

Are you taking your TABLETS?

For many people, anti-epileptic drugs spell freedom from seizures or at least a reduction in their severity or frequency. But not everyone chooses to take them. We investigate why.

Are you taking your tablets? It seems such a simple question. For up to two thirds of people with epilepsy, anti-epileptic drugs (AEDs) are the gateway to seizure freedom and a quality of life that can mean personal independence. Why wouldn't you take your tablets?

Indeed many people are happy with their medication, seeing it as a positive way of managing their epilepsy. Yet a significant number either can't or don't want to take their tablets at some point in their lives, even though they may run the risk of seizures and possible injuries from falls or burns.

Research into medicines adherence, or the decision to take prescribed medication, has been ongoing since the 1970s. A report by WHO – the World Health Organization – suggests that 30-50 per cent of people with long-term health conditions don't take their medicines as prescribed.

But it is a 15-year research programme by Rob Horne, professor of behavioural medicine at the School of Pharmacy, University College, London that has thrown new light on our decision to take the tablets – or not.

'Many people don't take medicines, not because they can't, but because they don't want to,' says Professor Horne. 'We make a decision to take medicines as prescribed, not to take them at all, or more commonly, to take them in a way that suits us, based on our beliefs about the condition and treatment.'

'Two types of belief govern our decision to take or not to take prescribed medicine. Firstly the degree to which we perceive a personal need for the medication and secondly how we

balance this against personal concerns about potential adverse effects.

'People do not blindly follow treatment advice, even from respected doctors or consultants. We evaluate advice and decide whether it is a good idea for us.'

Communication is key. If we are told to take medication our human instinct is to rebel. If the decision to take AEDs is made jointly between ourselves and the health professional, we are far more likely to take the tablets.

There are other influences too: concerns over possible side effects; fear of dependency and addiction; fear that the drugs will accumulate in our bodies and cause harmful long-term effects; fear that the drugs may mask the fact that the seizure wasn't epilepsy at all; reluctance to be defined by a condition – 'If I take the tablets I must have epilepsy.'

At Epilepsy Society, helpline team leader Christine Brock says that when people are diagnosed with epilepsy and prescribed their first AEDs, there is often a lot of information to take in. While the healthcare professional may have talked the person through their medication, the finer detail may have been lost in the overload of information.

'Some people don't realise that they have to take their tablets indefinitely. They think their AEDs are like antibiotics – once you get to the end of your prescribed dose, you stop taking them. Or, once the symptoms have gone away, you no longer need to continue with the drugs,' says Christine.

'A simple explanation of how AEDs work can often help in understanding the importance of taking medication on a regular basis.'

Personal story

Anya Buchan is 21 and studying creative writing at Bath Spa University. She was diagnosed with epilepsy just before her 18th birthday. Here she talks about the highs and lows of taking her medication.

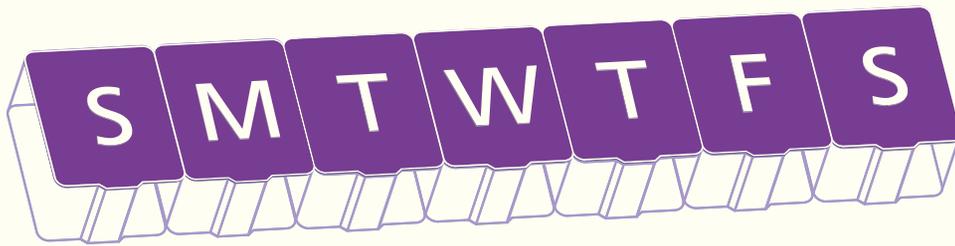
'When I was prescribed levetiracetam my tonic clonic seizures stopped almost instantly. At first this was great because I could start learning to drive again but then the negative side effects started.

'My whole perception of the world changed. It was like the colours were not so bright and I had difficulty feeling excited about anything. I lacked motivation. It seemed as though the medication was driving me and I was a passenger in the back seat.

'Part of me wanted to come off the drugs so I could feel myself again but at the same time I wanted to carry on learning to drive. It's a horrible decision to make. My mum would tell me to keep taking the tablets so that I was seizure free and could live my life, and although I knew she was right I found this really strained our relationship and I could become quite aggressive.

'My GP offered me anti-depressants but I didn't want to take more drugs. Instead I have reduced my dose and have learned to deal with my emotions while still enjoying the seizure freedom provided by the medication. Sometimes I go to my room and cry, then tell myself that I'm just being silly. I try to think positively and find a balance.'





Help taking the tablets

'Take two tablets daily' – the prescription sounds simple but the reality of taking medication on a regular basis is often more complicated than may appear. Day-to-day routines can easily come between us and the medicine cabinet as can memory problems and seizures. But help is at hand. Epilepsy specialist nurse Anthony Linklater explains

Taking medication on a regular basis is fundamental to gaining the best possible seizure control for most people with epilepsy. However, many people with epilepsy do not always take their medication as prescribed, increasing the likelihood of seizures.

But we are now able to offer much greater support in helping people get the most out of their medication and maximise seizure control.

Reminders to take medication come in many different forms and they really can make a difference. At the National Hospital for Neurology and Neurosurgery we piloted a text messaging service for people who had difficulties taking their medication. Almost 50 per cent reported a reduction in seizure frequency with the service and 25 per cent reported fewer visits to A&E.

But establishing the right support is very individual. Here we look at three key areas: developing good routines that will help you remember to take your tablets; medication aids; and digital alerts.

GOOD ROUTINES

- It can help to link taking your tablets with daily routines such as brushing your teeth, eating breakfast, lunch or dinner or even making a drink.
- Placing a post-it note on the fridge as a reminder is a good idea but permanent

reminders can become too familiar and may be missed.

- Try and avoid taking your medication last thing at night as there is no opportunity to remember if you forget.
- Enlist family support or the support of someone close to you to remind you to take your tablets.
- If you know you have problems taking your medication and may be missing several doses, discuss this with your neurologist, GP or epilepsy specialist nurse. Missed doses could be contributing to poor seizure control and this should be addressed before a change in medication is considered.

MEDICATION AIDS

Drug wallets Calendar based drug wallets and pill boxes with days of the week on them are useful for helping you to organise your tablets and provide a visual reminder to take medication. Some wallets have removable compartments so that if you are going out for the day you can take that day's medication with you. Some pill boxes have built-in alarms that alert you when your medication is due. They can also help to identify when doses are missed, which is important to know.

Always check the label or patient information leaflet that comes with your medication. Dispersible tablets that dissolve in water can't be stored

in drug wallets because they react to the air. If you have trouble taking your medication, it is always worth asking your GP or pharmacist whether it comes in an easier form of packaging.

At the end of this article is a list of some companies that sell medication aids and there are plenty more to choose from online.

Blister packs Some people may be able to receive their medication in blister packs prepared by their pharmacist, although this service is not available in all parts of the country. You can always ask for a free Medicines Use Review at your pharmacist when you can discuss your AEDs.

DIGITAL ALERTS

Mobile phones If you have a mobile phone it might be worth setting alarms/reminders for taking your tablets throughout the day.

Epilepsy Toolkit app Epilepsy Society's free app on the iPhone now has an alarm which can be programmed to remind you to take your tablets. You can also record the name, dosage and a picture of your tablets. The Epilepsy Toolkit app can be downloaded at 'App Store' on the iPhone.

Useful addresses

The following organisations and companies offer a range of medication aids for you to choose from. We do not endorse these companies.

www.epilepsysociety.org.uk/shop
01494 601 392
www.dudleyhunt.co.uk
01796 482 105
www.mobilitysmart.cc
0800 567 7222
www.tabtime.com
01270 767 207
www.procterhealthcare.co.uk
01323 417 508
www.yellowcross.co.uk
01252 820 321

Anthony Linklater is an epilepsy specialist nurse at the National Hospital for Neurology and Neurosurgery