The OTP Consumer Guidelines series is a targeted resource for people who use opioids and are thinking about starting, or are currently on, an Opioid Treatment Program in NSW. The OTP Consumer Guidelines series is distributed to Harm Reduction organisations and Alcohol and Other Drug services throughout NSW and is not intended for general distribution. Hard copies of all the booklets in this series are available. To receive your copy, email MOH-PopulationHealthResources@health.nsw.gov.au, or contact NUAA.

NUAA would like to acknowledge and show respect to the Gadigal people of the Eora Nation as the traditional owners of the land on which we work. We extend this respect to all First Nations groups upon whose land this resource is distributed.

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ABOUT THIS RESOURCE

The *NSW Clinical Guidelines: Treatment of Opioid Dependence - 2018* were written by clinicians and policymakers with input from NUAA and other stakeholders. They exist to give prescribers and dosers the who, what, where, how and why of the Opioid Treatment Program so that they are up to date with what is expected of them.

Anyone can look at the Clinical Guidelines (just search the title online), but they are written for doctors, not consumers. That's why NUAA has put together this set of resources for us - the *Consumer's Guide to the Opioid Treatment Program: Opening the Doors on Opioid Treatment*.

Our version is written by people who use drugs for people who use drugs. To make sure the info we gave you was correct, up to date and relevant, we got together a great Steering Committee, starting with consumers and including doctors, clinic managers, pharmacists and experts from the Ministry of Health. We asked

heaps of people on the program what they wanted to know.

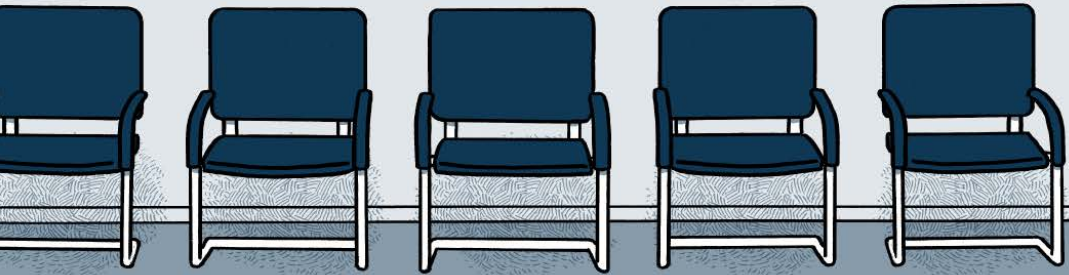
These guides tell you what you can expect on the OTP and what is expected of you. We give you the rules and facts as well as some useful tips and advice from peers. No matter where you are in your treatment journey, you should find information in these booklets to help you make decisions and get where you want to be with your drug use.

There is a larger document that includes a big range of info about the program called the *Consumer's Guide to the NSW Opioid Treatment Program*. There are also a set of bite-sized booklets that focus on particular situations or stages of life on the OTP.

This booklet, *Exiting the Opioid Treatment Program*, looks at the pros and cons of leaving the OTP and explains the process. If you're thinking about leaving the program, or are thinking of starting and want to know more about how your treatment might go, this is the one for you!

OTP CONSUMER GUIDELINES SERIES

- **The Consumer's Guide to the NSW Opioid Treatment Program**
- **Standalone Guide 1: Introduction to the Opioid Treatment Program**
- **Standalone Guide 2: Maintenance on the Opioid Treatment Program**
- **Standalone Guide 3: Your Rights and Responsibilities on the Opioid Treatment Program**
- **Standalone Guide 4: Pregnancy and Parenting on the Opioid Treatment Program**
- **Standalone Guide 5: Opioid Treatment Program in Regional and Rural Areas**
- **Standalone Guide 6: Pain Management and the Opioid Treatment Program**
- **Standalone Guide 7: Exiting the Opioid Treatment Program**
- **Standalone Guide 8: Depot Buprenorphine Starters' Guide**



DECIDING TO LEAVE OTP

People have different expectations of being on OTP. Some are happy to stay on the program for a long time, or even forever. Others plan on leaving it behind them once they get where they want to be with their life and their drug use.

Each person is different and wants different things from their treatment. There are no rules about how long you have to stay on the OTP - you can stay on the program as long or as short a time as you want. It is up to you and your doctor to decide together.

Opioid treatment is very different from abstinence-based “all or nothing” type treatments because it gives you a safety net while you stop your drug use. Once you have some distance from dependency on street drugs, you can reduce your OTP dose gradually and see what happens to your drug use (opioids and other drugs), lifestyle and mental health.

Some people will find it suits them to reduce from the OTP completely. Others will find that their health and well-being are better when they remain on a maintenance program.

You don't ever have to leave the program if you don't want to. Your doctor has prescribed methadone and buprenorphine to treat the medical condition of opioid dependence. There is no shame in being on the program any more than there is shame in being prescribed medication for any other reason.

There are many life-long health conditions that people manage by taking medication every day. For example, people with diabetes or high blood pressure take medication every day for their health and to improve the quality of their life. OTP is very similar in this sense. For some people, staying on the program is what is best for them.

“At first my doctor argued, but I felt I was ready. I think most people know what works best for them and doctors should listen. I wanted advice from my doctor about how quickly I should reduce, but I also wanted flexibility along the way.” - Tina

TREATMENT PLANS

When you first started on an OTP, you might have had a conversation with your doctor about how you wanted your treatment to go. Then you made a Treatment Plan based on your goals. You thought about what you wanted from the program and how long you wanted to stay on OTP.

"I just can't imagine life now as it was - doing methadone, drinking grog, eating (sometimes), passing out then waking up to do it all again. I feel amazing now, and I am pleased that I saw something through that took planning, commitment and overcoming set-backs." - William

It is worth having a look at your Treatment Plan from time to time and updating it. You may have found being on OTP different from what you thought it would be or things in your life might have changed. You might want to stay on the OTP longer or leave it earlier for all kinds of reasons. That's why it is worth thinking about your plan from time to time.

If you don't remember making a plan, talk to your prescriber - they may have some details on file. Either way, together you can talk about your time on the program and think about where you want to go now.

Many people don't come off the program even if they really want to, because they are worried about how difficult it might be. Talk to your doctor about how to manage exiting the program when the time comes. It will help you get in a positive headspace. They can explain what you should expect from withdrawal and can give you some tips to help make detoxing easier.

Knowing what to expect and how to help with the detox should make the idea of coming off your OTP medication a lot less scary. Then when the time is right, you will know what to do.

ARE YOU READY?

There are a lot of good reasons why you might be thinking about leaving treatment. You might be sick of the stigma of being on OTP. Appointments and dosing take a lot of time, and maybe you're tired of having to organize your life around OTP.

All reasons are valid, but you should think carefully about your choices. Be honest with yourself: are you ready?

It can be useful to write a list of reasons for and against. Will your life be better if you get off your meds or if you stay on the program? Are there other changes you could make – like changing where, how or how much you are dosed – that will give you the improvements you are looking for? Have you taken full advantage of the program and made all the changes you want? Talk it over with your partner, friends and doctor. It can really help to get other perspectives.

The best reason for leaving OTP is that you feel in charge of your drug use (whatever that means for you) and feel that you no longer need to be on the program.



Researchers have found that most people who have left the program successfully and move forward in life had some important things in common:

- They were on the OTP at least 1 - 2 years before thinking about exiting and were using their medication as prescribed.
- They were no longer using illicit (street) drugs.
- They were in stable housing and felt some security
- They had strong support from family or friends.
- They were working towards some stability with their physical and mental health issues. This included seeing health professionals such as a psychologist to learn how to deal with traumatic events and a doctor to get hep C and HIV tested and treated.
- They were involved in something that was important to them and lifted their self-esteem. For some it was their job/career, volunteer activities or study. For others it was parenting and family life. Others had a particular interest like art, music, sport, a hobby or an activity like gardening or sewing.

While no-one else can tell you if you are ready to move on, if you don't have at least some of these things in place, you may not be ready to leave the program. If you leave the program before you are ready, you could be undoing months' or years' worth of hard work.



Jeb's story: Exiting OTP after injecting

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I had always injected some of my takeaways. For many years this kept me from street drugs, giving me some financial stability. However, my veins became very damaged, and I started to inject in my hands and feet - particularly problematic with large volumes of liquid.

When I began reducing my methadone, I started injecting double doses to get a decent whack. This meant I was pigging out, then going without and feeling like shit. Once I decided to stop injecting, my withdrawal went a lot easier. I felt more even-tempered.

”

Your prescriber will be supporting your withdrawal plan, so when you are thinking of leaving OTP, ask them for their advice. They will be able to look at your situation and be honest about whether they believe it is a good idea. They may be concerned that you're not ready, or they could be completely supportive of your attempt.

If your doctor has concerns, ask them what they think you need to sort out to successfully come off the program.

It can also be worth talking to other people involved in your care, such as nurses, chemists, psychologists or clinic staff. Ask them what they think the best option is for you.

Talking to people who have been through the experience is also important. There is nothing like peer advice to work out the best ways to do something and the pitfalls you could fall into.

It's fine if you change your mind and decide to stay on the program for a bit longer. A good compromise might be to reduce your dose slowly and see how you go.

At the end of the day, you get the final say on whether you stay on the program. Your prescriber is not allowed to refuse to exit you from OTP.

WAYS TO COME OFF

If you want to exit the program, you have a few options:

Tapering

Slowly decreasing your dose, also known as tapering or titration, is the most commonly used, and most successful, approach for exiting the program.

Every time you drop down on your dose, you will likely experience some level of withdrawal symptoms, which generally will increase in severity as your dose gets closer to zero. The withdrawals usually peak between 1-4 weeks after your last dose.

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“I think we want to push ourselves to do it all NOW, but my doctor recommended the steady approach. When I started my reduction, my daily methadone dose was 100mg/20ml. It took me just over a year to reduce off at the rate of 5mg per fortnight at the beginning, then 2.5mg per fortnight once I had reached a ‘low’ dose.” - Sam

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Cold Turkey

Going “cold turkey” means to stop taking something abruptly and completely. In the case of exiting treatment, this would mean one day just stopping taking your regular dose, without coming down from it at all.

Cold turkey is the hardest way to come off and is not recommended by healthcare professionals or by most people who’ve tried it. Methadone and buprenorphine stay in your system much longer than other opioids, making the withdrawals last longer - up to 6 months or more.

The withdrawal symptoms from going cold turkey off the program are difficult to treat, and the higher your dose was, the more severe they will be. Stopping treatment suddenly also means you’re more likely to start using other drugs or end up back on the program.

Having said all of that, it is up to you how you decide to detox. Some people have found that a cold turkey approach worked for them. If you are going to come off the program this way, make sure you get some symptom relief.

Remember you are at risk of overdose if you use again after having no opioids in your body, so be careful. If you do use, split your dose, trying a little bit first. Use with a friend or at least let someone know what you are doing. Tell them you want them to call “000” if you drop. If you can, have naloxone in case you need to reverse overdose and choose a friend who has been trained in how to give naloxone or give them a crash course.

OTP reduction programs

There are residential rehabilitation programs that can help you exit the OTP. 'Resi rehabs' can be useful because not only can you physically detox, you also spend time working through major issues in your life and learning about yourself.

Rehabs offer intensive self-reflection and learning away from the usual triggers, responsibilities and stresses. As you slowly go down on your dose, you have time to think about where you want your life to go and how you want to get there.

If you go to 'resi rehab', you'll need to commit for a few months of your life. Before making this decision, you should consider commitments such as family, work, or study, and how resi rehab may impact these.

While residential rehab can be a great option for coming off methadone or buprenorphine, many in-patient rehabs don't accept people on OTP. Call ADIS on 1800 250 015 to find out your options.

Inpatient Withdrawal Management (Detox)

When tapering off their doses, people often say that it's very hard to make the final jump down from a small dose to nothing at all. Some people find that an inpatient detox can help because you can get the support you need from healthcare professionals (such as doctors, nurses, and counsellors) while going through withdrawals.

Most units will not admit someone for withdrawal from the OTP because the withdrawal tends to last at least a month and units usually only admit for 5 to 7 days. However, if you can negotiate a bed, you may benefit from being in a detox unit for some time after your last dose. Extra support is especially useful during this period, as it's when you're likely to get the most severe withdrawal symptoms. It is also when people are at their greatest risk of using illicit drugs or black-market prescription medication.

You can talk to your prescriber or contact your local detox clinic to see if this option is available to you.

Swapping Medication

Another handy tip to help with exiting the program is to reduce your dose slowly, and then swap medications when you're on a low dose. While this option doesn't work for everyone, it's worth thinking about – ask your prescriber for their opinion.

Some people on methadone find that swapping to buprenorphine works for them because the withdrawal symptoms from bupe are reported to be easier to deal with. Most people who do this reduce their methadone dose to around 30mg and then swap to a low dose of buprenorphine. From there, you can continue going down on your dose before coming off completely. Remember that withdrawal is an individual thing and this doesn't work for everyone, but some people have found it helped them.

This technique works both ways – you can also swap from a low dose of bupe to a very low dose of methadone. It may also help you manage the worst of your withdrawal symptoms from bupe, and the withdrawals from a tiny dose of methadone are usually manageable.

James' story: Swapping from Suboxone to methadone

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Going from 0.8mg to 0.4mg (of Suboxone) was really painful, so for my last step down to nothing, I ended up switching to 1mg of methadone a day - 0.2mL of syrup. It was enough to ride out my withdrawals comfortably and coming off 1mg of methadone was a walk in the park. I was on that for a month and then slid off. It was all over. I did something that, a year ago, seemed impossible.

”

WITHDRAWALS

Because your body has become dependent on methadone or bupe, you will go into withdrawal when you stop taking these drugs.

Methadone and buprenorphine (bupe) are both long-acting drugs, while heroin and morphine don't last in your body nearly as long. This means the withdrawal symptoms are often more uncomfortable and last longer than withdrawing from other opioids such as heroin.

Withdrawing from methadone or bupe is usually an unpleasant experience. You may experience hot and cold sweats, fevers, restlessness, anxiety, aggression, disturbed sleep, diarrhoea, running eyes and nose, muscle/bone/joint pain, yawning and sneezing, to name the most common symptoms.



If you are tapering your dose, every step down will bring on a new round of withdrawal symptoms. Withdrawal will be different for each person, depending on your how fast your body processes the medication and the amount you are decreasing. Withdrawal symptoms usually last about 4 days, but may last up to 14 days or even longer.

Remember that each time you make a reduction, you are reducing a larger percentage of your dose and so the symptoms will be stronger. To go down 5 mg of a 50mg dose will affect you more than going down 5 mg of a 100mg dose. You may need to reduce by smaller amounts as you progress in your tapering down, in order to make the withdrawal symptoms a little easier to tolerate. By the time you get down to reducing 1 mg of a 5mg dose, it is the same as if you had gone down 10 mg of a 50mg dose or 20 mg of a 100mg dose.

"I found that when I got below 30mgs/6mLs, I began to experience withdrawal symptoms that my dose didn't take away - muscle cramps, yawning, getting emotional and moody. To counteract all this, I ate regular healthy meals, did some exercise, tried meditation and rewarded myself with little luxuries. I also went onto anti-depressants." - Vivien

Withdrawal symptoms have been reported for several months following the final taper (when you jump off to nothing). Coming off methadone tends to take longer than coming off bupe. Even after your last dose, you may feel symptoms for 4-6 weeks (with bupe) or 6-10 weeks (with methadone) including restlessness, muscle pain and irritability.

Many people feel depressed, and the additional trouble with getting sleep after this final dose reduction can make you feel very down. If this is the case, you might want to think about trying antidepressants for a short time. Talk to your doctor about how to manage the final jump and the period after.

Remember, this is productive pain (just like having a baby), and once it is over you, will feel fantastic that you have reached your goal. However, there is no shame at all in deciding to go back up on your dose, although many peers report it merely delays the inevitable and can make withdrawal harder in the long term.



SYMPTOM RELIEF

Withdrawing from opioids is never going to be pleasant, but you can make it easier by addressing the symptoms individually.

Non-opioid painkillers (e.g. aspirin, ibuprofen/Nurofen, paracetamol/Panadol) can help ease aches and pains in your muscles and bones. However, you should keep their use short-term, as taking them for longer can lead to ulcers and kidney problems.

Sports cream like Voltaren, Deep Heat or Tiger Balm can also help with sore muscles. Magnesium can be useful for restless legs and muscle cramps/tension. You could even think about getting regular massages and having spa baths.

Your doctor can prescribe medication to help with nausea, stomach aches and diarrhoea.

Making sure that you're eating well is also important, as your body will be under a lot of strain. We suggest making sure your diet has lots of fruit, vegetables, whole grains and legumes. You might also want to think about taking a multivitamin supplement to make sure you're getting the nutrients you need.

Some people find that natural remedies can help. Echinacea is available at most chemists and can help with the head-cold symptoms of opioid withdrawal. Taking ginseng may help ease your fatigue and give you an energy boost. Some people try other alternative medicines like acupuncture.

Before trying any of these, you should talk to your doctor to see what they think. Keep in mind that there is little research to say that many alternative and naturopathic methods and remedies actually work, but you may find it's worth looking into them anyway.

You might have trouble getting a good night's sleep for a while too. If this is the case, talk to your doctor about what you can do – they might prescribe you a melatonin supplement, which can help fix your sleep pattern. Valerian root, a herbal supplement, might also help, but again, talk to your doctor.

It's also important to get into a healthy sleep routine. That means training your body to go to bed at a reasonable hour and wake up around the same time each day. If you're struggling, you might want to talk to your doctor about seeing a sleep specialist. There has been a lot of research about "sleep hygiene", and there are many tips and tricks associated with improving your sleep patterns.

"I think lack of sleep was the hardest thing to deal with. I didn't cope well. At first, my doctor prescribed a sedative short term which helped get my sleep back on track. From then I learnt how to sleep again. My sleeping patterns have changed dramatically, for example I sleep at night only and rarely sleep in." - Tim

POST-DETOX

While exiting treatment is hard, staying off opioids completely is harder. It may feel like your regular schedule has been disrupted, that the withdrawals and cravings will never end, or that you're missing something in your life now.

Having a strong support network makes it more likely that you will stay off opioids after exiting treatment. This support network could include your friends, family, prescribing doctor, or caseworker.

Your prescribing doctor or caseworker should continue to see you after they've exited you from the program and make sure that you're coping okay. You may also choose to attend support groups if there are any running in your area - again, ask your prescriber about what is available in your area.

Anna's story: Staying motivated during detox

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Even with four takeaways a week, I'd had enough of the restrictions. More importantly, I had fallen in love with a wonderful man and the time was finally right to have a baby. I wanted to do this without the complication of drug use. This kept me focused even when withdrawal was at its hardest.

”

The most important thing post-detox is the focus on the benefits you got from being on the program and working to keep them. For some, being on OTP means having stable living arrangements or holding down a job for the first time in many years. It could mean that your personal relationships (friends, family) have improved. These improvements in your quality of life are the long-term goal of being on OTP, and it's important to keep focused on them once you have left the program.

For those having trouble with the withdrawal but who are still committed to the goal, it may be about finding new ways to deal with the problems or feelings that are coming up.

A lot of people find it helpful to write down the reasons why they want to exit the OTP and look at the list every day. One of the best tips is to have something positive to focus on like work, study, family life or a creative project.



CHANGING YOUR MIND

Some people find it hard to taper down and don't cope well with withdrawal, particularly in the last stages. Some people start using again, even if they haven't for a while, or they might increase the amount they are using.

A lot of people simply miss the benefits that OTP brought to their lives, such as the routine of dosing and the better mood that being on meds brings.

Most importantly, you should talk to your prescribing doctor about how you are finding exiting treatment.

It may take a few attempts to come off the program. Your prescriber or GP can help you with working through withdrawal symptoms. They can slow down your detox until you get used to a smaller dose and decide it is time to start reducing again. A psychologist or counsellor can also help you adjust to life off the program. You may also need to be clear about your general goals and ambitions.

Exiting OTP can be hard and isn't right for everyone. Don't be ashamed or discouraged if you're finding it difficult or are thinking about starting on the program again.

If you have already left OTP, you should arrange an appointment with your GP or another prescriber to discuss your options.

Don't be afraid to ask for help from friends, family, or your doctor. For some people, the best option is to stay on OTP or start back on the program.

Remember, methadone and buprenorphine are medicines that are used to treat a medical condition – opioid dependence. There is no shame in returning to treatment, and it may result in better outcomes for you.

The OTP is a tool, and it's okay if exiting the program doesn't work for you the first time. The most important thing is getting back on the program, staying safe and healthy, and reflecting on what did and didn't work last time. You can always attempt to exit the program again later if you choose, or you may benefit from being on OTP for the rest of your life.


USING AFTER DETOX

Not everyone wants to stop using drugs forever - you may still want the occasional tickle. You might also find yourself using even if you don't want to.

Getting to where you want to be with your drug use is a huge process, so don't be hard on yourself. If you do use, don't forget all your harm reduction tricks and tips!

The risk of overdose is higher if you start using opioids again after having exited the program and if you are only using very occasionally. If you do decide to start using heroin or other opioids again, you need to remember that your tolerance will be greatly reduced: an amount which you would've hardly felt before may now be enough to kill you!

Mixing your opioids with benzos or alcohol is very risky. Remember how powerful some pharmaceutical opioids are, like fentanyl, and be especially careful.



If you do start using again, don't use alone - doing so increases your risk of fatal overdose. It's important to always have naloxone on hand. Try to use with someone who has naloxone and knows how to use it. Otherwise, get some yourself and make sure everyone around you knows what to do if someone overdoses.

Talk to your doctor/prescriber about getting a script for take-home naloxone, even if you are only thinking about using. It's best to have it there, just in case. You can also get naloxone over the counter at many pharmacies, although it's a bit more expensive than getting it on a script. Some health services in NSW now provide naloxone for free. Visit yourroom.health.nsw.gov.au/naloxone to find out where. Tell your friends you want them to call triple zero (000) if you drop.

You also need to avoid vein damage, dirty shots and blood-borne viruses like hep C and HIV. As always, use sterile equipment once only and don't share it with anyone else or reuse it yourself. Wash your hands thoroughly. Swab your equipment, injection site and fingers. Use water prepared for injection, or boil and cool tap water. Dispose of your equipment safely.

LIFE AFTER OR WITH OTP

Deciding whether to leave the program is personal. Many people do get through the long period of adjustment and stop using opioids altogether. The best way to do this is to make use of the help available, such as support from your prescriber and OTP staff as well as support from family or friends.

You might want to try antidepressants or natural remedies; maybe you would benefit from an exercise regime or regular yoga. Often, writing in a journal helps. Attending support groups with other people going through the same thing is also a good idea.

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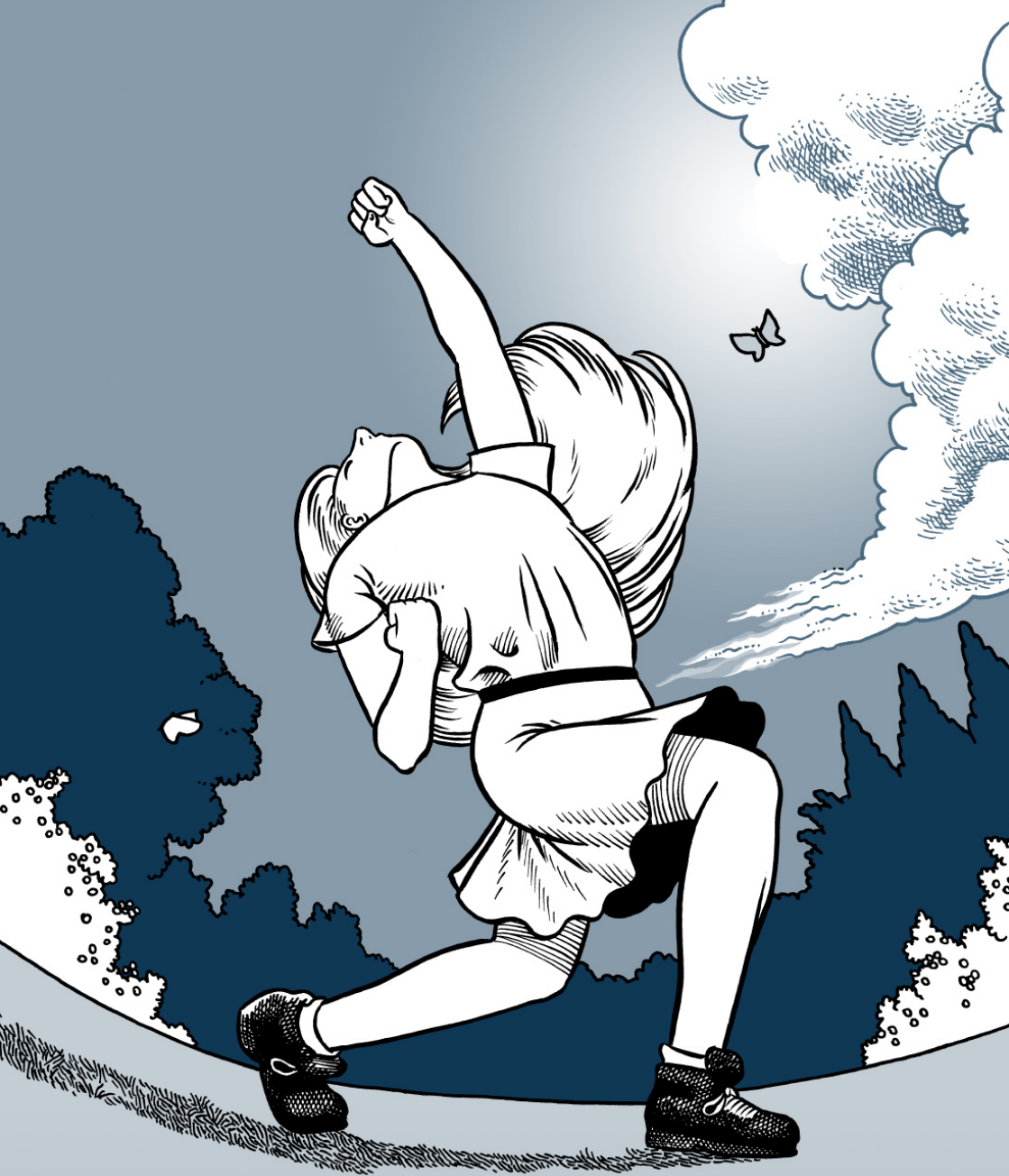
“Suboxone detox is a roller coaster ride with definite ups and downs. For those detoxing or thinking about it, all I can give you is my experience: it will be tough, but it is doable. There are good days and bad days, but eventually, it will all be okay. You just have to look after yourself – make sure you eat well, keep your fluids up, and are able to have some personal space when needed. And remember – the bad days are not forever, they’re just part of the process.” - Clyde

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No one is saying leaving the OTP is going to be easy – people who do it successfully put a lot of effort into making this big change, are patient, and use a combination of the tips above. But the most important thing to remember is that it is possible.

Before you decide if you are ready to exit the program, it's a good idea to talk to people who have done it successfully. How did they do it? What helped at first, and what helped in the months that followed? How are they doing now?

Gather lots of information from people who have gone before you. Then you will know if you are ready, and you will have lots of ideas for managing the process.



Write here any questions you have for your doctor and bring this booklet to your next appointment so you can ask them.



Looking to find out more about the
Opioid Treatment Program?

Look no further!

In your hands right now is the Consumer's Guide to the Opioid Treatment Program (OTP) - written by people who use drugs, for people who use drugs! This booklet is about Exiting the OTP. If you're thinking about jumping off the program, or are curious as to how you'd go about it, this resource should help you. Whether you're just starting to think about treatment or have been on the program for years, there's something in this series for everyone!

OTP Consumer Guidelines Series:

- Opioid Treatment Program Consumer Guidelines – Full resource
- Standalone Guide 1 – Introduction to the Opioid Treatment Program
- Standalone Guide 2 – Maintenance on the Opioid Treatment Program
- Standalone Guide 3 – Your Rights and Responsibilities on the Opioid Treatment Program
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