

CO-TB ALMOST KILLED ME



People with HIV are 50 times more likely to develop active TB disease than others, yet tests in current use have a pitiful detection rate. Activist **Paul Mayho** speaks to Calvin Holbrook about the Devil's Alliance of co-infection

To many, three months off from work in peaceful surroundings sounds like a dream. But if those three months are spent sick and isolated in a pokey hospital ward, out of it on medications and diagnosed with multi-drug resistant tuberculosis (MDR-TB), this utopia quickly becomes a nightmare.

Paul Mayho, 35, lived through this nightmare and his mission in life is to ensure no one else goes through the same thing. But if you are HIV positive, there's an increasing chance you could.

In 2005 alone, nine million were diagnosed with tuberculosis, an airborne disease, and two million died. UK cases rose to over 7,000 in 2004 and have doubled in frequency in London since the late 1980s, according to a Health Protection Agency report. Staggeringly, only five other, much less developed European countries have increasing TB rates. So what's going on? Paul, author of the *Tuberculosis Survival Handbook*, explains:

"I've been HIV positive since 1990 and around 1994 I became sick. It was during a stay in a west London hospital that I and seven others contracted MDR-TB from another patient due to poor infection control. We all ended up isolated. I'm the only survivor. The hospital staff had an inkling I'd been exposed but didn't tell me. I certainly didn't think I would

go into hospital and pick up a disease that could kill me.

"At the time I was volunteering for UKC and half of the office was isolated too. I became very sick and was given about ten weeks to live. With a CD4 count of two, I wondered whether the last thing I ever saw would be an isolation room ceiling with eyes peering at me over orange masks."

What exactly is TB?

Tuberculosis is an infectious disease that usually attacks the lungs but can affect almost any part of the body. It spreads

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through the air when people with TB in their lungs cough, sneeze, or even talk. But there is an important difference between latent TB infection and active TB disease.

Latent TB

You are infected with TB bacteria but do not become ill or infectious. The World Health Organisation (WHO) estimates a third of the world's population is latently infected. Only ten per cent go on to develop active TB.

Active TB disease: pulmonary and extra pulmonary

Active TB disease can show anywhere in the body but most commonly in the lungs as pulmonary TB. As TB is an airborne disease, it needs to be exhaled by someone who has pulmonary TB to be passed on. Elsewhere in the body, it's called extra-pulmonary TB and cannot be passed on.

MDR-TB

The type Paul had. MDR-TB is resistant to the two first-line therapies used to treat active TB. Worryingly, the World Health Organisation (WHO) reports a new strain of MDR-TB resistant to second-line drugs is becoming increasingly prevalent.

"TB treatment is very long," says Paul. "For drug sensitive TB it can be six to nine months. If you're HIV positive too, it can take up to two years. I was on treatment for two and a half years: about six pills a day

and three injections a week. It was pretty gruelling; they were old, second-line drugs because I was resistant to the newer, first-line. Some had to penetrate the brain barrier to ensure there was no TB left there. They gave me strange nightmares, delusions, paranoia... It's a long haul and I understand why people stop taking the medication."

Paul successfully adhered to his meds, cleared the TB and was released from hospital. However, he had no chance to celebrate his new-found freedom.

"I'd lost everything. I was homeless as I couldn't go back to live with my partner because he was HIV positive too. My TB could have reactivated and I could have infected him. I couldn't volunteer either. I pursued legal action and about three years later it was settled out of court and I was awarded damages.

"With me, the doctors freaked because they had never come across MDR-TB on an HIV ward before. It was the first time and nobody knew what they were doing. Nowadays, they have much more experience."

Why TB with HIV is a big concern

If your immune system is compromised, it may not keep any latent infection in check, developing into active TB. People with HIV are 50 times more likely to develop active TB disease than others. Coinfection with TB and HIV is known as the 'Devil's Alliance' as each infection speeds up the other.

Dr Marcos Espinal, executive secretary of the WHO's Stop TB Partnership, says around 13 per cent of the 8.9 million new TB cases in 2004 were HIV infected; around 33 per cent in Africa. "The HIV crisis is the biggest challenge the TB epidemic faces."

Antique tests failing people with HIV

Current TB detection tests are inaccurate, particularly in people with HIV.

"The government relies on the 115-year-old Mantoux test. It's not even licensed in this country," says Paul. "Tuberculin is injected to see if it creates a lump which would show a response to TB. It's a visual diagnosis: is there a lump or isn't there? It's hardly scientific. People with TB are often missed by this Victorian technology.

"HIV positive people have weak immune systems and often don't have an immune response to Mantoux, so produce a false-negative result. This test only has a 40 to 60 per cent success rate in those with healthy immune systems, so it's pointless for those with HIV. We're not identifying latent TB."

Paul is campaigning for a newer more effective test: T-SPOT.TB, a rapid blood test 94 per cent effective in people with HIV. "We need to embrace these new technologies, but the government doesn't seem able to get their act together."

It may be health ministers are deterred by the potential cost: £25 for T-SPOT.TB compared with £5 for Mantoux. But because T-SPOT.TB is more accurate, the long-term gain to the NHS would be less spent on treating TB disease itself. London's Chelsea and Westminster hospital is one of only a few currently using this test.

However, the campaign for introduction received a boost this month when the National Institute for Clinical Excellence (NICE) issued guidelines recommending T-SPOT.TB for those immuno-compromised.

Symptoms of active TB

Latent TB has no symptoms but it's worth investigating active TB if you experience the following:

- A bad cough that lasts longer than three weeks
- Pain in the chest
- Coughing up blood or sputum
- Weakness or fatigue
- Weight loss/lack of appetite
- Night sweats/fever

TB is diagnosed through investigating these symptoms combined with chest X-rays and sputum smear microscopy.

When to test

Paul is adamant all people living with HIV should be tested for latent TB, especially the newly diagnosed, so doctors know to look for future symptoms of active TB.

"TB creeps up on people insidiously. The bacteria replicate slowly, so it can be some time before doctors realise patients have active TB. Meanwhile they're infecting everyone else. People with HIV tend to associate with others with HIV so that only increases the problem."

Stuart Rose, from T-SPOT.TB makers Oxford Immunotec, thinks treating latent TB is one solution. "People with HIV should test for TB at least once; if I were HIV positive, I'd want to know my TB status. If you were latently infected, ideally you would get rid of it with antibiotics. It's much easier to treat TB in its latent form, while your immune system is relatively healthy than waiting for signs of active TB disease, which is harder to treat."

But Paul reiterates that the benefits of test- ▶

▶ ing all HIV positive people can only be realised if the T-SPOT.TB test is widely introduced. "There is a two-tier latent TB diagnostic system operating in this country and people with HIV are at the bottom of the pile," he says.

The Global Plan

Unlike HIV, TB is curable. But it still kills 5,000 people a day, globally. In January the ambitious \$56 million Global Plan to Stop TB 2006-2015 was launched. Its main goals are:

- To treat 50 million people
- Introduce, in 2010, the first new TB drug in 40 years
- Develop an effective vaccine before 2015
- Save 14 million lives

be breathed on by other people. I swing between claustrophobia and agoraphobia."

"In many respects the isolation was harder to deal with than the disease itself. When I went from deprivation to having a life, there were times I wanted to go back to that isolation room because I felt safe there."

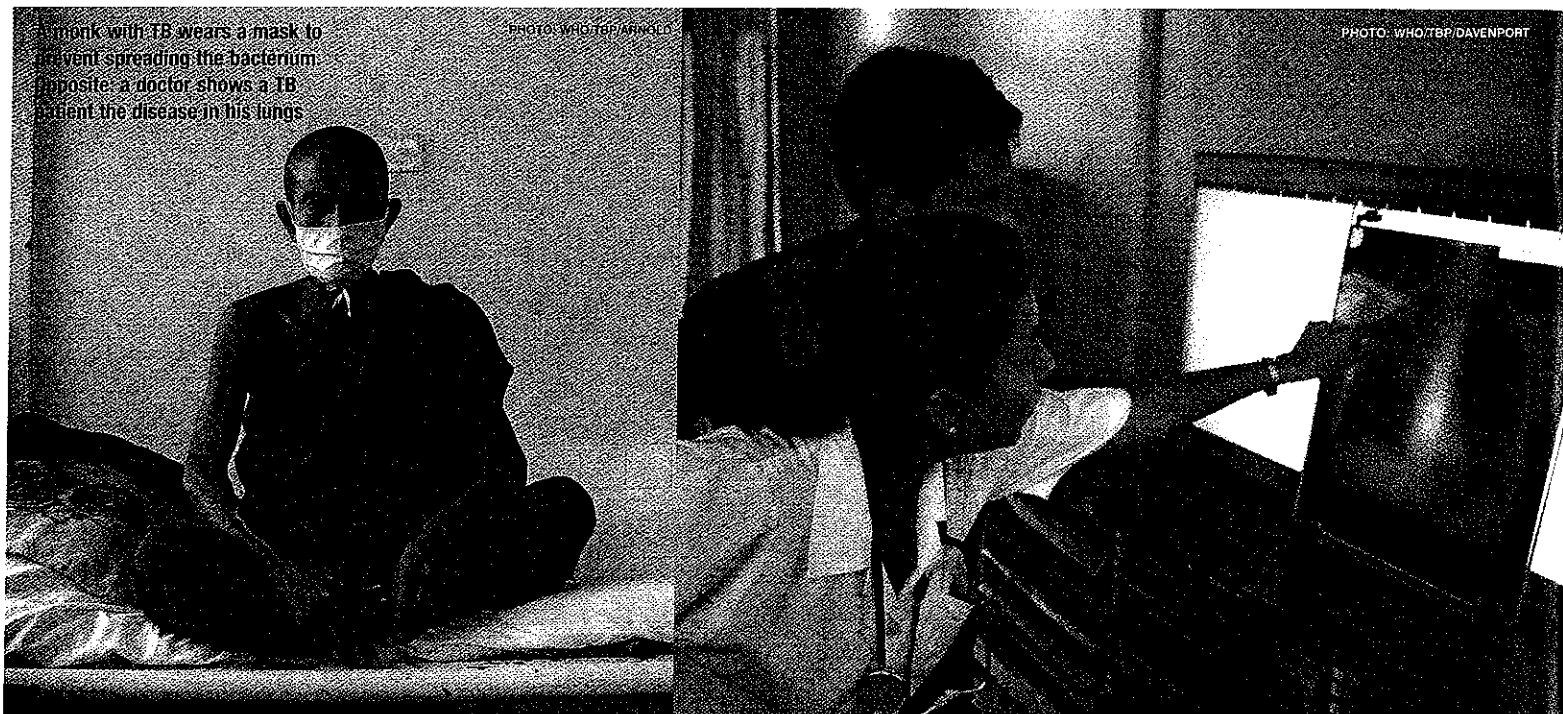
Paul has since devoted his life to fighting TB, with ten per cent of royalties from the second edition of *The Tuberculosis Survival Handbook* going to the UK charity TB Alert.

"I ripped out two-thirds of the original book and rewrote it. Quite a bit has changed in TB over the past five years, particularly in the growing patient movement. It includes tips healthcare workers find useful; things people

"I've turned what could have been a very negative experience into a career. I'm writing about what I know about. If TB and HIV hadn't happened, I wouldn't be doing what I am doing now."

"Now my health is good: my CD4 is about 400, I'm undetectable and I don't take any notice of my HIV. I've been on therapy since my TB treatment stopped in 1998. It's highly unlikely my TB will come back. The longer you don't see it again, the better it becomes."

Paul is proof that HIV and TB coinfection doesn't necessarily equal death, but sadly that is not the case for many in the developing world. "The only reason I'm here now is because of geography. I survived because I



A young boy with TB wears a mask to prevent spreading the bacterium. Opposite: a doctor shows a TB patient the disease in his lungs.

PHOTO: WHO/TBP/ANNICCI

PHOTO: WHO/TBP/DAVENPORT

"This is completely attainable," says Paul. "TB actually kills more people than HIV and malaria put together; it's the leading bacterial cause of death. The plan is to eradicate TB by 2050 but there are also plans to find drugs that work a lot faster; instead of six-month treatment, we'd like two or one-month. That's the crock of gold, what we're aiming for."

Paul says people need to stop associating TB with consumptive writers like Keats and the Brontë sisters because, these days, there is a cure. "Two million people die needlessly every year. In some countries treatment cost is as low as \$10. It's an international embarrassment."

Emotionally scarred

TB gave Paul emotional as well as physical scars (three cavities in his chest).

"Being isolated in a 12ft by 9ft room sends you insane. Physically, you start to feel better quickly with TB, but you have to stay in that room. I still fear hospitals and always ask to be put in a side room because I don't want to

wouldn't necessarily think of: like not to have a ticking clock in your isolation room because it drives you insane.

Patient involvement

"In the last few years we've seen a growing patient movement, much of it coming from the US HIV community, active in bringing both TB and HIV up the agenda. Nelson Mandela has also said: "We can't tackle HIV if we don't tackle TB."

"People with HIV often want to campaign, as it's something that affects them for life," says Paul. "With TB, once cured, many want to forget it. We're losing our patient experts and need to find ways of retaining them. They have a lot of knowledge to share."

Paul is attempting to do this with his Tuberculosis Survival Project, a "21st century people's diary" where people leave their own stories (www.tbsurvivalproject.org).

Paul managed to turn his life around when he could have spiralled into despair.

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live in a country where I could access care, medication and antiretrovirals. Had I been elsewhere in the world, I'd be dead by now."

If you are suffering any of the symptoms of TB contact your clinic doctor and ask for a TB detection test

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- www.stoptb.org, global movement to stop TB
- www.tbalert.org, the UK's TB charity
- www.tbsurvivalproject.org
- *The Tuberculosis Survival Handbook* (Merit, £14.95), is available at www.amazon.co.uk