



# A bitter pill to swallow?

One would think that obtaining prescription medication for a complex or long-term condition would be a straightforward process – but as **Annie Makoff** discovers, that's not always the case...

**I**t should be easy to obtain a prescription from your GP to deal with an illness or health condition, especially if the medication has been recommended by a hospital consultant or specialist.

Indeed, most people have no

problem accessing prescriptions – that is, after all, the job of the GP, or should be.

However, according to Dr. Richard Grünewald, a consultant neurologist at the Royal Hallamshire Hospital in Sheffield, this is not always the case.

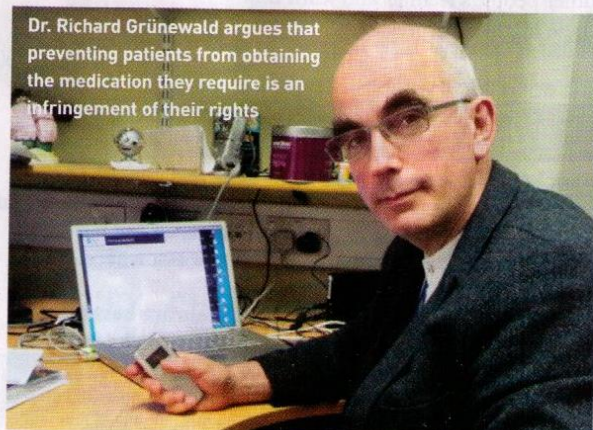
"Many disabled people struggle to get the medication that they need because their GPs are either unwilling to prescribe it, or they make patients call several times a month for their prescriptions" he explains. "I have known GPs who feel it is 'inappropriate' for them to prescribe specific medications, and others who say they don't know enough about the medication to prescribe it safely."

But rather than being an issue of competence among individual GPs, Dr. Grünewald insists it is more to do with the culture of Area Prescribing Committees, which are responsible for

guiding local GPs with medication advice. He sees Area Prescribing Committees as promoting a "doctor-centred approach, rather than patient-centred care."

Refusing to prescribe medication can make life very difficult for someone with a disability. Hospitals generally prescribe one-off treatments, rather than ongoing medication prescriptions. Dr Grünewald believes that fragmenting prescribing and making it difficult for patients to obtain their medication is an infringement of their rights.

"Every patient is entitled to the highest level of service. Disabled people have rights under the Equality Act and really, the NHS has an obligation to go the extra mile to ensure that disabled people get what they need, when they need it," he says.



Dr. Richard Grünewald argues that preventing patients from obtaining the medication they require is an infringement of their rights



my disability, but whenever my consultant recommends a drug for pain control, my GP refuses. They don't seem to deal with multiple impairments, so they refuse any kind of increase and any new medication. It's getting to a point of desperation because my pain isn't being controlled."

London-based Lisa, who has the brittle bone condition osteogenesis imperfecta, has also struggled with obtaining medication. Osteogenesis imperfecta can lead to scoliosis – the

shortening of the spine – and severe digestive problems, making it difficult to eat. Lisa

was prescribed esomeprazole, a 'cleaner, modern drug', by her gastroenterologist, but because the pharmacy didn't stock it she

was put on a different version of the drug instead that made her so ill she was unable to eat solid food for several months.

"I was told that they won't prescribe esomeprazole because there wasn't enough evidence to demonstrate its effectiveness," she recalls. "My GP said the PCT just wouldn't pay for it when generic versions of the drug are available



instead – even though the other versions made me really ill."

Lisa was eventually put on different medication that she believes simply isn't as effective as the drug her gastroenterologist originally suggested. "I have indigestion constantly and the pain is so bad I can hardly move. My breath frequently tastes of vomit and I often end up with a nose full of stomach acid, which doesn't help my knackered sinuses."

### "It's crazy..."

Lisa's struggle to get the right medication for her condition is not unusual. Dr Grünwald recalls several patients who have been refused drugs by GPs.

"I've had patients where GPs have refused to prescribe a drug for a

***"Many patients with a disability find it impossible to negotiate the obstacles required to get the treatment they need"***

"Some of my patients are on seven different drugs and the GP only renews one item at a time, so patients often find themselves going back twice a week. Imagine your whole life revolving around getting a new prescription.

He adds: "All too often doctors behave as if patients are lucky to get what is offered. Many patients with a disability find it impossible to negotiate the obstacles required to get the treatment they need."

### Access denied?

To find out more, I spoke to several disabled people via Twitter and Facebook forums who said they were experiencing difficulties in accessing essential medication.

Alex Watts, who has a chronic pain condition from a facet joint injury tweeted: "My pain consultant has prescribed me various drugs over the years, but my GP has always been reluctant and unwilling to adjust these when I have a pain flare. I then have to ask my consultant (who isn't always readily available) to ask my GP to increase the dose."

Philippa Willitts has been refused medication on the basis that she already takes too many. She tweeted: 'I take a lot of medication because of





migraine, patients with epilepsy who have been refused specialist medication and patients with Parkinson's who have been refused a drug – forcing their carer to collect it from the hospital, leaving them by themselves," he explains. "It's not unusual for me to pick up an urgent note at 7pm on a Monday from a patient who has run out of an anti-epileptic drug and their GP has refused to prescribe it, leaving them high and dry. It's highly dangerous."

23-year-old Daniel and his family have been facing a three-year battle with their GP to get Melatonin prescribed. Daniel, who has epilepsy, quadriplegic cerebral palsy and several other health conditions, needs Melatonin to help him sleep. He was initially prescribed the drug by his paediatrician, but by the time he was transferred to adult services at the age of 20, his family were told they would no longer be prescribing Melatonin for him.

"We were told it is only prescribable for under 18s and over 55s," says his mum and fulltime carer, Diane. "Daniel is on nine other drugs and Melatonin is actually very mild. Our brains produce melatonin naturally to help us sleep, but because of Daniel's brain damage, his brain doesn't do this, so he just doesn't sleep without the right medication."

Melatonin is widely available in the US and can be picked up in any supermarket. Because it's not addictive, Daniel was able to take Melatonin when he needed it, to get into a healthy sleep cycle, rather than other drugs – particularly sleeping pills and sedatives – which need to be taken every day.

"Daniel can wake up six or seven times a night and he struggles to get off to sleep, too," Diane explains. "The GP will only prescribe sedatives, which we tried, but I hated the effect it had on him. I had to watch over him the entire night because he just didn't move, and the next morning he was almost zombie-like."

Epilepsy symptoms worsen with tiredness, so Daniel's seizures have increased as a result. Even after a recent meeting between his neurologist, his GP and his family, no resolution was reached, despite the neurologist's recommendations.

"It's crazy. If Melatonin is safe to prescribe to vulnerable people like children and older people, then it's safe for everyone. My other son is 16 years old and he sleeps soundly. Why can't Daniel have the same rights as him?"



**Philippa Willitts** was refused pain reducing medication by her GP because she already 'takes too many'

### "Shifting costs"

Tanya Elliot, who has severe ME, has also been refused Melatonin. Her GP advised that her specialist should prescribe it to her instead, but Tanya is housebound and only sees her specialist once a year. She tweeted: "There is nothing I can do. This drug was my only chance to get biomedical treatment for my condition, but they won't prescribe it."

While Telford-based GP, Teresa McDonnell, admits that there can be issues with prescribing certain drugs, she believes it's because many GPs don't feel they have enough expertise or because the drug needs to be prescribed by a specialist.

She says: "Some of this is about shifting costs from secondary to primary care, which some consultants try to sneak onto us. GPs can refuse to

prescribe, even if it's been recommended by a consultant – but in my area, the problem is usually sorted by using a 'shared-care' agreement."

Responding to the aforementioned issues regarding Melatonin, Dr. Imran Rafi at the Royal College of General Practitioners said: "The issue is to do with the licensing of the drug and the fact that there is very little long term data on its effects. It is only licensed for the short-term treatment of insomnia in adults over 55 years. Most GPs would refer to the British National Formulary which confirms this, and would be hesitant to prescribe off-license drugs unless there were strong indications that all GPs would follow GMC guidelines on good prescribing in relation to 'off license' use."