

16th Annual Conference of the
National HIV Nurses Association (NHIVNA)



Adrienne Seed

Positively UK

26-27 June 2014- City Hall, Cardiff

LATE DIAGNOSIS

Adrienne Seed



My name is Adrienne Seed and the subject of this presentation is late diagnosis. Because I am a visual artist I believe in the power of imagery so I am going to use a selection of pictures combined with words in an attempt to portray what the impact of late diagnosis meant to me and how it affected my life.



1996

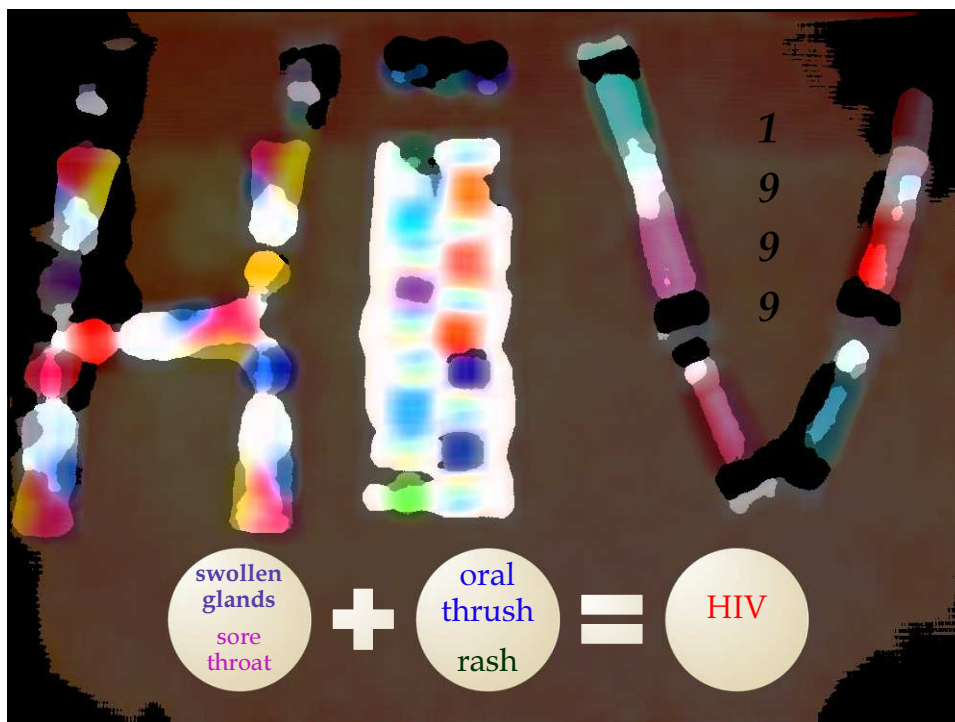
This is a picture of my partner and I on the yacht in the South of France. As you can see we looked the picture of health and had everything to live for.

1998



A few years later another picture of us only three months before my partner died. He had been suffering from thrush, strange fevers and unexplained bruising to his body, but he was receiving the best private medical care, so we didn't think there was cause to worry. Shortly after that photo was taken - completely out of the blue - he was diagnosed with liver cancer and told he only had six months left to live.

After he died I started to suffer from ill health - sore throats, swollen glands, loss of voice, constant thrush in my mouth and strange itchy rashes, in fact the same symptoms as my deceased partner. I visited my family doctor on numerous occasions trying to get rid of the thrush which was stopping me from eating. I thought that's why I was losing so much weight and why my hair was starting to fall out. I became so used to feeling ill that it became the norm and I just battled on, but getting weaker and weaker all the time. This was a very low point in my life - I also found out that my partner had been two timing me with a beautiful Russian girl who apparently had medical problems and was using him to get a visa to escape from Russia. I was yet to make any connections.





Whilst on holiday in Spain I became very ill and ended up in Can Misses hospital in Ibiza with pneumonia, during which time I had countless blood tests, but obviously I was never tested for AIDS. Maybe they should rename the hospital Can Missed it because somehow they did!

On my return to England I showed the x-rays and results from the Spanish hospital to my family doctor. He gave me yet more antibiotics and potions for the thrush and the itchy rash and sent me on my not so merry way.



The test was confirmed at the GUM at Blackburn Hospital. At that point I had a viral load of over two million and my CD4 was 21. I was started straight away on medication. The medication - which was more difficult to take in those days - gave me hallucinations as well as many other side effects.



Shingles - back



Shingles - front



Being diagnosed so late meant that my body had become very weak and I was finding it hard to fight off infections. I was constantly ill - then I developed the most horrendous case of shingles, which was so bad they kept a photograph at the hospital for their medical records.



When the medication had done its miraculous stuff and my viral load became undetectable, I enrolled at university to study counselling, the idea being that when I qualified I could help newly diagnosed people, so unlike me, they would have somewhere to turn to. Once I'd told my son, who was 22 at the time, which was the worst thing I ever had to do, I could finally come out of the HIV closet and become an activist. I joined Poz Fem and ICW where I met many inspiring women and also many women who had experienced late diagnosis with near death experience like myself. I decided to use my art for activist purposes to raise awareness.

2007 started writing my blog



I started my hivine website and blog after speaking on the Jeremy Vine show on radio 2. In those days there were very few people blogging about HIV. My goal was to lessen the isolation many of us are forced to suffer due to stigma. I often use humour as a bait, or cunning ploy, to lure non positive people to the site in an effort to defeat HIV related stigma and also to encourage people to get tested. Knowing your status earlier than later gives you a better chance of survival.

www.hivine.com

www.hivine.com

International AIDS Conference Mexico 2008



Some amazing things have happened to me because of HIV - for example I fulfilled my dream of going to Mexico where I acted as a representative for Body Positive North West at the International AIDS conference. During my time there I met many women who had been diagnosed late like me and only survived by the skin of their teeth.

Annie Lennox



This is Annie Lennox at the conference wearing the tee shirt I designed.

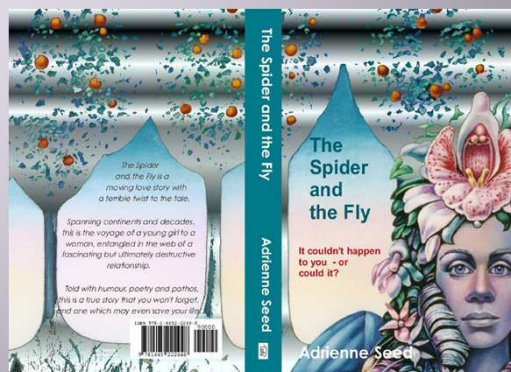
2008 Graduated from University



That same year I also graduated from University a fully fledged counsellor.

2009 Published my autobiography “The Spider and the Fly”

www.lulu.com



I published my autobiography, The Spider and the Fly. It was considered for publication by Random House but finally turned down because they thought HIV was not a big enough hook. I wonder in view of the rising statistics, especially amongst women, heterosexuals and older people, if they would see it differently now.

2009 started HIV support group Thrivine



I started Thrivine an HIV support group based in Blackburn. In that year alone we supported over sixty people and their families. We're still going strong and hold regular monthly meetings.



NHS
2010



Thrivine won an award from the NHS Dragon's Apprentice to produce the Positive Picture, an art project which I facilitated and which was exhibited at Blackburn Cathedral for World AIDS day.

The Positive Picture Project



These are some paintings from the positive picture

Thrivine won the Gilead Putting Patients First Award 2010



Thrivine won the Gilead, 'Putting Patients First' award for the UK and Northern Ireland.



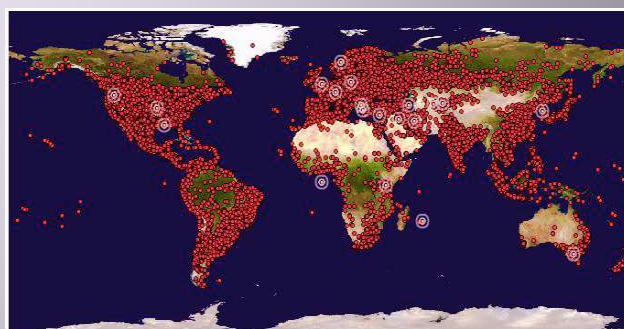
This is my painting, entitled, 'The last Supper'- it's all about my experience of being diagnosed with HIV - the huge pills, the pallbearers carrying me off to my death, the white rabbit - time was running out, my dead partner's empty shoes.

Paris Congres - International Conference of Cytologists 2013



The painting was exhibited last year at the Paris Congress at the International Conference of Cytologists.

visitors to www.hivine.com



44 cities & 25 countries online



10,149,607 visits since July 14, 2010

To date and to my immense pride my blog and website hivine has received over ten million hits worldwide. Every red dot represents visits from all the many towns, cities and countries - even the remotest places like Iceland and Alaska and tiny little known islands floating in the pacific. Places I've never even heard of. Hivine is currently receiving 5 to 6 thousand hits a day.



My stat globe - I love seeing all the different flags and knowing those people are on line and hopefully finding comfort and support or information that will give them some hope. I wonder sometimes who all these people are and if they even understand my often 'eccentric' blogs, especially as my dog Lady Doodles sometimes writes them for me. Last year the website was hacked by anti-gay protesters and I lost everything - but not a one to be beaten, especially by stigma and homophobic nutcases, I managed to put some if not all of the content back. If you want to join the hivine please visit me at www.hivine.com

Melancholy - get a dog!

ME AND LADY DOODLES



HIV can certainly make you feel alone and melancholy at times - my advice if you are feeling melancholy - get a dog. A dog loves you unconditionally no matter what you've got!



This is my painting of my HIV world – my HIV mandala, controlled by the HIV virus which is central to my life. Had this virus not been detected – albeit at a very late stage, I would not still be here on this beautiful planet.



The virus is controlled by the drugs I take, which since I started, have been many different combinations. It's hard to remember or even pronounce all the different names. Most positive people I know if you ask them what meds they're taking will say - not sure, a pink one a blue one and an orange one

LOVE HAART



Love heart - H- A-A-R-T - Highly Active Antiretroviral Therapy. I try to imagine these toxic lifesavers as something beautiful.

Sunday Times
10th April 2014



- THE former partner of a multimillionaire inventor has backed a new government campaign warning women that they may unknowingly be carrying the Aids virus.
- Adrienne Seed, 64, was in a relationship with Brian Mercer — the creator of Netlon plastic mesh, for more than 30 years. She believes he unwittingly infected her.
- “My reason for speaking out is not for sensationalism or to cast blame but to raise awareness and hopefully save lives,” said Seed, who found she was HIV positive in 2001.
- Figures from Public Health England show the number of heterosexual women over 50 diagnosed with HIV has doubled to more than 200 a year in the past decade. Experts believe there may be many more undiagnosed infections and the government has reversed a ban on the sale of instant result home test kits.
- Seed, an artist who trained at St Martin’s School of Art in London, was diagnosed by a homeopathic doctor when she went to Spain to recover from what she thought was pneumonia.
- At least 100,000 people are infected with HIV in Britain with an estimated 25% of those unaware they have it.
- Public health England said the first home test kits were going through the regulatory approval process and would be available within months.

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I feel I've done everything I possibly can in the intervening years since I was diagnosed to raise awareness and encourage people to get tested, so the same thing doesn't happen to them as happened to me. I've spoken on the Jeremy Vine show BBC Radio 2, on Women's Hour radio 4, I've sat on the famous sofa on ITV's This Morning being interviewed by Holly and Philip, I've even been on News at ten. I thought I'd round it off, at least for now, with the Sunday Times - what better way. So this presentation ends where it started off, at least with the same photo, although really I suppose I should have used a more updated image. I was 52 when I was diagnosed and I'm 64 now

So much has happened in between and I am no longer the same person. HIV has changed me beyond all recognition, but it hasn't beaten me although it very nearly did. If I hadn't of been tested for HIV I would not be standing here now. I hope perceptions and stereo-types have changed - had I come to you in 1998 showing what we now know to be typical symptoms of HIV infection, would you have offered me a test for HIV - and if, as a straight, white, heterosexual woman of a certain age, would you now?

My feelings about late diagnosis - Better late than never. Listening to one of the HIV nurses talking about stigma this morning reminded me that is not only us the patients who have to suffer from stigma but also the people who care for us and that includes our HIV nurses. I remember asking mine why she also had to remain 'invisible' and she told me it was to protect us and to protect our families. HIV nurses play a key role in the lives of HIV positive patients so on behalf of us all I would like to say a great big thank you.