

Investigation A bitter pill

The cocktail of drugs that Mark Ward (right) has to take every day



WHAT DOESN'T KILL YOU MAKES YOU OLDER

Mark Ward caught HIV from a blood transfusion in his teens. Now, at 40, he has the body of a pensioner. Are the drugs that saved his life to blame? By Christine Toomey. Portraits: Tom Pilston

The main building of the Mildmay Mission Hospital in the East End of London lies largely abandoned now. From time to time its draughty corridors, still strewn with the disused medical equipment of what was once Europe's first HIV/Aids hospice, echo to the sound of film crews shooting dark psychological thrillers. They come here in search of a bleak setting.

There was a time when this was a place of fear and hopelessness. When the Mildmay first opened its doors to Aids sufferers in the early years of the disease in 1988, ambulance crews bringing new patients drew up to its gates dressed in chemical hazard suits. "They looked like spacemen. It was really quite horrific and very frightening for the patients to be treated in this way until they arrived here and were given proper care," remembers Kathleen Nash, the then receptionist.

At that time, most large hospitals had dedicated Aids wards. Mildmay was where many patients were brought when these wards could no longer cope. Eighty per cent died within a few weeks or months of arriving. Many of them were young gay men suffering the tortures of severe Aids-related dementia, which left them paralysed and often in a child-like state.

All that changed with the advent of antiretroviral (ARV) drugs in the mid-1990s, rendering HIV infection more manageable. Today, many of those diagnosed with HIV soon after becoming infected have a near-normal life expectancy, if prescribed the right combination of drugs for their symptoms — a pharmaceutical cocktail that can range from one pill to more than a dozen daily.

Now, however, evidence is mounting of another kind of unforeseen and potentially devastating Aids crisis. As HIV patients live longer, many — including those in their twenties and thirties born with HIV contracted from their mother — are showing signs of gradual deterioration of their mind and body in ways normally associated with old age. Aids dementia and brain damage are once again emerging as serious problems, ones that are wrecking lives.

While only a small percentage, 2-4%, now develop "classic" Aids dementia — of the sort that saw early patients at Mildmay so deranged that some of them had to be locked in a special ward on the top floor of the hospice for their own safety — experts believe between 20% and 40% of those with HIV in the UK could now be suffering some form of cognitive impairment.

You need look no further than what remains of Mildmay to find proof that this problem exists. Now located in a refurbished annex of the old hospital, Mildmay UK operates as an independent charity and is once again at the forefront of HIV treatment and research. It is the only specialist unit for people with HIV-related brain impairment in Europe.



The first time I catch sight of Sam at the Mildmay it is from the back, and I mistake him for an old man. He is bent and shuffling. He is only 25. Before I sit down to talk to him I am told by one of the specialists treating him that a recent MRI scan of his brain was "quite frightening". His grey matter — the nerve cells that do the thinking — had degenerated to the extent of a 90-year-old.

At first Sam seems quite lucid. He delivers a quick rundown of his short life with the occasional spark of humour and no hint of self-pity. When I ask him what memories he has of his childhood he laughs, and without irony states: "My life's been great!" He begins by telling me he was born in a hospital called "Sunrise" in Las Vegas. "Great name, eh?" he

THEY ARE UNSURE WHETHER SOME OF THE SYMPTOMS OF SENILITY, BRAIN IMPAIRMENT, ORGAN FAILURE, MUSCLE LOSS, ARE RELATED TO THE VIRUS OR LONG-TERM USE OF THE DRUGS

grins. From here the details become darker.

Both Sam and his brother, Tyler, younger by a year, were born with HIV. Their mother was a heroin addict and the boys were born addicted to the drug. Sam knows nothing about their father and doesn't want to. He only knows that his mother died and he and his brother were put into foster care as babies. Sam was quickly adopted by one family who fostered him "because I was a cute baby" he says, grinning broadly again.

Sam's adoptive parents were British and brought him back to the UK when his father developed heart problems. His adoptive father died when Sam was four. His adoptive mother, who remarried, died of lung cancer five years later and Sam went to live with his stepfather. His brother, meanwhile, was adopted by a Mormon family living near Las Vegas and, so far, seems to have escaped the serious health problems that Sam is now suffering.

Sam has only ever held down temporary jobs for a few weeks and has not worked for the past six years. In addition to brain degeneration he suffers from deep-vein thrombosis and other

Right: Sam is 25, but has the symptoms of a 90-year-old. Left: Mildmay UK, a unit for HIV-related brain impairment. Below: Mark Ward, 40, thinks some of his ageing may be a result of HIV drugs



complaining of any symptoms of cognitive loss — found that a third were nonetheless beginning to suffer brain impairment.

"We tried to tease out the factors associated with what we were finding and discovered it was not age-related. We saw cognitive impairment in all age groups, from those in their twenties to

those in their fifties," says Winston. The study has established that the problem is significant. It will now be investigated further in a larger UK study.

Doctors are unsure whether the symptoms of early senility that many HIV patients are now experiencing — including not only brain impairment but bone weakness, muscle loss, fatigue, organ failure — are related to the virus itself or to the lack of early treatment with antiretroviral medication. "It may be that treatment is starting too late," says Winston.

There is also another alarming possibility: the symptoms may be the side-effects of long-term use of the drugs.

Antiretroviral treatment is still a boon for most patients in the short term. Unlike people suffering from incurable dementias such as Alzheimer's, HIV patients usually see some cognitive improvement thanks to the medication. Achieving the best combination of antiretroviral drugs to treat symptoms of brain impairment depends on the patient's particular problems. "There is no 'best' treatment," stresses Winston, explaining that some drug combinations seem to be better than others in penetrating the brain. "It is an area of active research." Most big pharmaceutical companies are involved in such research, as is the Medical Research Council in this country and independent groups such as those working at St Mary's Hospital and Imperial College, London. In the US, generous funding for

such research is also available from the government. It may be that the HIV virus itself is responsible for the dementia, according to the latest research, but that the drugs are causing the other symptoms of premature ageing, such as bone loss and heart problems due to increased cholesterol. "At the moment there are a lot more questions than answers," Winston concludes.

Mary Jones is 66 years old. She describes herself as "middle-aged, middle-class and living in Middle England" when she was diagnosed with HIV in 1995 at the age of 52. "I had flu-like symptoms and felt very ill indeed. I discovered my partner at the time had been unfaithful and, because he travelled abroad a lot for work, I decided to go for tests.

"It was a huge shock when they told me I was HIV-positive. When you're middle-class, white, straight and diagnosed with HIV, doctors assume you must have been a drug-user."

Mary was not prescribed antiretroviral drugs at first. Her CD4 count — the blood's white cell count indicating the strength of the body's immune system — was still high at 800. (According to current guidelines, antiretroviral treatment is only recommended once a person's CD4 count falls to 350.)

At the time Mary was running her own business, and once she began to feel better continued working successfully until her health started deteriorating again in 2001. When Mary started noticing her memory was failing, her reactions were becoming slow and her driving erratic, doctors initially ignored it. "The problem when you are a middle-aged woman is that doctors put everything down to the menopause. So they took little notice of it," she says. When she was eventually sent for a brain scan it revealed the HIV virus had caused pockets of fluid to form there. Although she was then prescribed ARV medication, she became so depressed and withdrawn her business crumbled and she retreated within the four walls of her home, often forgetting to take her medication and even eat.

One friend was so concerned she recommended Mary be sectioned under the Mental Health Act, and in 2006 she was admitted to a psychiatric hospital where she stayed for the next 14 months. After she was referred to the Mildmay, the right combination of drugs was finally found and Mary's health began to improve. She has since started giving talks on the dangers of HIV infection, particularly to the middle-aged.

Only those people fortunate enough to be referred to the Mildmay by their local health service benefit from its expertise. The standard of treatment for Aids-related dementia, as with all healthcare, remains something of a postcode lottery, with many left to be looked after by their families — often without a proper diagnosis of their problems — or placed in nursing homes with variable care. ➤➤➤



Both Sam and Mary's stories appear to highlight the dangers of failing to start medication early, or starting and then stopping it. "Ninety per cent of our referrals are either people diagnosed late or people who dropped out of medical care," says Dr Simon Rackstraw, medical director at Mildmay UK. "Dementia is often not picked up until relatively late. I don't know what it says about our working environment that sometimes symptoms in those who work are not noticed until they are very extreme. I think it is a much bigger problem than has so far been documented."

But in contrast to the symptoms of those suffering from forms of dementia such as Alzheimer's, who become increasingly apathetic as their memory and bodily functions fail, those with HIV-associated dementia generally remain mobile, energetic and verbally fluent, Rackstraw explains. For those with HIV-related dementia it is the brain's executive function, its ability to make choices and decisions, that is most affected.

"Some of those I have treated have been in high-powered jobs like teaching or aircraft mechanics and can often sound plausible when they talk about things. But they flounder if you try to go into any depth," he continues.

The large-scale Charter (The Central Nervous System HIV Antiretroviral Therapy Effects Research) study of 1,555 HIV patients carried out in the US in recent years showing 52% had some form of brain impairment also revealed that this was only clearly apparent in a small proportion of those affected, some of whom developed noticeable tremors, had difficulty with their balance or experienced seizures or changes in character. Specialists working with such patients in New York, where

Mary Jones (above), 66, discovered she was HIV-positive at 52. She went for a test after finding out her partner had been unfaithful

an estimated 145,000 people live with HIV, tell heart-wrenching stories of men in their forties who once enjoyed high-flying careers but are now fully aware that they are slowly losing their minds. One 46-year-old diagnosed with HIV in 2001 talked of how, at first, his life returned to normal after being put on a drug cocktail; he stepped up his exercise regime, studied for a master's degree and rose to a senior position in a telecommunications firm with a six-figure salary. But then gradually his memory began to fail and he fell into what he described as "an Alzheimer's-like state". He lost his job, now lives on disability allowances, and talks poignantly of wanting "more out of life".

Another 44-year-old high-achiever in the field of scientific research spoke of his shock at flunking the first semester of an advanced degree recently, because he couldn't remember what he was studying and even struggled to find words and understand conversations. "I started to be like a zombie," he confesses. He has since been diagnosed with mild HIV-related cognitive disorder. "That's the hardest part, when you cognitively know you're losing yourself," said a male dancer suffering from the same condition.

Tony Whitehead has been riding the precarious rollercoaster of living with HIV since contracting the virus from a male partner 25 years ago. As one of the founders of the Terence

Higgins Trust, he has more knowledge and experience than most of how it devastates lives. Yet he is unsure if the symptoms of premature ageing he is experiencing are a result of the virus he contracted in 1984 or the drug treatments he has been prescribed since then.

"I joke that I am much older than my years because of everything I've gone through. But people actually think I am. They assume I'm an old-age pensioner, but I'm 55."

When Tony developed full-blown Aids in the 1980s, he was prescribed the only treatment then available — AZT, a toxic old drug first developed for cancer treatment. AZT worked by blocking the reverse transcriptase enzyme the HIV virus needs to replicate and it prolonged the lives of many. But used alone as a treatment, it did not stop the ability of the virus to mutate.

"In the years before better drug treatment came along, it was like being in a war against an enemy you could not see. In our peer group, friends were disappearing at an astonishing and terrifying rate," says Tony, whose CD4 count fell to zero in 1996, and it seemed he, too, had only a short time to live.

His life was saved by the introduction that year of the first experimental ARV protease-inhibitor drugs. These block the enzyme allowing HIV infected cells to replicate. Later came combination therapy, where two or more ARV drugs are taken at the same time, and treatment was revolutionised.



During these years, as soon as news leaked of a new drug being developed, HIV lobby groups would demonstrate outside the headquarters of pharmaceutical companies to push for their quick release. "It was like a land rush," recalls Lisa Power, of the Terence Higgins Trust. "So it's unlikely there would be legal recourse against drug companies for the side effects these drugs caused as they could argue they acted in good faith." Nevertheless it meant many people were on experimental regimes for years. These were not kind on the body. "I never thought I would still be here to discuss Aids and ageing and I am delighted that I am," says Tony, who, like his partner, was on a succession of such therapies. "But I am also very concerned. Nobody is sure what the long-term implications of this will be."

Among those affected by HIV who wish pharmaceutical companies had disclosed more of what was known about the harmful side effects of early HIV drugs, such as AZT, are some surviving haemophiliacs who contracted the virus through being given contaminated blood products. Throughout the 1970s and '80s, 4,670 British haemophiliacs who received blood were infected with hepatitis C, and 1,243 of them also contracted HIV. Nearly two-thirds of the 4,670 have since died — many within just a few years of being diagnosed.

Mark Ward was one of those not expected to live long. Together with his younger brother, also a haemophiliac, he contracted HIV from blood

transfusions in the early 1980s when he was in his teens. Both boys had been in hospital at the same time, Mark recovering from a knee operation. "As we were leaving the hospital, one of the nurses shouted after our parents, 'By the way, d'you want to know the result of the boys' HIV test? They're both positive. See you next time,'" Mark, now 40, recalls with a bitter laugh.

'IT WAS A HUGE SHOCK WHEN THEY TOLD ME. WHEN YOU'RE STRAIGHT, MIDDLE-CLASS, WHITE AND DIAGNOSED WITH HIV, DOCTORS ASSUME THAT YOU MUST HAVE BEEN A DRUG-USER'

"Our parents were told to take us home and spoil us a bit. Take us to Disneyland quickly if they wanted to, because we only had a couple of years to live."

What followed for Mark were years of experimental drug therapy. While his brother remained well, when Mark first started to fall ill in the early 1990s, he was prescribed AZT.

"I was 21 and lived every day as if it were my last. I was partying hard and often forgot to take the drug. I believe now that that is what saved my life. Many of those who took high dosages of AZT died very quickly."

If taken in high doses, AZT, which was originally patented by the UK-based Burroughs Wellcome & Co (now GlaxoSmithKline) in the mid-1980s, could damage bone marrow. Since the HIV virus itself also damaged bone marrow,

Tony Whitehead (below) and his partner, Francisco. Tony caught HIV 25 years ago. 'People think I'm a pensioner, but I'm 55'

these effects combined sometimes proved fatal. The drug is rarely used today, but if prescribed is used in combination with other medication to avoid such problems.

When ARVs and combination therapy came along, both Mark and his brother were put on a succession of different treatments.

"We felt like we were pieces of meat being experimented on for years by the drug companies." As a result of this, Mark believes, he has developed a range of medical complications more usually associated with ageing, including severe gastric problems, renal failure, heart abnormalities and high cholesterol.

"Doctors told us when we were young we were survivors of a terrible accident, and we felt grateful for every day we were alive. But now we believe a lot of the problems we have suffered have been caused by the side effects of some of the treatments we were getting, and we feel like victims," says Mark, a member of the campaign group Tainted Blood, which is engaged in a lengthy battle against the government to get financial compensation for the part it played in haemophiliacs becoming infected with HIV and hepatitis C through contaminated blood products.

Although the potential side effects of all HIV medication are listed on the packet, as Mark points out, "If you're given a drug and told it's going to save your life, you don't ask too many questions." But, as he concludes, "Every single day that those of us with HIV live is a new

day being written in the Aids manual. We are all still learning."

Little priority is now given by the government to warning the public of the continuing dangers posed by HIV/Aids. Compared to the blitz of publicity and health warnings issued when the disease was in its infancy in the mid-1980s — when less than 10,000 had been diagnosed with HIV in the UK and a leaflet was sent to every household in the country explaining ways the virus was transmitted — "HIV has gone off the public radar," says Lisa Power.

In the wake of the hard-hitting 1980s "Don't Die of Ignorance" television campaign, showing tombstones with Aids chiselled on them, new diagnoses of HIV dropped by a third and remained relatively stable at around 3,000 a year until 2000. Since then, the number of ➤ 45

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new diagnoses each year has climbed rapidly.

Yet young people particularly often see HIV as a curable disease. And many older people also run the risk of infection through ignorance or indifference. The number of HIV-positive people approaching old age is increasing, not only because newer drug treatments have improved survival rates, albeit with medical complications, but also due to new infections in older people.

In 2008 there were 10,208 people over the age of 50 seeking treatment for HIV in Britain — a number set to double to more than 20,000 in the next five years — with 816 over-fifties newly diagnosed in 2008; this is nearly double the number of over-fifties newly diagnosed five years ago.

“A lot of people newly on the dating scene because of divorce or separation in their middle years are putting themselves at risk because they don’t use any protection when having sex,” explains Mary Jones. “The men come from a generation that thinks it’s a woman’s responsibility to take precautions and the women don’t insist on their partners wearing condoms because there’s little chance of them getting pregnant.”

As doctors and older patients themselves rarely perceive older people to be at risk of contracting HIV, the latter are less likely to undergo testing. Misdiagnosis is common and, if diagnosed at all, the virus is detected much later in the course of infection, when it has caused more damage and increased the risk of dementia.

There is also still a lingering misconception that HIV only affects gay men or people from sub-Saharan Africa. But an estimated 58% of people newly diagnosed with HIV in the UK in 2008 acquired their infection through heterosexual contact, and more than a quarter of these — 1,092 out of 3,717 in total — were not of Black-African or Caribbean origin.

Heterosexual people tend to be more reluctant to be tested, but the later the diagnosis is made, the more likely it is that complications will have set in and respond less well to treatment.

Moreover, taboos and stigma attached to openly discussing HIV still hamper efforts to eradicate the disease. As two day-patients undergoing treatment at the Mildmay explain, the threat of rejection by friends and family is a deterrent to disclosure.

Nancy has not heard from her mother in Nigeria since she told her she was HIV-positive seven years ago. The 30-year-old hairdresser came to this country when she was 20 to work and send money back to her family. She did not know then she was infected, and when she was diagnosed and told her mother she was denounced. “Everyone in my village knows I have HIV now. My mother says I am a prostitute. I can never go home,” says Nancy, who is now blind and mentally confused.

George is so frightened of how his family in Jamaica will react if they know he carries the virus that he vows he will never tell them. He was diagnosed with HIV six years ago, shortly after moving to this country. “In Jamaica, if people know you have HIV they don’t come near you. They leave you to die,” says the 45-year-old, whose cognitive functioning is now so impaired he has to be accompanied everywhere by his wife for his own safety.

Worldwide, more than 33m people are infected with the virus. In the UK alone, according to the Health Protection Agency’s latest figures, there were an estimated 83,000 people infected with HIV at the end of 2008 — a quarter of whom are unaware that they are carrying it. More than 7,000 people are newly diagnosed each year. This means the overall number infected with HIV in the UK is expected to rise to around 100,000 by the end of this year.

“The problem today is that too many people think if you get HIV you just take some pills and it will go away,” says Peter Adams, 62, another Mildmay patient, whose career in finance crumbled after he was diagnosed over 10 years ago.

As the stories of the people I met for this article show with alarming clarity, this is far from the truth ■ *Some names have been changed to protect identities*

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