Life with a nightmare

or: If I had not been a doctor

I am a 76-year-old former paediatrician. I practiced general paediatric medicine in a small town for 27 years. Since 1991 I am retired. Four years ago, I lost my wife. Since then, I am living alone in a rather large house situated in a small village in the mountains.

In 1995, I developed paraesthesia, numbness and slight weakness of the left side of my body lasting nearly two days. A thorough investigation revealed, as the cause of the classical transient ischaemic attack (TIA), an unstable plaque in the right carotid artery with a 40% stenosis at the bifurcation. Aspirin and a statin were prescribed and no further neurological events occurred until January 2004. In the meantime, I had a pacemaker implanted because of a sick sinus syndrome, with intermittent atrial fibrillation and tachy-brady-cardia. Thereafter, anticoagulation with oral phenprocumon was started and maintained at an INR between 2.5 and 3. Aspirin was stopped.

In January 2004 – while sitting quietly at my desk – I experienced again paraesthesia and numbness, this time on the right side of the face, in the tongue and in the right arm. The symptoms lasted approximately a minute. The frightening episodes recurred, first at intervals of a few days, but soon more frequently. By mid-February I experienced paraesthesia and numbness almost daily, with slightly, but steadily increasing intensity and lasting up to 5 minutes. The sensation sometimes spread to my right leg causing an odd feeling, without affecting the fine tuning of the movements of the muscles involved. For myself and my doctors there was no doubt that I suffered again from TIA's – now on the other side of my body – although the episodes were shorter than those in 1995, lasting mostly for only one or a few minutes. A CAT scan in January 2004 raised the suspicion of a few microvascular lesions in the white matter of my brain – a finding already present in 1995.

Being a paediatrician, not very familiar with ischaemic events in adults, I turned to the literature, and – with the help of some medical friends – I discovered the November 21, 2002 issue of the N Eng J Med (NEJM Volume 347, Number 21), which contains a thorough review on TIA's and two additional updates. From this work I retained three facts which I thought relevant for my case.

First, 10 to 20% of all patients with a single TIAs suffer a stroke within 90 days and in half of them the stroke occurs within 24 to 48 hours. I wondered what the risk estimate would be for patients with repeated TIA's, but I could not find an answer, perhaps fortunately so. Second, the preventive efficacy of anticoagulation – although the treatment of choice for most authors except for severe carotid stenosis and recent attempts of thrombolysis in a few highly selected cases – has never been proven beyond any doubt. Besides, anticoagulated I was already because of my sick sinus! Third, the classical belief that the symptoms of a TIA persist for a couple of hours, but resolve within one day is no longer accepted. Indeed, 90% of all TIA's last less than 10 minutes – just as in my case.

So, contrary to my ardent hopes, I not only failed to find any reassuring facts, but I was now convinced more than ever before that I was faced with an impending catastrophe. Driven by fear and the slim hope – shared by my solicitous primary care physician – that something could be done to avoid the worst, I wanted to be admitted to the hospital.

There, the recent CAT scan was not repeated and I was informed that MRI – the most informative investigation according to the experts – could unfortunately not be done because of my pacemaker. Duplex ultrasonography of the extracranial vessels confirmed the known plaque in the right carotid artery and raised the suspicion of an intracranial stenosis of the vertebral artery, while no significant abnormalities were found in the arteries of the left side. An EEG with compression of the left carotid artery was normal, as was echocardiography. The consultant professor of neurology confirmed the interpretation of my neurologic attacks as TIA's. He advised me to try to live with these events without taking them too seriously. This was certainly a most honest attempt to soothe my worry, but the impact on me was rather devastating: I wondered whether the professor was aware that he had just told his patient – who happened to be a doctor too – not to worry, if he had to share his room with a terrorist who frivolously tinkered with a bomb every day.

After returning home, I had an emergency call device installed in my house which I could activate from a button mounted on a wristband. It was only a few days later that I realised I had to wear that band on my right wrist, should I really be able to reach the button with the unaffected hand in the case of the feared emergency.

To comply with my urging wish to try every possible way to improve the quality of my life, it was decided to add first aspirin and later on clopidogrel to a carefully monitored oral anticoagulation. I was informed about the increased bleeding risk with this combination (which is, as I learned from the scarce literature, about double that of oral anticoagulation alone), but I was fully prepared to accept the additional risk. Unfortunately, nothing changed. After two months, I still had the same almost daily attacks.

I was still not willing to accept my condition without going to the extreme end of my cumbersome way. I realized that at this far end were the vessels within my head. We all knew – my doctors and I myself – that the chances to find a narrowed artery accessible to some therapeutic intervention, except the risky anticoagulation I already had, were almost nil. Nevertheless, I wanted to know. So I was referred to the neuroangiologic unit of a university hospital, where I was immediately accepted as an emergency. After a thorough investigation of all accessible intracranial arteries by Doppler ultrasonography, the professor told me that there was not much wrong with my cerebral blood flow. Moreover, he thought I did not have TIA's but that I had simple partial, primarily sensory seizures – for me, as a paediatrician, just a form of plain epilepsy! He added that I should immediately cease adding antiplatelet drugs to my oral anticoagulation and instead take the antiepileptic drug carbamazepin in increasing doses.

At that very instant I felt bewildered, stunned and unable to grasp the full meaning of the message. Instead, a bad memory popped up in my mind. The many painful moments when I myself, practicing paediatric, had to explain the diagnosis of epilepsy to young patients and their parents – usually with devastating consequences. Should I now also have epilepsy in addition to all my other problems? In a strange and somewhat numb state of mind I left the office, got in my car and drove the rather long way to my lonely home (although the professor of neuroangiology had just advised me not to drive for a couple of months!). Back home, I immediately called my old doctor-friend, who had supported me closely throughout my worrisome time. It was only then, during that phone call, that it dawned on me that I had just received very good news. Being a paediatrician faced almost exclusively with genuine epilepsy, I was not aware of the profoundly different nature of epilepsy in elderly people, its dramatically higher incidence with advancing age – 100 000 new patients share my fate each year in the USA alone –, the many different causes of the disease and the fact that complete control is achievable with antiepileptic drugs in about 70% of patients. It is only during the following days that I learned this and much more about epilepsy in old-age from the literature (eg Lancet 2000;355:144148. N Engl J Med 2001;344:1145). For the moment, I was advised by my friend to celebrate with a glass of the best champagne in the house that the diagnosis of my attacks had switched from the frightening and intractable TIA's to a much more benign and treatable disease. First, I drove to the pharmacy in the next village and took a pill of carbamazpine as soon as I was back in the car. When I was safely home, I followed the advice with the champagne.

A few days after taking 200 mg carbamazepin a day (the highest permissible dose being 2000 mg) the intervals between the formerly almost daily episodes of right-sided dysaesthesia and numbness began to increase and the severity of the episodes appeared less intense to me. Since I experienced no side-effects, I increased the dose to 400 mg. A few days later, the episodes disappeared completely and never came back.

By now – 2 years later – I am no longer driving my car with a bad conscience and I have put the wristband with the emergency call button on a shelf near my bed. The whole story appears to me like a nightmare.

However, one thought often crosses my mind: What, if I had not been a doctor myself, supported by friends who were also physicians, and who encouraged me to explore all available diagnostic options? How about all those patients who are not in this privileged position?

Anonymous (reported by Professor Hugo Studer, Professor emeritus of Medicine, University of Berne)

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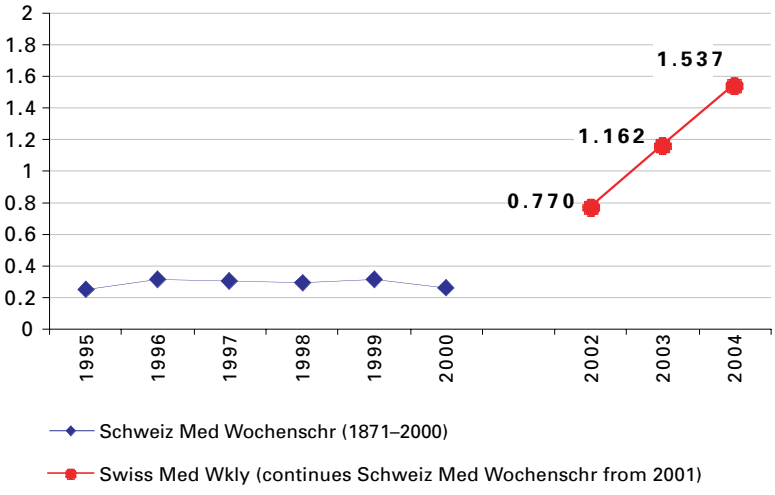

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