

## How do I manage my epilepsy?



There are many sides to managing epilepsy: looking at the type of seizures you have and how they affect you, whether you take medication and if it controls your seizures, and how epilepsy affects you generally in all aspects of your life.

Managing epilepsy usually involves a specialist (a neurologist or epilepsy specialist) and your GP. You might also have an epilepsy nurse and other doctors. But you also have an important role in managing your epilepsy. This includes being involved in discussing, and making decisions about, your epilepsy and its treatment. You may also want to think about keeping a diary of your seizures to discuss with your clinician.

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## What is monitoring medication?

Part of managing epilepsy is looking at the practical things: if you have seizures you might want to try and get them better controlled (stopped), or if your seizures are well controlled but you have side effects from the medication, you might want to know what the options are for changing this.

Managing epilepsy involves *monitoring* (keeping records of) what medication you take, how it affects you, when you have seizures, and what they are like. This is a way of seeing if your treatment is working.

## Medication

The aim of epilepsy treatment is to stop seizures happening. For most people, seizures are controlled with anti-seizure medication (ASM). The aim of treatment with ASM is to stop the seizures with the smallest dose of the fewest number of ASMs, and with the least side effects (called optimal therapy).

So taking medication involves getting the right balance of the dose, seizure control, and side effects. This varies from one person to another.

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## Doses and concentrations

When you take ASM, you take a particular number of tablets, and each tablet is a certain strength. The strength is a measure of the amount of the active ingredient in the tablet. Adding the number of tablets and their strength together gives you the dose that you take every day. For example, taking two 200mg tablets twice a day is a dose of 800mg per day. The dose is a measurement of how much ASM you take.

How well a drug works depends on it getting to the part of the body it needs to work on (the site of action). How effective it is, and how much is getting to the site of action, is found by measuring the amount in the blood (rather than just the dose that you take). This is called your 'drug concentration' or 'blood level' and is found by doing a blood test.

The dose of ASM you take affects the concentration that is in your body, but dose and concentration are not the same thing. Our bodies are all different and we each react to, and metabolise, drugs differently. How we metabolise drugs is affected by our age, our gender, any other conditions we have, and any other medications we take. So if five people all take the same dose of the same drug, they will not necessarily have the same amount of the drug in their body.

If you have epilepsy, how it is managed is very important. This factsheet is about how doctors monitor epilepsy, looking in detail at monitoring medication and therapeutic drug monitoring.

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## Reference ranges and individual therapeutic concentrations

'Reference ranges' and 'individual therapeutic concentrations' are terms that doctors might use when talking about epilepsy treatment and ASM.

The reference range (RR) is a range of drug concentrations in the body within which a drug is thought to be most likely to work. Under the lower end of the range, the ASM is not likely to control seizures and above the upper end, toxic effects are likely. This range is composed using data from a range of people. However, individuals vary in how they respond to treatment.

Some people will get seizure control under the lower limit, which suggests that a lower limit is not a useful measure (only that seizure control is less likely at lower concentrations).

The individual therapeutic concentration (ITC) is the drug concentration which has the best result for a particular individual. Individuals will have ITCs below, within, or above the reference range.

Once the person's seizures are controlled, their ITC can be measured from blood samples taken over a period of time, for example, at regular clinic appointments.

### What do blood levels show?

Blood levels may be measured after you have been taking a new, or increased dose of an ASM for a few days. This is called a 'steady state' because the blood test result will be a reliable measure of their concentration.

### How are blood levels measured?

During a blood test the blood is analysed and the concentration of drug in it is calculated.

The best time to have a blood test is just before your next dose is due and you have the least amount of drug in your body. This is called the 'trough level'. Although this is the ideal time, it is not always possible: if you take your drugs at 7am and 7pm, it is hard to get an appointment just before 7am or 7pm.

If the doctors know when you took your last dose they can try to work out how near your trough level you are when you have a test.

Note: In some cases, for example children, people with a learning disability, or people who do not like having blood taken, saliva levels can be checked instead of blood. This is a simple test and the drug levels are measured by taking a saliva (spit) sample. This test is useful for several ASMs including carbamazepine, clobazam, eslicarbazepine acetate, ethosuximide, gabapentin, lacosamide, lamotrigine, levetiracetam, oxcarbazepine, phenobarbital, phenytoin, primidone, vigabatrin and zonisamide.

### What is therapeutic drug monitoring?

Therapeutic drug monitoring (TDM) means using blood levels to individualise epilepsy treatment to get the best seizure control with the least side effects for each person. Measuring the amount of drug in the blood is a way of looking at the link between drug concentration and its effect on seizures (whether it stops seizures or causes side effects).

It is better to measure how effective an ASM is using concentrations in the blood rather than looking at the dose taken, because not all of the ASM taken (the 'dose') will get into the blood or have an effect on seizure control.

How useful TDM is depends on the reason it is being done (see below), how the ASM is absorbed in the body, and how well it works.

### When could TDM be useful?

Although TDM is not always done, there are many situations when it can be useful in managing epilepsy.

- **When medication is started.** Usually, when ASM is started, it is taken in small doses and gradually increased until it controls the seizures. Often the ASM dose is within a range of doses that is thought to be effective for that particular ASM. This range shows the likely effective dose for 'anyone' and does not predict what dose is likely to be best for a particular individual.

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TDM helps to work out an expected effective concentration for an individual, depending on their individual characteristics (such as age, gender, and any other medical conditions).

- **When epilepsy is controlled with ASM.**  
When an individual's seizures are controlled, TDM shows the ideal ASM concentration (their individual therapeutic concentration or ITC) to stop their seizures.
- **When someone who has been seizure-free starts having seizures again.**  
If the person's ITC is known (see above) and seizures start again, their blood levels can be checked. If their blood level is at the ITC, the seizure was not caused by a problem with the medication. If the blood levels are not at the ITC this could be the reason why the seizures have started. Blood levels can change for many reasons including starting other medications, developing another condition, or with age.
- **When someone is still having seizures.**  
ASM works best when it is taken regularly: the right dose at regular times. There are many reasons why someone might not take their medication regularly and TDM can be used to see if this is the reason why they are still having seizures. TDM can also look at whether the person is having seizures because they are not taking enough ASM or because their body is not reacting to the ASM as expected.
- **When different forms of ASM are used.**  
If ASM is changed from one form to another (for example from a brand to a generic version) this can affect drug concentrations and seizure control. TDM before and after changing ASM can help to see if the new form is affecting the concentration in the blood.

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- **When someone takes more than one ASM.**  
If someone has seizures that do not respond well to taking one ASM on its own, they may be prescribed more than one ASM.

Some ASMs interact or interfere with each other, and this can affect how well they work. If it is likely that one or more of the ASMs need to be increased because of interactions, TDM can be used to help guide the increases in dose so that the concentrations in the body are kept stable. Also, if the person has side effects or toxicity, TDM can show which ASM is causing this.

- **To diagnose toxicity.**  
If someone starts to show signs of drug toxicity (such as being very drowsy or dizzy), blood levels can show at what concentration they react badly to the drug. TDM also helps to show toxicity in people who might find it difficult to explain how they are feeling (such as young children or people with a learning disability).
- **When someone has other medical conditions or medications.**  
Having other medical conditions, or taking other medications, can affect how ASM is metabolised. Other medications might also interact with ASM. Because this can affect ASM levels, TDM can be used to manage any changes to ASM that might be needed to keep the drug concentrations stable in the body.

## Special situations

There are some situations where it is likely that someone will need changes to their medication:

### Children

How drugs are absorbed and work in a child's body change as they get older. Generally, a child's body will metabolise (break down) ASMs quicker than an adult's. This means that children may need to take more of an ASM (based on their body weight) than adults because the ASM doesn't stay in their body as long. Therefore it can be hard to predict how much ASM a child will need, and how this will change as they get older.

Also, side effects can be different, and harder to see, in children than in adults. TDM can help to work out what amount of ASM is needed for an individual and check to see if side effects are happening.

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## Pregnancy

Pregnancy will affect how drugs are metabolised. TDM can help to work out what effect pregnancy may have on a woman's ASM and what changes to her ASM might be needed to control her seizures. Also, when a woman who is pregnant takes ASM, her baby is exposed to some of the drug. Most women with epilepsy will have a normal pregnancy and labour, and over a 9 in 10 (90%) chance of having a healthy baby, but TDM can be useful to keep ASM levels to a minimum to reduce any exposure to the baby.

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## Older adults

Age can affect how well drugs are metabolised, and this varies from one person to another. As people get older they may develop other conditions, take other medications, or become more sensitive to the effects of medication.

Older people may develop memory problems and so may forget to take ASMs, not take enough, or take too much. All these things can affect drug concentrations, and seizure control. TDM can help to work out the best dose to reduce side effects.

Also, if seizures happen, TDM can help to work out whether this is because they are not taking the medication regularly or because their body is not absorbing it.

## Should everyone be monitored?

Once epilepsy is stable, ITC needs to be established. It is advisable that people have their ITC established and monitoring should be part of their annual review. Currently not everyone has TDM and some people only have TDM if they are on phenytoin (because it is well known that this ASM is unusual in how it distributes around the body, and TDM can help to check this).

If you have any questions about whether you should have TDM, talk to your GP or neurologist.

Facilities are available in the Chalfont TDM Unit and in hospitals across the UK.

Visit [epilepsysociety.org.uk/therapeutic-drug-monitoring](https://epilepsysociety.org.uk/therapeutic-drug-monitoring)

## Summary of terms

**Active ingredient** – the chemical part of a drug that makes it work.

**Blood levels** (also called plasma or serum concentrations, or levels) – a measure of how much ASM there is in the blood, plasma or serum. Plasma is the fluid part of blood that carries blood cells and clotting-agents (that help blood to clot). Serum is the part of plasma without the clotting agents.

**Brand name** – the name of a drug which is given by the company that makes it. The brand does not say what the active ingredient is, and there can be many brand versions of the same generic drug.

**Dose** – the amount of the drug that is taken, for example as a tablet, each day.

**Generic name** – the name of a drug that tells you what the active ingredient is. All drugs with the same active ingredient have the same generic name. One generic drug can be made by many different companies and can have many brand names.

**Individual therapeutic concentration (ITC)** – the concentration of an ASM which gives the best response in an individual (optimal therapy).

**Metabolise** – breaking down substances, such as drugs, in the body so that they can be more easily removed (excreted) from the body.

**Optimal therapy** – when someone is on the best treatment for them, when their seizures are controlled (stopped) with the smallest dose of the fewest number of ASMs, and with the fewest possible side effects.

**Range** – a scale of something, such as drug concentrations, which has a lower and upper limit.

**Reference Range (RR)** – a range of drug concentrations that are likely to be effective for most people.

**Site of action** – the part of the body where the drug works. In the case of ASM this is the brain.

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**Steady state** – where the drug has been taken for a few days and the blood levels are a reliable measure of the concentration in the body. Steady state usually happens after about five 'half-lives' of the drug (the time taken for the amount of drug in the body to reduce by half). Half-lives vary between ASMs but if the half-life is 12 hours, steady state would happen after 2½ days (5 x 12 hours).

**Therapeutic drug concentration monitoring (TDM)** – the system for monitoring ASM to study the relationship between drug dose, concentration and effect.

**Toxicity or toxic** – when the concentration of a drug causes harmful side effects to the person taking it.

Epilepsy Society is grateful to Frank Quinlivan, Head of Therapeutic Drug Monitoring Unit, Epilepsy Society, who reviewed this information.

**For a printed copy of this information contact our helpline.**

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