How to: Coming off psychiatric drugs



how to

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Coming off psychiatric drugs

Many people would like to stop their psychiatric medication, but coming off can be difficult. This booklet is for people who are thinking about coming off their medication and for friends, family and others who want to support them.

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Is coming off my medication right for me?

You may take psychiatric drugs for a variety of conditions. You may only need them for relatively short periods, but your diagnosis and symptoms may mean that you are expected to take them for a long time – perhaps indefinitely.

Many people who have come off their medication, even after taking it for a long time, find that in fact they can manage well and often feel better without it.

If you are taking psychiatric drugs and feel that you no longer need them (or do not wish to take them for a long time) you may want to see if you can manage just as well, or get on better, without them.

I have chosen to come off medication several times and been forced to come off it many times as well.

Some reasons why you might want to come off medication

- it has done its job, and I no longer need it
- I have found other ways of coping with my mental health problem
- it is not helpful I have been told my condition is 'treatment-resistant'
- it has unpleasant side effects which make it hard to tolerate
- it is affecting my physical health
- it makes me lose touch with my feelings
- it reduces my energy and enthusiasm, which affects my relationships and my ability to work
- I would like to start a family and am afraid the drugs may affect my baby while I'm pregnant or breastfeeding.

Alternatively, you may find your medications helpful and feel that the advantages outweigh the disadvantages.

Some reasons why people have decided to stay on medication

- since I found a drug that suits me, I have been getting my life back together
- I feel I benefit from taking the drug and so it's worth putting up with the side effects
- my doctors think I should continue with it, and I value their advice
- I have tried to come off in the past and found it difficult to cope
- my family would be really worried if I stopped taking it
- I need to stay well for my baby
- I think I still need it at the moment, but might consider coming off at another time.

Weighing up the advantages & disadvantages of coming off

It's very important to think about the decision to come off medication and whether it is right for you.

You might find it helpful to use a decision chart, like this example:

	Advantages	Disadvantages
Coming off medication	 I will be able to drive again I will have more energy I want to lose the weight I've gained 	 I might have another breakdown my partner will be angry with me
Staying on medication	 I'm quite stable at the moment – why rock the boat? I don't want to risk the withdrawal effects I don't want to risk a relapse 	 I don't feel truly myself my sex life is affected it makes me very sleepy all the time

If you decide to try coming off your medication, it's very important to:

- get support, preferably from others who have come off successfully or from a professional who understands the process
- find out the possible risks and how to minimise them
- come off gradually, over a period of time.

If you have been told that you must not stop your medication, even though you would like to try, see the Mind resource *Your right to refuse medication*. You can also ask for a second opinion, if you feel that would be helpful – you may need to talk to your GP about this.

My current doctor is great, and has always said that it is up to me if I take the medication or not, which makes me feel a lot better about it as I feel more in control.

How do I look after myself as I come off?

Choose a good time to come off

Coming off medication may be difficult and, if so, it may be hard to do other things at the same time.

If you currently have stressful things to cope with in your life, it may be best to not also try to come off medication, but to wait until things have settled down.

Stresses might be:

- moving house
- a new baby in the family
- · serious illness of a family member
- job instability.

But coming off may be just one part of a whole lifestyle change that you are undertaking. If you are consciously taking control and revising other aspects of your life – e.g. finding new interests, perhaps meeting new people – all this may also help you to come off.

It's important not to replace your medication with alcohol or street drugs. See Mind's resource *The mental health effects of street drugs and alcohol* for further details.

Plan your withdrawal

Having a personal withdrawal plan for reducing your medication over a number of weeks, months or even years can help you to stick to your original aim. You can always modify this as you go along, depending on how you progress.

Tell people close to you

Explain to your friends and family what you are planning to do and how this may impact on your mood and emotions.

If your feelings have been suppressed by medication, explain that it may take some time for you to get used to feeling emotions fully again.

Tell them about withdrawal symptoms, so that they understand what is happening to you, and can help you to cope.

Prepare an Advance Decision

An Advance Decision is a legally binding document, also known as an 'advance directive' or 'living will'. In it you can say how you would like to be treated if, for example, you have a serious crisis during the withdrawal process. See Mind's *Advance Decisions* resource for further details.

If you make an Advance Decision, you need to make sure that you give a copy to someone you can trust. Also give a copy to your doctor or psychiatrist, providing they are in agreement with your plan to come off medication.

Get to know your triggers and warning signs for crisis

Many people get to know what situations they find stressful, and either avoid them completely or prepare themselves carefully so as to minimise the stress. You, your friends or family members may learn to recognise warning signs which suggest you may be becoming unwell. Keeping a diary may help you to spot any patterns.

Monitor your mood

Monitoring your mood during the withdrawal process can help you to spot subtle trends that might otherwise get overlooked. You could use:

- a diary
- an online tool such as Moodscope (see **moodscope.com** for details)

Recording any side effects can help you to remain objective and recognise any less obvious patterns.

I've tried to come off my medication because I'm scared about what the medication is doing to my brain, and whether it is changing who I am as a person.

Trust your own feelings

If you feel that something you are experiencing is a side effect of medication or a withdrawal effect, take this seriously. Other people may think that your symptoms indicate that your illness is coming back, but you may feel sure it is not.

If you are following a programme of slow dose reduction and you reach a difficult phase, don't be afraid to slow down, or to stop at the dose you are on for longer than you had planned. Adapt your plans to fit your experience.

Learn how to look after yourself

- Don't be afraid to say 'no' if you feel something will be too much for you.
- Ask your friends or family for help, if that's what you need to keep well. For example, you may find it much easier to keep an appointment if you have someone to go with you.
- Use a comfort object. If you have to do something you find stressful, it might help to take a particular comforter with you (for example: a scarf, a special stone to hold in your pocket, a teddy or whatever

works for you). Don't be afraid to use such things if they help you to cope and get on with your life.

Look after your diet

You may find it helps to:

- eat regularly, starting with breakfast
- avoid sugary foods and drinks because they cause big fluctuations in blood sugar which can cause mood swings and anxiety
- be aware of foods and drinks that trigger depression or other mood changes in you.

Keeping a diary of what you've eaten may reveal reactions that you weren't aware of. See Mind's *Food and mood* tips for more information.

Get enough sleep

Sleep is one of the most important factors in maintaining mental health. If you are coming off medication and one of the withdrawal effects is sleep disturbance, you may have to be prepared to put up with this for a while. You could find ways to minimise the ill effects, however – see Mind's resource *How to cope with sleep problems* for details.

Exercise

This can help to reduce stress and anxiety, and can be prescribed as a treatment for depression.

Taking exercise out in the fresh air, in the country or the park is most effective. See Mind's resource on *Physical activity, sport and mental health*.

Be prepared to change your plans

Coming off can sometimes be a big disappointment if it doesn't bring the improvement you hoped for, or you find you can't manage without medication after all. But even if you don't manage to come off completely, you may succeed in reducing your dose, and this could make a significant

difference to how you feel.

In fact, trying to come off a particular medication can be a good way of finding your 'threshold dose'. This is the lowest amount of medication required to relieve your symptoms and keep you well.

You can also consider trying again at a later time. The fact that things did not go as you wished this time does not mean that they never will.

Some people find out that they are happier taking medication after all. This is also helpful to know: it may be easier to get on with the rest of your life once you have accepted that medication is part of it, and you feel that the decision was yours rather than your doctor's.



I hope I can come off medication completely one day.



How should I reduce my dose?

The longer you have been taking a drug for, the more your body and brain will have adapted to it.

This means that if you have been taking a drug for more than two or three months and suddenly stop taking it, you may:

- experience withdrawal effects which may make you very ill
- become unwell again with your original problem
- find it hard to tell which of these is happening (see the 'Withdrawal symptoms' section for more information on this).

Although some people can stop taking medication all at once, with no ill effects, many people become very unwell if they do so. It's impossible to tell in advance, so everyone is advised to withdraw slowly.

If you reduce slowly, you give the brain time to adjust back to being without the drug. The time this takes depends on how long you have been taking the drug, for example:

- If you have been taking a drug for six months, you may find it takes another six months to come off it completely.
- If you have been taking it for 20 years, you can expect to have to reduce very slowly indeed (perhaps over a period of years) before coming off completely.

It is usually easier to come off a drug with a long half-life. Drugs with short half-lives are more likely to cause withdrawal effects. The half-lives of individual drugs are shown on the Mind website's information page for that drug.

Choosing to stop suddenly

If you already have experience of coming off psychiatric medication suddenly and it was OK, you may choose to do this again.

Some people simply prefer to stop abruptly and put up with the with-drawal effects because they want to get it over with. This may be easier if your main withdrawal effects are physical. But if you find that your original mental health symptoms seem to be returning – as may happen, especially when stopping an antipsychotic – this can be very frightening, and it is advisable to withdraw more cautiously.

If you become agitated during withdrawal, your doctor may agree to prescribe a small amount of diazepam (Valium) for you to take if absolutely necessary. The simple fact that you have it, and can perhaps keep it to take tomorrow, may be all the reassurance you need while getting through the worst effects.

Some drugs are dangerous to stop suddenly if you have been taking them for more than two or three months. These include

clozapine (an antipsychotic), lithium and benzodiazepine tranquillisers.

Unfortunately going 'cold turkey' has for the most part been absolutely catastrophic and in the last instance ended up with me taking the highest level of completely new medications.

Having to stop suddenly

In some circumstances, such as experiencing a rare life-threatening side effect, you may need to stop taking your medication immediately, with no chance for reducing slowly.

This would normally happen under medical supervision, usually in hospital, due to the seriousness of the adverse effect.

How much should I reduce the dose?

It is often suggested that you should start withdrawal by reducing your dose by 10 per cent (one tenth). For example, if you are taking something at 20mg per day, you would reduce your dose by 2mg and take it at 18mg per day for a few days. If you get on all right with this and do not develop any withdrawal symptoms, you can reduce by a further 2mg and take 16mg per day.

As you reduce the doses, you might need to reduce by smaller amounts (e.g. 10 per cent of the new dose you are now on). Many people find they are more likely to get withdrawal effects as they reach lower doses.

With a drug with a long half-life (more than 24 hours) you may be able to make a larger reduction to begin with, and go more slowly later on.

Accurately making very small dose reductions depends on your drug being available at different doses, or in liquid form. It also depends on your prescriber being willing to prescribe it to you in different doses or in liquid form.

Some people may suggest reducing a dose by spacing the doses out more – but if the drug has a short half-life this may cause big fluctuations in the drug levels in your body, and make the withdrawal problems worse.

Each dose reduction may cause side effects such as:

- anxiety
- sleep disturbance
- being sick.

These are signs that you are reducing too quickly, and you should put the dose back up to the last level at which you were feeling OK. Your symptoms should then stop. When you feel ready, you can try reducing again, by a smaller amount. At each stage, make sure you are OK on the dose you have reached before reducing further.

You could make a chart showing how much of the drug you will be taking each day. This keeps the end goal in site and helps you keep track of where you are in the reduction process. This may be something that a psychiatrist, doctor or pharmacist can help with. But the plan is always flexible, and you may find you need to adjust it as you go along.

Many people find that the hardest part of withdrawal is the last part, when you are on a very low dose and might feel that you can now just stop because such a small amount can't make much difference – unfortunately this is usually not the case.

Tablets

Tablets are often scored across, which means it should be fairly easy to cut them in half. You can buy pill-cutters for this purpose from some pharmacies. But the smaller the dose reduction you want to achieve, the harder it is to be accurate when cutting tablets.

Some drugs come as rapidly dissolving tablets, which you can take in a drink. If you have these, you could make sure you always dissolve them in

the same amount of water or juice each time, and then gradually reduce the amount you actually drink, perhaps using an oral dosing syringe (used for babies and pets – it doesn't have a needle). The smallest of these are calibrated to provide doses of less than 1ml.

Capsules

If your medicine is in capsules, you may be able to open them and remove some of the contents – but you should be cautious about doing this because some drugs are irritating to the skin, and it may be difficult to be accurate with the dose.

A pharmacist may be able to advise you on the best way to do this; however some people think it is never a good idea.

Liquid medicines

Many medicines come in the form of a liquid as well as tablets and capsules. The liquid may be a solution, a suspension or a syrup.

With a liquid it is easier to make very small reductions, sometimes by gradually diluting the medicine.

The Patient Information Leaflet that comes with your medicine will tell you if it already contains purified water. If you want to dilute it, it's a good idea to use bottled or filtered water rather than tap water. This prevents any chemicals in the tap water affecting the medicine.

As you get down to very low doses, it may be easiest to use an oral dosing syringe (see above). But again, this method may not be accurate enough, and you may want to get help from a pharmacist with this.

Depot injections

If you are taking an antipsychotic as a depot injection (an injection into a large muscle every 2-4 weeks) there is usually no need for gradual withdrawal. This is because the drug is slowly excreted over a long period

anyway, and withdrawal problems do not seem to occur.

Some doctors or other professionals may be concerned if you say you wish to stop the injections, and may try to dissuade you. However it should usually be your choice whether or not you accept medication in this form.

What if I take more than one dose per day?

If you are coming off a drug that you take more than once a day, start by reducing just one dose. Which dose you reduce first partly depends on the type of drug; for example, if it's a drug that makes you sleepy, you might want to start by reducing the dose you take in the morning.

Some people reduce by cutting out doses entirely. Depending on the halflife of the drug, this may cause fluctuations in the level of drug in your blood, which may increase withdrawal symptoms. In this case, it may be more manageable to gradually reduce each dose.

What if I take more than one drug and want to come off all of them?

It's usually best to come off your drugs one at a time.

Which drug to start reducing first depends on what they are prescribed for, and how long you have been taking them. This is something to consider on an individual basis, preferably with the help of a professional.

But if you are taking one drug to help with the side effects of another, it's best to reduce the original drug first, before coming off the drug for side effects. For example, if you are taking an anti-Parkinson's drug to control unwanted side effects from an antipsychotic, it's best to reduce the antipsychotic first before coming off the anti-Parkinson's drug.

Drugs often affect how other drugs work. So if you take different types of drugs at the same time, you will probably have had the doses adjusted to allow for these effects. This means that you need to be very careful when reducing one drug, as the levels of another may change.

For example, imagine someone was taking carbamazepine (a mood stabiliser) with olanzapine (an antipsychotic). Carbamazepine changes the rate at which the body deals with olanzapine, so if they withdraw carbamazepine first, their dose of olanzapine would probably need adjusting.

It would be advisable to ask your doctor or a pharmacist about possible interactions between your medications, as well as reading the Patient Information Leaflet.

Withdrawal symptoms

As all psychiatric drugs change brain and body chemistry, they may all cause withdrawal symptoms, especially if you have been taking them for a long time. You will not necessarily get any withdrawal symptoms when coming off, but many people do. The symptoms differ to some extent between drug types.

Information on the withdrawal effects of different types of drugs is given in the following Mind online resources:

- Antidepressants
- Antipsychotics
- Lithium and other mood stabilisers
- Sleeping pills and minor tranquillisers.

Information about the withdrawal effects of individual drugs is on Mind's information page for each drug, found in the relevant A-Z on our website (**mind.org.uk**).

How can I tell whether I have withdrawal symptoms or my mental health problem is coming back?

Symptoms caused by drug withdrawal	Symptoms caused by relapse
 usually happen very soon after you start to come off. This is related to half-life – in a drug with a long half-life, withdrawal effects will be delayed by as much as two weeks. 	 are delayed, and are not related to the half-life of the drug
 are often different from anything you have had before 	 are the same as the symptoms you had before – when you first started the drug
 go as soon as you re-start the drug 	 get better slowly if you re-start the drug
 will eventually subside without treatment if you don't re-start the drug 	 continue indefinitely without other treatment

Switching drugs to help withdrawal

If you are taking a drug with a short half-life and having problems with withdrawal symptoms, it may be possible for you to switch to a related drug with a long half-life, which should be easier to come off. You will need the help of a doctor to switch drugs because your prescription will need to be changed.

Tranquillisers and sleeping pills

The benzodiazepine tranquilliser with the longest half-life is diazepam (Valium). If you are coming off one with a short half-life (such as temazepam) you could switch to diazepam.

Some people also use diazepam to help come off the 'z' sleeping pills, which act in a very similar way to benzodiazepines.

Equivalent doses for benzodiazepines and 'z' sleeping pills

Change to **5mg of diazepam** (Valium) from:

- chlordiazepoxide 15mg
- loprazolam 0.5–1.0mg
- lorazepam 500mcg (0.5mg)
- lormetazepam 0.5-1.0mg
- nitrazepam 5mg
- oxazepam 15mg
- temazepam 10mg
- zaleplon 10mg
- zolpidem 10mg
- zopiclone 7.5mg

Antidepressants

The SSRI antidepressant with the longest half-life is fluoxetine (Prozac). It may be helpful to switch from a drug with a short half-life (such as paroxetine) to fluoxetine and slowly withdraw from that. As fluoxetine takes a little while to build up in your system, some specialists suggest starting it while you lower the dose of the other drug, taking both drugs together for a week or two.

Equivalent doses for SSRI antidepressants and venlafaxine

Change to 20mg fluoxetine liquid from:

- citalopram 20mg
- escitalopram 10mg
- fluvoxamine 50mg
- paroxetine 20mg
- sertraline 50mg
- venlafaxine 75mg

When coming off antidepressants, an alternative to fluoxetine is to switch to clomipramine 100mg/day.

Antipsychotics

Drug switching techniques may be used with antipsychotics but you would need advice from a psychiatric pharmacist or psychiatrist on which drug to switch to.

Half-lives of all psychiatric drugs are given in our comparison tables for each drug type, as well as the Mind information page for each drug.

Lithium and other mood stabilisers

You would need advice from an experienced psychiatrist or psychiatric pharmacist on whether this technique would work for mood stabilisers, and which drugs might be suitable to switch to.

It's possible that you might be advised to switch to antipsychotic medication.

Who can I talk to about my options?

Local support groups

People who have successfully come off medication usually say that the most helpful advice comes from other people who have themselves successfully come off. Look for local self-help, peer support or 'coming off' groups and programmes, which may be run by a local Mind or the Hearing Voices Network for example (see 'Useful contacts' on p.26).

Coming off medication may form part of what's called the 'Recovery approach' to mental health problems. Support in this may be available from Recovery and Wellbeing centres or Recovery Colleges, if you have any in your area.

These groups can help you with the practical side of dose reduction as well as:

- Low self confidence, especially if you have been taking medication for a long time. This may be due to your mental health problem or the side effects of the drug.
- Helping you decide to try coming off, and then stick to it. You may feel quite anxious about whether you will actually be able to manage without your medication, for example.
- Understanding the withdrawal effects and how you might be feeling.

Mental health professionals

Ideally the best person to talk to about stopping or continuing your medication would be your GP or psychiatrist. However, some doctors are reluctant to agree to withdrawal. They may not have much experience or knowledge about the best way to go about it.

Guidance published for doctors tends to suggest that drug withdrawal is easier and can be done more quickly than is often the case. But if you want to change your prescription in order to help you come off, you will need to discuss this with the doctor or nurse who writes your prescriptions to get their agreement.

If you are taking more than one drug, you need to check with a professional (such as a pharmacist) to see whether altering the dose of one will affect the action of another. If you come off one drug, the doses of others may need adjusting. If you are planning to come off more than one drug, you may also need to discuss which drug to come off first.

You might also find help is available from a local drug dependency team. Although you may not feel comfortable using a service primarily aimed at street drug users, the actual process of coming off is not very different.

My GP took the possibility of withdrawal symptoms very seriously. He gave me the confidence that I could manage the reduction myself and helped me with practical issues about how a very gradual reduction of medication can be administered.

Online support groups

You may find useful support and information online – particularly for withdrawal from SSRI antidepressants and benzodiazepines. There is less information on coming off antipsychotics or mood stabilisers.

Always remember that there is a lot of unreliable information on the internet. Try to use websites from well-known sources; don't rely on opinions from personal posts. See the Mind resource *How to stay safe online* for more information. Some support websites are also listed under 'Useful contacts' on p.26.

Whatever you do, whether you choose to stay on your meds or come off them, DON'T go through it alone. You might feel alone at times, but there is an intricate web of people who are so connected to you, you just have to reach out to them.

What other treatments might be helpful?

Talking treatments

You may want to try a talking treatment to talk through feelings such as:

- anxieties about whether you will be able to manage without medication
- re-adjusting to your feelings your medication may have suppressed your emotions and creativity, so you have to learn to cope with them in other ways

• changes in your relationships, especially if people close to you are unhappy with your decisions.

You should be able to get a referral for a talking treatment from your GP or they may be available locally, either privately or through local support groups.

Arts therapies

Art, music, dance, drama or writing can all be very helpful and supportive ways of expressing your feelings, as well as being very enjoyable. There may be groups in your area or you may prefer to work alone. Groups may be quite informal or may be run by qualified therapists.

For formal therapy, you may be able to get a referral to an arts therapist through your GP or mental health team. See Mind's *Arts therapies* resource for more information.

Complementary and alternative therapies

Some GPs may prescribe exercise for depression, and some have other complementary therapies available, such as acupuncture.

However, in some areas you may have to find and pay a qualified practitioner for this kind of help (see Complementary and Natural Healthcare Council in 'Useful Contacts' on p.26).

You may also find relaxation classes, meditation, yoga, massage and aromatherapy available locally.

How can friends and family help?

This section is for friends and family of someone who is thinking about coming off medication.

As a concerned friend or family member, you may be quite anxious about your friend or relative becoming ill again if they tell you they want to come off their medication.

Your caution may be understandable if, for example, you have been involved in difficult decisions to have them assessed and sectioned under the Mental Health Act 1983. You may have been very relieved to see them coming out of hospital more stable on medication, and do not want to see them distressed again.

You may need them to be very clear about how things have changed for them since then, why they want to stop the medication, and what other forms of support or treatment they are intending to use if they come off the drugs.

The following are some ways you can help them, and also gain a better understanding of how they are feeling and what they are trying to achieve:

- talk to them about why they want to stop their medication this will help them feel listened to, and also help you appreciate how important it is for them
- ask them how they are planning to do it
- be prepared to tell them if your shared past experience of withdrawal means that you think they are being unrealistic
- ask them how you can help
- help them to find support from other people who have done the same thing, or from their doctor or other health professional
- offer to go to appointments with them, if they would like you there

- join them in a new activity, if they ask you, or ask them to join you in one
- help them to work out reduced doses
- be supportive if they find the withdrawal process difficult, and make allowances if they are struggling with physical withdrawal symptoms or with feeling emotional
- allow them to make their own decisions and learn from their mistakes
 be prepared to take some risks with them
- be positive if they decide to change their plans.

Useful contacts

Battle Against Tranquillisers (BAT)

0844 826 9317 web: bataid.org

Information and support for those coming off tranquillisers and

sleeping pills.

benzo.org.uk

web: benzo.org.uk
Information on benzodiazepine
and z-sleeping pill addiction and
withdrawal, with detailed dosing

schedules.

Bipolar UK

0333 323 3880

web: bipolaruk.org.uk Support for people with bipolar disorder, including a network of self-help groups.

British Association for Counselling and Psychotherapy (BACP)

01455 88 33 00

web: itsgoodtotalk.org.uk Details of local counselling and psychotherapy practitioners.

Complementary and Natural Healthcare Council (CNHC) 020 3178 2199

web: cnhc.org.uk Register of regulated complementary therapists.

Elefriends

web: elefriends.org.uk
A supportive online community
where you can talk openly about
your mental health.

eMC

web: medicines.org.uk Patient information leaflets and summaries of drug characteristics.

Hearing Voices Network

web: hearing-voices.org
Self-help groups for those who hear

voices.

Mad in America

web: MadinAmerica.com
Critical articles about different
aspects of psychiatric medication,
including information on coming off.

No Panic

0844 967 4848

web: nopanic.org.uk Support and information for people with anxiety problems.

Rethink Mental Illness

0300 5000 927

web: rethink.org

Advice, information and support groups for people with mental health problems.

ricaiar problems

Seroxat & SSRI User Group

web: seroxatusergroup.org.uk For people who are taking or withdrawing from paroxetine (Seroxat).

Surviving Antidepressants

web: survivingantidepressants.org Peer support online for coming off antidepressants.

The Icarus Project

web: theicarusproject.net American project which publishes the *Harm Reduction Guide to Coming off Psychiatric drugs* on its website.

Turning Point

web: turning-point.co.uk Recovery services for people with substance misuse problems and mental health issues.

Further information

Mind offers a range of mental health information on:

- diagnoses
- treatments
- practical help for wellbeing
- mental health legislation
- · where to get help

To read or print Mind's information booklets for free, visit mind.org.uk or contact Mind Infoline on 0300 123 3393 or at info@mind.org.uk

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