

weighted heavily towards science, whenever and wherever sound evidence is brought to light.

I thank Mr Lawrence Stevenson and Ms Pamela Slaughter for assistance in the preparation of this article, which is dedicated to the memory of Prof Adam L Linton.

References

- 1 Tanenbaum SJ. What physicians know. *N Engl J Med* 1993; **329**: 1268-71.
- 2 Brook RH, Chassin MR, Fink A, Solomon DH, Kosecoff JB, Park RE. A method for the detailed assessment of the appropriateness of medical technologies. *Int J Tech Asses Health Care* 1986; **2**: 53-64.
- 3 Park RE, Fink A, Brook RH, et al. Physician ratings of appropriate indications for three procedures: theoretical indications vs indications used in practice. *Am J Publ Health* 1989; **79**: 445-47.
- 4 Leape LL, Park RE, Kahan JP, Brook RH. Group judgments of appropriateness: the effect of panel composition. *Qual Assur Health Care* 1992; **4**: 151-59.
- 5 Kahn KL, Park RE, Brook RH, et al. The effect of comorbidity on appropriateness ratings for two gastrointestinal procedures. *J Clin Epidemiol* 1988; **41**: 115-22.
- 6 Fraser GM, Pilpel D, Hollis S, Kosecoff JB, Brook RH. Indications for cholecystectomy; the results of a consensus panel approach. *Qual Assur Health Care* 1993; **5**: 75-80.
- 7 Brook RH, Kosecoff JB, Park RE, Chassin MR, Winslow CM, Hampton JR. Diagnosis and treatment of coronary artery disease: comparison of doctors' attitudes in the USA and the UK. *Lancet* 1988; **i**: 750-53.
- 8 Scott E, Black N. When does consensus exist in expert panels? *J Publ Health Med* 1991; **13**: 344.
- 9 Phelps CE. The methodologic foundations of studies of the appropriateness of medical care. *N Engl J Med* 1993; **329**: 1241-45.
- 10 Lomas J, Anderson GM, Enkin M, Vayda E, Roberts R, MacKinnon B. The role of evidence in the consensus process. *JAMA* 1988; **259**: 3001-08.
- 11 Thomas L. On the science and technology of medicine. In: Knowles JH, ed. *Doing better and feeling worse*. New York: W W Norton and Co, 1977: 35-46.
- 12 Kassirer JP, Moskowitz AJ, Lau J, Pauker SG. Clinical decision analysis: a progress report. *Ann Intern Med* 1987; **106**: 275-91.
- 13 Antman EM, Lau J, Kupelnick B, Mosteller F, Chalmers TC. A comparison of results of meta-analyses of randomized control trials and recommendations of clinical experts: treatments for myocardial infarction. *JAMA* 1992; **268**: 240-48.
- 14 Chalmers I, Enkin M, Kierse MJNC. *Effective care in pregnancy and childbirth*. New York: Oxford University Press, 1991.
- 15 The Canadian Task Force on the Periodic Health Examination. *The Canadian guide to clinical preventive health care*. Ottawa: Ministry of Supply and Services, 1994.
- 16 Chassin MR, Kosecoff JB, Park RE, et al. Does inappropriate use explain geographic variations in the use of health care services? A study of three procedures. *JAMA* 1987; **258**: 2533-37.
- 17 Merrick NJ, Brook RH, Fink A, Solomon DH. Use of carotid endarterectomy in five California Veterans Administration medical centers. *JAMA* 1986; **256**: 2531-35.
- 18 Bernstein SJ, McGlynn EA, Siu AL, et al. The appropriateness of hysterectomy: a comparison of care in seven health plans. *JAMA* 1993; **269**: 2398-402.
- 19 Hilborne LH, Leape LL, Bernstein SJ, et al. The appropriateness of use of percutaneous transluminal coronary angioplasty in New York State. *JAMA* 1993; **269**: 761-65.
- 20 Bernstein SJ, Kosecoff JB, Gray D, Hampton JR, Brook RH. The appropriateness of the use of cardiovascular procedures. *Inr J Tech Asses Health Care* 1993; **9**: 3-10.
- 21 McGlynn EA, Naylor CD, Anderson GM, et al. Comparison of the appropriateness of coronary angiography and coronary artery bypass graft surgery between Canada and New York State. *JAMA* 1994; **272**: 934-40.

Living with Lyme

Ilkka Vartiovaara

In spring 1987 my book about burnout finally came out. So I was feeling good when a few weeks later I flew as the representative of the *Finnish Medical Journal* to the Vancouver Group's meeting, this time in Vancouver itself. The hosts put us into an empty, nicely situated, student campus. My room was on the ground floor with big windows looking onto a subtropical background. There was also a door that opened to a large field—beautiful with all the undergrowth.

The meeting was important and went on effectively. However, already on the first night I woke up because something was bitterly biting me. I was sleepy, but I recall having picked the something from my face, just above the hair-line. I snapped my fingers and fell soundly asleep again. On a few more nights I went through the same ritual. Even through the deep sleep I realised it must be some kind of insect, but I did not worry: every Finn expects to be bitten hundreds of times by bugs during the summer—it is part of the short summer's joys. On the last morning I woke up, went to open the curtains, and in an ashtray on the window-sill I saw a small bug, full of blood, obviously soundly asleep in its turn. Now I knew who had been my uninvited bedroom companion, but I had never seen anything like it before. When travelling I always carry

cameras with me. I took the macro lens and snapped some pictures of the bug. Then I rather gladly smashed it and flushed it down the tubes. I thought the pictures would serve as some sort of joke at home: Go west, son, and get bitten. That was my primitive impulse then.

After this I totally forgot the incident till, while waiting for my plane to Helsinki, I had an airport meeting with Dr Tuula Fabrizio, the *Finnish Medical Journal's* American correspondent. She lives in Norwalk, Connecticut, which is rather near the town of Lyme, as I later learnt. She asked if the meeting was good. I said yes and that I had also had a bloodthirsty bug as a bedfellow. After this I flew back to Helsinki and started working normally, forgetting all about the bug.

Cause for alarm

Three weeks after Vancouver my feet, knees, and wrists became painful. When the others complained about the 25°C warmth in June and wore swimsuits, I was so chilly that I needed long underclothes. Then I lost the normal contact with my heels—it felt like I was walking on the bare calcaneus bones, and was quite unpleasant. Soon after this I realised I was not hearing well and my balance was defective; then my skin sensation changed—it was at that time hyperaesthetic. The worst thing was and still is the strong pain that was not relieved by the usual painkillers. When my eyesight started getting worse I got

Kaavintie 17B, 01650 Vantaa, Finland (I Vartiovaara MD)

really alarmed. I just could not see with my pretty new glasses, and the power of accommodation seemed to have gone. I contacted a neurologist friend and there I had my first stroke of bad luck. When writing the burnout book I had consulted this friend for a nasty tension neck . . . so the two processes overlapped in a bad way. I thought, on the one hand, I might have another tension neck episode; but then, on the other hand, I had not been writing as hard as on the first occasion. But if not tension neck, what was it?

In summer 1987 my colleagues started the Great Hunt. Having excluded the tension neck my doctor team, as it had grown into, was looking for either brain cancer or multiple sclerosis. I'll never forget the times in a metal cylinder—CT and MRI—when I tried to lie motionless, with pain everywhere. What would be the verdict: cancer or MS? Two very awful things. If cancer, would it be operable? If MS, how on earth could I cope with that fact? I even felt some self-pity: I was only 41 years old . . . I just did not want to die, not yet, or to be a hopeless invalid.

Personally I never thought it could be anything but a somatic disease. As a psychiatrist I felt I could distinguish between psychogenic and somatic illness: the messages my body screamed out were clearly serious, not neurotic. The trouble was that Lyme disease was little known in Finland at that time. Even as the editor of a medical journal I was no exception. I had never even seen a living and walking tick; they were just blood-filled lumps you twisted out from dogs as a child during the summer. Though I knew I was seriously ill, transferring this belief to my colleagues was not easy. "But Ilkka, you look just fine! Why don't you take some days off the journal and we'll see all is fine." Well, sometimes I had the good manners to say thank-you very much for the advice, but later I just remarked that the pain has no real "volume dial" visible like an amputation.

One of my personal handicaps—thinking about those years now—is that I never could be demanding. I did not want to use my position on the *Finnish Medical Journal*. I just wanted to be a normal patient, cooperating eagerly, doing everything they wanted. And I did do all they wanted. But deep inside myself I knew all the time my machinery was out of synchronisation. I just could not get my colleagues and friends to see this. In my hospital records they said "the patient is cooperative and behaves well". But they did not say what was the matter with me.

Problem patient?

After sixteen months I was in a bad state, hardly able to drive a car, type with my fingers, stay at the office for the formal hours. At home I could only walk with orthopaedic shoes, keeping close to the walls so as not to fall down. Despite the severe pain I did not and do not want to use opioids.

I felt myself gradually becoming a "problem patient". No Ca, no MS. "Perhaps you just have too much stress, Dr Vartiavaara?" I can in a way understand this. None of the symptomatic treatments helped. I did not fit in with the healing tradition whereby the patient is studied, the illness is diagnosed, and the basis for curative treatment is established. The dissatisfaction of some of my doctors could be clearly read between the lines, the words, the frontal skin furrows.

There was a time, I found out later, when the soft feathers of Destiny touched my chin. One of my

colleagues had listed along with all the other possible laboratory examinations borrelia antibodies, model 1988, and had told me that all the results were normal. The lab computer had not put an asterisk beside the borrelia antibody findings because the test result was a hair's breadth below the watershed mark. Nobody paid attention to the raised titre and that was my last chance to get diagnosed and treated on time. About that I am still a little bitter.

In the late summer of 1988 I was in such bad condition I could hardly force myself to go daily to the journal office. I had no energy, wanting just to sleep and be pain-free. Soon after this the hospital said there was nothing they could or would do. No hope for me! Nor any backup-plans. Now I was virtually alone with all my symptoms.

Then came a day when I dictated, since I could no longer write, a farewell letter to Dr Fabrizio telling her something about my illness.

Dawn and dusk

A few days later I got her reply, saying I absolutely must have Lyme disease. She had remembered the incident with the bug in Vancouver, and said that all the symptoms and findings perfectly matched that disease. The next day brought me an article from *Time* nicely putting together that what was known about Lyme disease in the USA at that time and complete with a colour picture of the tick. When I saw it I went to my shoe boxes and found the pictures I had taken in Vancouver—the ticks were 100% identical.

I picked up the phone and told a colleague that now I knew what was the matter with me and soon afterwards I found myself in the university hospital's infection department. I still felt awful, but also good because I knew why I was so ill. Strangely, the laboratory tests for borrelia antibodies were still negative; I understand it is because different strains have different antigenic properties, and at that time the strains on the west coast of the USA differed from those on the east coast. By the way, I never had erythema migrans—only a big lump on the forehead.

I had my first ceftriaxone intravenous treatment in August, 1988, and it lasted for 2 weeks. With that it was supposed to be all over. And according to that time's knowledge it should have been so. But slowly I returned to my former bad state: the pathological changes in my nervous system continued, as well as the pains in almost all the joints and muscles. In spring, 1989, I went again to the USA and to the Vancouver Group meeting. But I had done some homework, keeping in close touch with Dr Fabrizio. She knew that physicians at the Stony Brook Hospital, especially Dr David Volkman, were highly knowledgeable about Lyme disease. So I went there before the meeting. One of the tests was the T-cell proliferation test, which turned out to be clearly and undoubtedly positive. It was the first time a lab test had been positive, and it confirmed my own suspicion that the infection was still going on. After that I had two months' heavy treatment with oral doxycycline 300 mg a day. I was a little better after it, but only for about two months. Then it started all over again, and got worse.

Since my spirochaete was from the USA, I wrote to my two friends in Boston, the *NEJM*'s editors Dr Arnold S Relman and Dr Marcia Angell and asked if they had any ideas about what to do. They had, and soon I learned I

could go to the Massachusetts General Hospital and be seen by Prof Morton Schwartz. I went there in January, 1990, for a week. Dr Schwartz's verdict was that I had had a serious borrelia infection but everything pointed to the probability it would gradually get better. This was a great ray of hope, and it sustained me through hard days at the *Finnish Medical Journal*.

But I just knew the spirochaete was still alive and well. The next try at treatment, with ceftriaxone, was in spring, 1992, after which my colleagues said there was nothing more to be done.

The last battle?

As early as spring, 1991, my rheumatologist had expressed the view that I ought to retire on permanent pension, but at the time I was completely averse to the idea: I did not want to stop working, I just wanted to get better. I was only 45, after all. But when there was nothing good on the horizon, I realised I did not have a choice. So I said "yes" to this colleague, who together with other specialists wrote the necessary documents. On Jan 9, 1992, after much bureaucratic activity, the final decision was made, and I was the first person in Finland to get a pension on the basis of Lyme neuroborreliosis. Now began a totally new period in my life. I knew I would miss the important feeling I had always got through the *Finnish Medical Journal*—so many interesting contacts and meetings, and now it was over. As editor I had already done my best to highlight the disease by inviting articles for the journal and providing hints to many lay journalists. Today I am happy to know that Lyme borreliosis is a regular "tough nut" question in pre and post doctoral examinations. And people seem to know the tick disease rather well. The point is that if one gets the right diagnosis early, it is very simple to treat.

I tried to arrange my days in some meaningful way, deciding to play all the classical music I had collected over some 30 years, to read the piles of books that every doctor has set aside for leisure times that usually never come, and to walk as much as I could during the 2–3 morning hours when the pain was least troublesome.

It was a great plan, but I could not make it work. My neurological and musculoskeletal symptoms grew worse all the time. Then by chance I heard of Dr Jarmo Oksi, whose laboratory in Turku was doing a polymerase chain reaction test for borrelia, the best and most specific test that exists today. It was good news for my new "own doctor" and myself. We sent blood and spinal fluid to Dr Oksi and they turned out to be positive—in other words, the spirochaete was still alive in my body after six years, despite the antibiotics. A new battle started on Feb 18, 1993. The massive treatment began with intravenous ceftriaxone 2 g and azithromycin 250 mg daily for four weeks then we continued with kefixime 400 mg twice daily plus the same dose of azithromycin alternate weeks. This went on until the end of June, almost half a year. The idea, naturally, was to kill the microbe both intracellularly and extracellularly. Some of us did wonder who would die first, me or the spirochaete, but I absolutely wanted to take the risk. It was hard on my stomach, and I needed omeprazole. But my real secret weapon was Gefilus sour milk, which includes enormous amounts of lactophilus bacteria. When on ceftriaxone treatment I had had much trouble with colon yeasts; now I drank 2 litres of sour milk a day and felt fine in that area.

Several months after the treatment was over we repeated the PCR and it was negative in both blood and spinal fluid. One of the best things for years. We all thought the hard days would be over now. But I was wrong. The spirochaete had had too much time to harm me and the process had changed to an autoimmune one. My symptoms are on the move again. I have very weak reflexes in the lower limbs, have a total saddle back and chest anaesthesia, and my hearing and balance are poor. My eyesight is still rather bad, but the nature of the damage remains uncertain.

Now I am 49 years old, an invalid with a totally unknown prognosis. Without my contacts brought by the editorship I do not think I would be alive today, because of the totally black perspectives combined with the symptoms. I think of the many Lyme patients who remain undiagnosed: in Finland today about 400 new patients are diagnosed a year, and there must be many who never get the tests. They must suffer enormously, running from doctor to doctor seeking help in vain. One of the worst insults is to be labelled a chronic complainer. Doctors must diagnose new cases as early as possible, and test old pain patients just in case, since treatment has given good results many years after the primary infection. What should be done when a patient has the typical Lyme disease history but negative serology? This is still a hot question especially in the USA. My strong opinion is that oral antibiotics should be given in such cases. Ordinary laboratory tests cannot be relied upon and the PCR is too expensive for routine use. When the whole picture leans towards Lyme borreliosis it is both ethically and medically right to treat.

New horizons

Some people believe a serious illness ripens the personality, giving it beneficial experiences and inner frameworks. This may be so in some cases, but I see nothing purifying or spiritually uplifting when I have the pains and lie thinking of my family and what I have lost—a good job, many friends at work, and my former social meaning. True, I have learnt a lot about the experience of illness, and a key point is the absolute necessity of having one good doctor to lead the medical orchestra, especially if you are a doctor yourself. Until 1993 I had no-one to take overall responsibility for my well/ill-being: now I have Dr Heikki A Salmi as my "conductor", and I no longer have to decide which specialist to call when new symptoms arise; when you are in a whirl you cannot see the core issues. Some people say that to be a good doctor you need to have been seriously ill yourself. I am inclined to agree. As doctors we underestimate the fear of getting blind, deaf, immobile, insomniac, short-fused. I can easily understand those who get religious when life truly turns against them. If you have tried everything on the usual ground level and it has not helped, why should one not look up and try to find some consolation from there? As an agnostic I have not got help that way, but now I understand religious ideas better than before. In some illnesses the patient is just as vulnerable as a newborn baby, with the difference of lacking a caring mother. And we can be very scared indeed when nothing seems to make sense. If I could practise medicine now, I probably would be a better doctor than I was some 20 years ago.