

Handy Guide Coming off mental health medicines

What the problem is:	Why it is important to you:	How you can help yourself:
<ul style="list-style-type: none"> Medicines can get you well and keep you well But you might not want or need to take them for ever 	<ul style="list-style-type: none"> Coming off too soon, too quickly or even sometimes at all means your symptoms could come back 	<ul style="list-style-type: none"> Know the pros and cons of stopping Make any changes slowly with support Only make one change at a time It may be a change in dose does what you want Get advice from a health professional you trust

Very few people actually want to have to have to take medicines every day, but many people do e.g. for diabetes, high blood pressure, low thyroid, epilepsy, arthritis, Parkinson's Disease, heart problems and so on.

People take them to help control the symptoms or problems. This then helps them get on with their lives.

Everyone needs to decide what are the pros and cons of taking a medicine e.g. the risks of taking medicines and the risks of becoming unwell again if the medicine is stopped.

**This is not a definitive guide.
It's not even completely scientific.
These are, however, ideas, views and thoughts gathered together over many years.
The aim is to help you have a meaningful discussion with your health professionals.
This is a really important decision for you.**

Some reasons you may want to come off a medicine

- You may feel that the medicine is no longer be needed – your life may have changed, your environment has got better, relationships have got sorted out and you now less stress
- It might not have helped much, or even made things worse
- You are getting side effects
- You have concerns about long-term side effects
- Fear of addiction or dependence to the medicine
- Not being able to take something else that interacts with it e.g. pain killers
- You're too unwell to remember to take a medicine regularly or reliably
- You think you're taking too many medicines
- You're pregnant or want to breastfeed
- The cost
- The medicine has been withdrawn, is not available in UK, or no one will prescribe it for you.

Some of the advantages and disadvantages of coming off a medicine

What are some of the advantages of coming off a medicine?	What are some of the disadvantages of coming off a medicine?
<ul style="list-style-type: none"> • No side effects (short-term or long-term) • No need to collect medicines monthly or have an injection • No stress of trying to remember to take medicines every day • Being better able to drive (e.g. if the medicine is making you feel sleepy) • Relationships might improve if the medicine is making you sleepy • Less stigma or peer pressure of 'taking medicines' • Feeling better in yourself because you're managing without medicines • To find out whether the medicine was working for you or not – if you get unwell again at least you'll know it was working • To save the cost of the prescriptions. 	<ul style="list-style-type: none"> • The risk of becoming unwell again and what might then happen e.g.: <ul style="list-style-type: none"> ○ Effects of the symptoms on your relationships e.g. conflict with, and upsetting, your family and friends ○ Effects on your work (either getting or keeping a job) ○ Effects on you e.g. the distress of getting unwell again, and the need to start treatment again. You might actually end up needing more medicines than you would have had if you'd carried on • The possibility of having to go into hospital or seeing the crisis team again because you're having a crisis or are unwell again • Your GP getting frustrated if you get unwell again having not followed his or her advice • Getting some withdrawal or discontinuation effects • Symptoms coming back if you stop too quickly.

You might want to add any other advantages or disadvantages important to you in the spaces above.

If you think we've missed any advantages or disadvantages then please let us know (via admin@choiceandmedication.org.uk) and we'll add them to the lists to help other people.

How can I work out the possible risks of coming off a medicine?

Have a look at this table on the next page and tick the boxes for the nearest answer that matches you. Then add up the number of ticks in column, multiply it by 1, 2, 3, or 4 and then add up the total to get your score.

Some questions to help you make a decision about coming off a medicine

Stability (how stable you have been recently)				
I have been:	<input type="checkbox"/> Stable for many years with no symptoms	<input type="checkbox"/> Stable for a couple of years or just had a few wobbles	<input type="checkbox"/> Stable for about a year	<input type="checkbox"/> Unwell in the last year
How often I have been unwell:	<input type="checkbox"/> I've only been unwell once before	<input type="checkbox"/> I've been unwell a few times before	<input type="checkbox"/> I've been unwell quite a few times and/or had quite a few wobbles	<input type="checkbox"/> I've been unwell lots before and/or episodes may be getting closer together
Severity (how badly unwell you have been)				
In the past when I've been unwell:	<input type="checkbox"/> I've been managed and supported by my GP	<input type="checkbox"/> I've been managed as an out-patient	<input type="checkbox"/> I've been an in-patient or needed the crisis team	<input type="checkbox"/> I've nearly been sectioned or have been sectioned
Support (from family, friends, carers)				
I have:	<input type="checkbox"/> Good family/carer support	<input type="checkbox"/> Reasonable family/carer support	<input type="checkbox"/> Some family/carer support	<input type="checkbox"/> Very little or no family/carer support
Relapses (getting unwell again)				
If I start to get unwell again it happens:	<input type="checkbox"/> Slowly over several months	<input type="checkbox"/> Gradually over several weeks	<input type="checkbox"/> Quickly over a week or so	<input type="checkbox"/> Quickly over a few days
If I start to get unwell again:	<input type="checkbox"/> I notice early on	<input type="checkbox"/> I notice but often not how badly	<input type="checkbox"/> I don't notice until it's got quite bad	<input type="checkbox"/> I don't notice until it's too late
	<input type="checkbox"/> Other people notice early on and say so	<input type="checkbox"/> Other people notice and don't say but would if I asked	<input type="checkbox"/> Other people don't really notice or wouldn't say	<input type="checkbox"/> Other people don't notice at all
	<input type="checkbox"/> I listen to, and believe, other people and seek help early on	<input type="checkbox"/> I hear other people and might be willing seek help early on	<input type="checkbox"/> I don't listen to what other people think	<input type="checkbox"/> I don't listen to what other people think and wouldn't want any help anyway
Medicines (the one(s) you are taking for the mental health problem)				
Long-term side effects:	<input type="checkbox"/> I get side effects and find them hard to cope with	<input type="checkbox"/> I get some side effects which I can just about cope with	<input type="checkbox"/> I get some side effects but I can cope with them	<input type="checkbox"/> I don't seem to get any side effects at all
Do medicines help?	<input type="checkbox"/> I'm sure the medicine doesn't help. Nothing at all has got better since I started it	<input type="checkbox"/> I'm not sure if the medicine(s) help me	<input type="checkbox"/> I'm fairly sure I started to get better within a month or so of the medicine starting	<input type="checkbox"/> I started to get better within a month or so of when the medicine(s) started
If I've tried stopping medicines before:	<input type="checkbox"/> I stopped easily with no problems	<input type="checkbox"/> I stayed well for a year or so	<input type="checkbox"/> I became unwell in a few months	<input type="checkbox"/> Became unwell again very quickly
If I then restart medicines:	<input type="checkbox"/> I get well again in a few weeks	<input type="checkbox"/> I get well again in a few months	<input type="checkbox"/> It took months to start to feel better	<input type="checkbox"/> It took much longer to feel well again
Consequences (what would happen if you became unwell again)				
If I get unwell again:	<input type="checkbox"/> My GP should be able to help me	<input type="checkbox"/> I'll probably end up as an out-patient	<input type="checkbox"/> I'll probably end up with the crisis team	<input type="checkbox"/> I'll probably end up as an in-patient
If I get unwell again it would:	<input type="checkbox"/> Really only affect me	<input type="checkbox"/> Affect me and my family and friends	<input type="checkbox"/> Affect me, my family and lots of others	<input type="checkbox"/> Be a disaster for me and my family, friends and/or work
Risk factors (see the "What will affect the chances of <my condition> improving", especially the "Things that may lead to a poorer outcome (a poor prognosis)" on our C&M website for the symptoms you are taking the medicine for)				
I've looked at the list and:	<input type="checkbox"/> I haven't got any extra risk factors	<input type="checkbox"/> I have a few minor risk factors	<input type="checkbox"/> I have a few risk factors	<input type="checkbox"/> I've got lots of extra risk factors
Number of ticks	x1 = a	x2 = b	x3 = c	x4 = d

Your relapse risk score is: $a + b + c + d =$

Score	Comment
	(Caution: these scores aren't scientific and some items may well be more important to you than others)
50-60	You are at very high risk of becoming unwell again. So, you really should not even think about stopping the medicine or medicines
21-49	The higher the score the higher the risk of becoming unwell again. It needs more thought and advice. Ticks in the right hand columns are especially important.
15-20	Lowest scores possible - well worth trying to think about gradually come off a medicine

You might want to get someone you trust to cross-check your answers with you. They may have different views and experiences if they have known you when you were unwell.

What else might I need to think about before stopping a medicine?

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| <ul style="list-style-type: none"> Have you tried coming off before? If it didn't go well, it could be that you tried too quickly and coming off more slowly may be more successful An alternative to stopping completely can be reducing the dose for a good length of time | <p>(e.g. for 6-12 months) then thinking about it again. With antidepressants the rule is that "the dose that got you well keeps you well". That may not be true for some antipsychotics and mood stabilisers, which may need much longer.</p> |
|--|---|

Does it matter when to try?

Choosing the right time to start reducing doses is vital. Coming off a medicine when you are stressed, have been unwell or have changed care teams is less likely to be successful.

Questions to ask yourself	Examples	What to think about
How stable is your life at the moment?	Are there changes in e.g. housing, relationships, work, family?	Try to sort out any of these problems first.
Are there any changes or events coming up that might be stressful?	e.g. anniversaries, Christmas, moving home, or anything that has stressed you in the past?	Think about waiting until after these have passed.
Have you recently been unwell or changed care teams or doctor?	Have you just come out of hospital? Have the care services been reorganised?	You should think about not making any changes until after these have stabilised again.

How do I go about stopping safely?

There are two Golden rules:

1. Talk to your health professional first

- e.g. your doctor, pharmacist, case manager or anyone from the mental health services
- They should know your history and will know other people with similar problems. They will be able to advise you about what may help you.

2. Go slowly - whatever you do, do it gently

- There is no single right way of coming off a medicine, but lots of wrong ways
- As a general rule, the longer you have been on a mental health medicine the longer you should take coming off it e.g. over several months or even years

- If you reduce your dose of a medicine, leave it at least 3-4 weeks (or much better 2-3 months or even longer) before the next drop in dose.

Think of it as a bit like stopping a car suddenly without your seat belt on – you *can* do it quickly, but it can hurt and can damage you and others around you. It's much better to slow down gently. Many of the people seen by crisis teams have stopped their medicines too soon or too quickly.

Why should I come off a medicine slowly?

You should be gentle with your brain. It's the only one you've got, it's unique and it's delicate. Reducing your dose by about a quarter every month and taking a bit longer with the last few doses is one plan. We have some fact sheets on coming off SSRIs, based on dose and how long you've taken it.

The advantages of stopping slowly are:

- Less risk of relapse from stopping too quickly
- Less risk of confusing your old symptoms coming back with any new discontinuation effects from the medicine
- Less risk of getting withdrawal symptoms
- If the symptoms begin to reappear you can deal with them quicker
- Even if your symptoms do come back big-time then you can restart or go back to the original dose. The relapse won't be as bad as if you had stopped suddenly
- The longer you've been on a medicine, the slower you should come off it
- Stop slowly to give your brain time to adjust. If you're too quick, you'll never know if you may have been able to cope if you'd had time to adjust.

What else can I do to reduce the risks?

- **Only stop one medicine at a time**, or you won't know what the effect of each medicine is or which one might be the important one
- Make sure you have as much support as possible from family, carers and friends if you become unwell again
- Make a list of things that can trigger being unwell or stress you. If these start to mount up get extra support from relatives, friends or health professionals. Don't be afraid to ask
- If you start to feel rough or are getting symptoms go back to the dose you were on before your last reduction and restabilise on this for a month or so before trying again
- If you find you can reduce the dose, but can't stop completely, then do **not** see this as a failure. Medicines **do** work and perhaps you now know the lowest dose that works for you
- If you are adjusting your dose carefully you

may find it useful to buy a tablet splitter (for some medicines) or have a liquid (if available) and use oral syringes to get an exact dose of it

- Be patient – you've got a lot to lose by doing it too fast.
- Think about making an Advance Directive while you are well – this will help other people know what you'd not like if you can't communicate as well as usual. These can include symptoms, who to contact in a crisis, how people can help you, and any treatments you would not want
- Look after yourself, more so your physical health e.g. get enough exercise, sleep, and good food
- Make sure any physical health problems are being looked at **and** treated
- Make sure you have other support in place if you need it e.g. friendships, support groups
- Consider stopping or reducing alcohol and any other recreational drugs e.g. smoking.

What should I do if I think I have withdrawal or discontinuation symptoms?

- Keep some medicines in reserve in case you need to start again or go back up a dose, or you feel a wobble coming on
- You can take a small dose of the medicine again:
- If the symptoms go away within a few hours they may well be discontinuation or withdrawal symptoms. If this happens go back up to the dose you were on before the last dose drop and settle on that before having another go
- If they don't go away then something else is happening
- Either way, it's best to contact your health professional.

What is the bottom line?

Think – do you think that taking a medicine helps you get on with your life?

If it does not, you may decide the benefits of gently stopping are worth the risks.

If it does, you may decide stopping and the risk of relapsing is too great at the moment.

Treat your brain with respect. Treat the medicine with respect.

We also have a shorter version of this fact sheet

The small print: This leaflet is to help you understand more about stopping medicines. Do not share medicines with other people.
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Handy fact sheet Coming off antidepressants

Antidepressants can help depression but also many other symptoms as well e.g. OCD, PTSD, anxiety disorders, some eating disorders, panic and seasonal affective disorder. This fact sheet applies to all of these not just depression. *You must first read our fact sheet about "Coming off mental health medicines" which covers the pros and cons, the risks and timing for you.*

What the problem is:	Why it is important to you:	How you can help yourself:
<ul style="list-style-type: none"> • Antidepressants can keep you well • But you might not want or need to take them forever 	<ul style="list-style-type: none"> • If you stop too soon or too quickly your symptoms could come back • You could also get discontinuation symptoms 	<ul style="list-style-type: none"> • Know the pros and cons for you of stopping • Get help from a health professional • If you make any changes make them slowly, and with support

What are the problems with stopping antidepressants?

There are two main problems with stopping, or reducing the dose of, an antidepressant:

1. The symptoms coming back:
 - They could start to come back in 2-3 weeks but they may take longer e.g. months
 - If you stop too quickly (e.g. over 1–7 days) you are **more likely to become unwell** again than stopping slowly (e.g. over 14 days or longer). It may happen quicker.
2. Getting discontinuation or withdrawal symptoms:
 - These symptoms usually start within about 1–4 days of stopping or reducing the dose
 - They start to wear off within 1–6 hours if you restart the medicine
 - They can even occur with missed doses
 - About a third to half (33-50%) of people get these discontinuation symptoms.

- ☞ The problem with the word 'withdrawal' (rather than 'discontinuation') is that it implies that the symptoms are the same as those from addictive drugs such as alcohol, caffeine, heroin or nicotine
- ☞ Antidepressants do **not** cause craving or a reward so are not the same as these addictive drugs
- ☞ See the next page for more about this.

How will I know if I have antidepressant discontinuation symptoms?

They vary between medicines but can include:

- Feeling dizzy, 'electric shocks' in the head, not sleeping, stomach cramps, flu-like symptoms
- Having vivid dreams or a headache
- Feeling lightheaded, sick and tired.

We're not sure why they happen but are more common with medicines that boost brain serotonin.

SSRIs

- Fluoxetine (low risk): discontinuation symptoms are unlikely, even if stopping for a week
- Paroxetine (highest risk): About 10% (1 in 10) people get some marked symptoms. You may need to restart and stop more slowly
- Other SSRIs (low risk); e.g. citalopram, escitalopram and sertraline.

SNRIs (e.g. duloxetine and venlafaxine)

- Duloxetine (higher risk): about 2 in 3 people get some symptoms if they stop suddenly
- Venlafaxine (highest risk): discontinuation symptoms seem to be more common, even if stopped slowly.

Tricyclics (medium/high risk) (e.g. amitriptyline, clomipramine, dosulepin, lofepramine, imipramine)

- Other symptoms can include feeling restless and diarrhoea.

Others: Agomelatine, bupropion, mirtazapine, reboxetine, moclobemide, vortioxetine, St. John's wort:

- Very little has been reported (low risk).

If you get uncomfortable discontinuation symptoms when stopping, start again at your previous dose and cut down more slowly. Your local pharmacist can help you with this. See our website for a fact sheet about stopping medicines.

How long before the symptoms start?

- For most antidepressants they usually start in 2-4 days after the last dose

- They can start as soon as 24 hours after stopping paroxetine or venlafaxine
- For fluoxetine it may be after 2-4 weeks.

How long do the symptoms last?

- This varies from person to person
- Usually they can last for up to a couple of weeks and then gradually fade away
- They can last a lot longer e.g. several months with paroxetine and venlafaxine in some folk.

Does this mean antidepressants are addictive?

No. But it shows that antidepressants have effects on the brain. You need to treat both the medicine and your brain with respect.

A drug needs four effects to be truly addictive:

1. Tolerance - need more to get the same effect.
2. Withdrawal symptoms - when stopping.
3. Craving – you must want to take it.
4. Reward - you must know within 1-2 hours that you've taken it. No one is addicted to something they don't know they've taken!

The classic drugs of addiction e.g. alcohol, heroin, painkillers, cannabis, nicotine and caffeine, have all four of these. Antidepressants do **not** lead to tolerance, craving, nor a reward. But you can get symptoms if you stop them suddenly, like some medicines for hypertension and stomach ulcers.

It seems that about 1 in 6-7 people (15%) get at least one discontinuation symptom from stopping an antidepressant, with about 1 in 45 (about 2.5%) getting severe symptoms (see review of 21,000 people in <https://pubmed.ncbi.nlm.nih.gov/38851198>).

Who is more likely to get antidepressant discontinuation symptoms?

You are more likely to get these symptoms if you:

- Had a lot of side effects when you started
- Are taking paroxetine or venlafaxine
- Get symptoms if you miss a dose or two
- Stop suddenly e.g. in under a week
- Have been taking a high dose
- Have taken them for a months or years
- Are unlucky.

What should I do if I think I get discontinuation symptoms?

You can do a simple test by restarting the antidepressant at about half your last dose:

- If the symptoms start to go away in 1-6hrs then they're probably discontinuation effects
- If they don't start to go away in 1-6hrs, then they are probably caused by something else.

What to do next if you get symptoms:

1. Starting again, then reduce the dose more slowly, probably best over about 12 weeks;
 - Try a drop every few weeks, making sure you settle down before trying the next drop
 - Use lower strength and half or parts of tablets to get small dose drops
 - For many of the antidepressants you can switch to a syrup. You can then use a syringe to take ever smaller doses.
2. Switch to fluoxetine - then reduce slowly as fluoxetine has very few problems.
3. Tough it out by treating the symptoms e.g. sickness, poor sleep, headache etc.

☞ Ask to see our fact sheets on coming off citalopram, escitalopram, fluoxetine, sertraline or paroxetine, based on what dose you are on and how long you've taken it

☞ Also ask for advice from your health professional.

How can I help myself?

- Do not miss any doses or run out of medicines
- Don't forget to pack some when going on holiday or away from home
- Carefully plan coming off the antidepressant with your prescriber
- Don't stop antidepressants suddenly – come off them slowly to give your brain time to get used to the change
- If you want to stop, make sure your relatives and carers know what is happening just in case you get any symptoms.

☞ If you think you have had discontinuation symptoms before then tell your prescriber to be aware of this

☞ Ask for help, but take a copy of this as not every health professional has heard of these effects.

We also have a shorter version of this fact sheet

The small print: This leaflet is to help you understand more about coming off antidepressants. You **must** first read our fact sheet about "Coming off mental health medicines" which covers the pros and cons, the risks and timing for you.

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