

Early community involvement 1981-1998



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Disclosure

No personal financial conflicts of interest.

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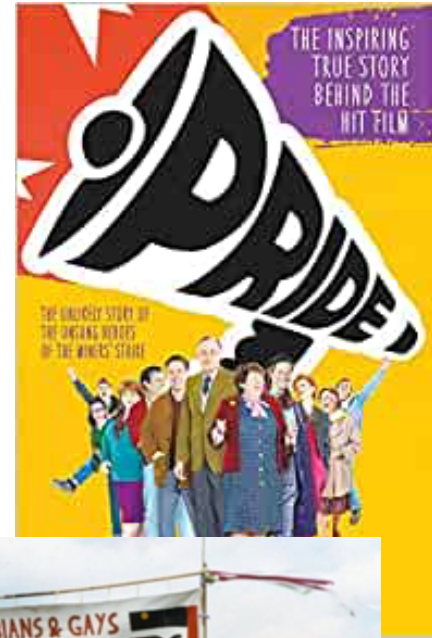
Background

Apologies: Subjective, London-based, white, gay, male perspective...

1980s were divisive. Privatisation of coal, steel, gas, water, electricity, BA, airports, rail etc. (Funded tax cuts for business and the wealthy, who donated to one political party). Four million unemployed. Social policy on “family values”.

NHS, Royal Mail and air were narrowly saved.

Community: anti-racism, anti-apartheid and the miners strike. Some local Labour councils challenged central government and supported lesbian and gay rights.



Timeline 1 - First responses

Unless you were directly affected by HIV, the UK was behind the US by several years.

There was sex before HIV – and low awareness meant this that continued to the mid 80s.

July 1982: Terry Higgins died

Nov 1982: First article in Capital Gay

1983: early Terry Higgins Trust meeting in Conway Hall that included Jonathan Grimshaw and Dr Ian Weller.

1983: AIDS Action Group

Dec 1984 – THT safer sex leaflet included not having sex with Americans or people who were ill.



Nov 1982

Early reports

Dec 1984

But from 1983/4 first reports in Capital Gay were in single and then double figures (compared to many thousands in the US).

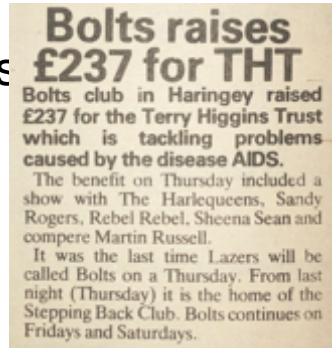


May 1983



Timeline 2: Community Fundraising – peer support

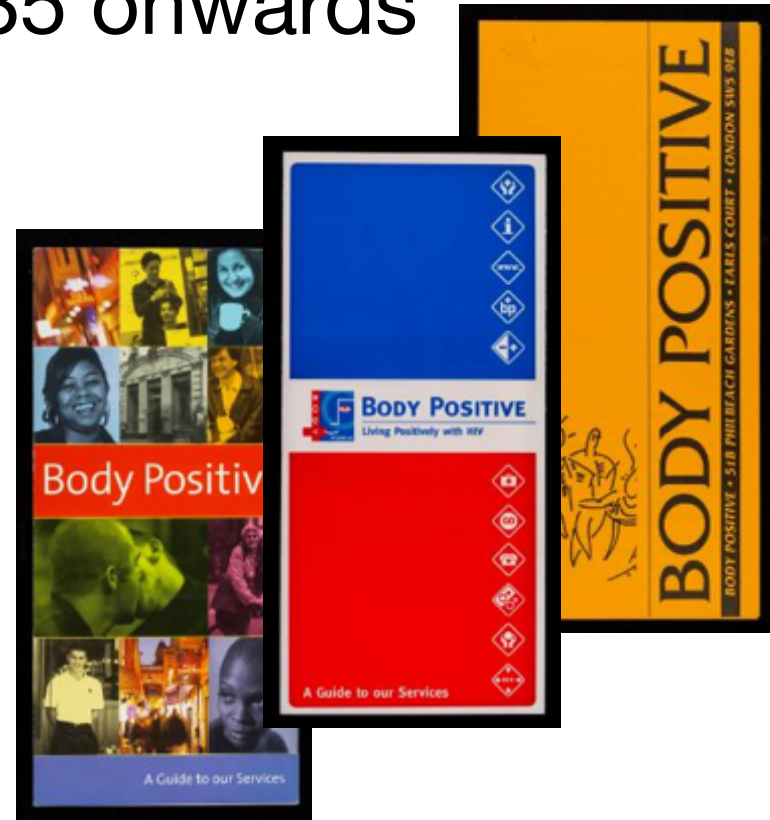
- 1984 – THT becomes a charity, first helpline.
- 1985 – Body Positive - later expanded to many local and regional groups - first HIV test, first candlelit vigil.
- 1986 – AVERT – education in schools
- 1986 - CRUSAID – (Kobler Centre and Walk for Life marches)



Body Positive – 1985 onwards

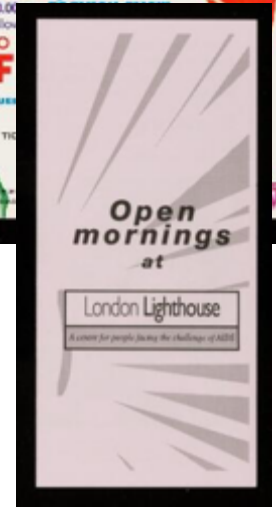
Self-help, peer support, phonenumber,
small grants
Youth group
Women's group
Drop In Centre
Lunch meals

Newsletter – no. 240 (nov 1999)
Many local organisations in the UK:
Lincs, Dorset, Blackpool (94), Birmingham (89),
Wear, Cheshire & N Wales, Somerset, Derbyshire,
Brighton, Hertfordshire, Cardiff, Bedfordshire,
Shropshire, Kent, Thames Valley, Devon, Mid
Sussex, BP North East, BP North West.



London Lighthouse – 1986

Pioneering centre for respite and palliative care - when people with HIV were being turned away from existing hospice services. (Model for Bethany Trust, Sussex Beacon etc)



Timeline.3 Late 80s: Key projects for diversity

- 1986 – Birchgrove Group
- 1987 – National AIDS Trust.
- 1987 – National AIDS Manual.
- 1987 – Positively Women,
Mark Ashton Trust.
- 1988 - London Lighthouse.
- 1988 – Kobler Clinic
- 1988 – Blackliners
- 1988 – Food Chain
- 1989 – Mainliners
- 1989 – Frontliners



Birchgrove Group – 1986

- Sept 1983 – first haemophilia cases in UK.
- 1985-91 – Legal action (MacFarlane Trust)
- 1986 – Mary Dykes supports Birchgrove meetings in Cardiff – different to Haemophilia Society.
- 1988 – provides peer support services and fundraising for residential support and relaxation weekends.
- 1990 – expands to Manchester and London.
- 1993 – First conference.
- 1996 – First trees bought.
- 2004 – Woodland opens

<https://www.birchgrovegroup.org>



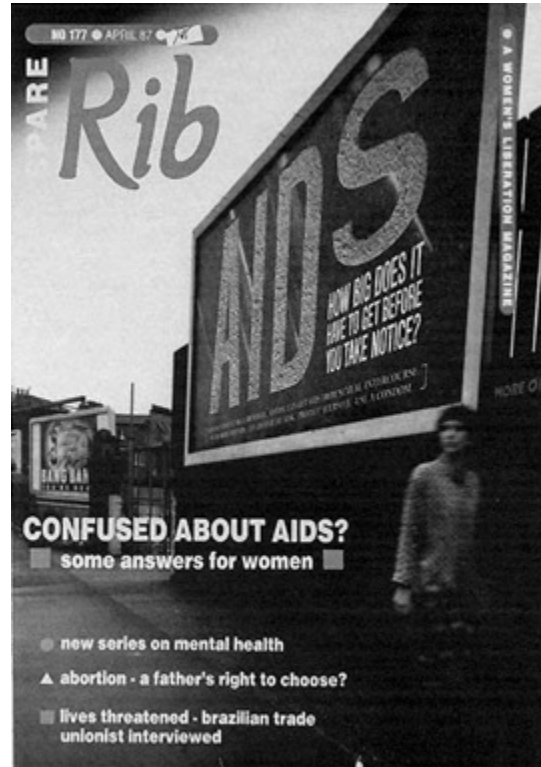
Slide: Robert James

Positively Women – 1987

By and for HIV positive
women

1987 – Spare Rib
interview

1991 – leaflet for
women's drop-in
support service

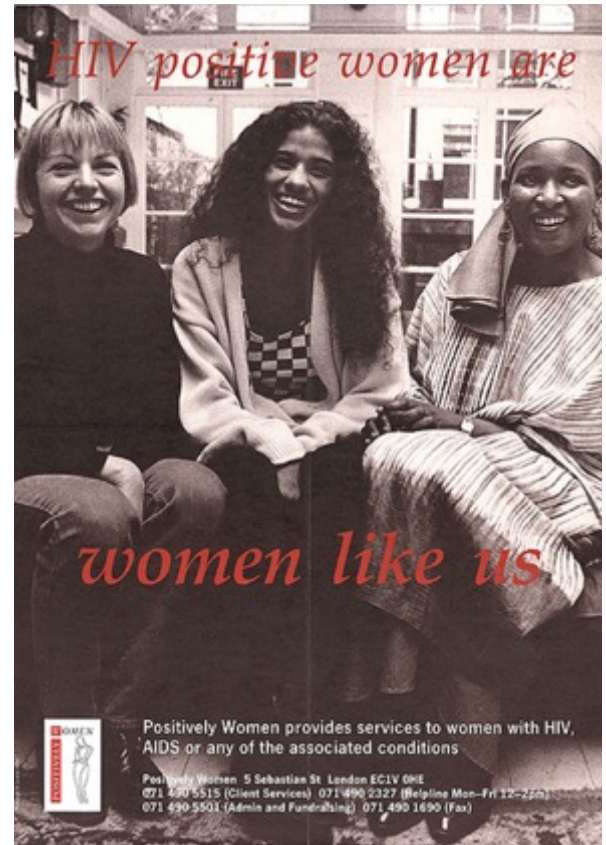


Slide: Jo Manchester and Jane Shepherd

By and for HIV positive women 2:

Resources produced by and for women living with HIV, London 1990 and 1992

Produced by Positively Women.



Slide: Jo Manchester and Jane Shepherd

By and for HIV positive women 3:

Awareness booklet for young women, Cardiff, UK, 1990.

Cardiff AIDS Helpline.

A Positive Woman's Survival Kit, London, UK, 1999

ICW

YOUNG WOMEN & AIDS
SAFER SEX and SAFER HEALTH

DON'T SWITCH OFF! AIDS AFFECTS ALL OF US WHO HAVE SEX
*Whether with men or women. *Whether for pleasure or for business

SO READ ABOUT IT... THINK ABOUT IT... TALK ABOUT IT...



GOOD HEALTH IS IMPORTANT
WE ALREADY KNOW A LOT ABOUT AIDS—AND THE MORE WE KNOW, THE MORE WE CAN DO TO PROTECT OURSELVES. IT'S NO GOOD SAYING, 'IT CAN'T HAPPEN TO ME.' IT COULD, BUT YOU CAN DO A LOT TO PREVENT IT.


WHAT IS AIDS?
IT'S A MEDICAL CONDITION WHERE THE BODY'S IMMUNE SYSTEM (WHICH PROTECTS IT FROM INFECTION) BECOMES DAMAGED. THE BODY IS THEN UNABLE TO FIGHT OFF ILLNESSES.
THIS EFFECT ON THE IMMUNE SYSTEM IS CAUSED BY A VIRUS CALLED HIV. PEOPLE WHO HAVE THE VIRUS CAN CONTINUE TO BE WELL AND DO NOT NECESSARILY GO ON TO DEVELOP AIDS.

HOW IS THE VIRUS SPREAD FROM ONE PERSON TO ANOTHER?
THE VIRUS IS SPREAD BY THE BODY FLUID OF A PERSON WHO HAS THE VIRUS ENTERING THE BODY OF ANOTHER PERSON'S BODY FLUID (MENSTRUAL BLOOD AND SEMEN (SPERM, CLM)).
THE MOST COMMON WAYS IN WHICH BLOOD OR SEMEN CAN GET INTO YOUR BODY ARE:
• PENETRATIVE SEX (i.e. PENIS IN THE VAGINA OR PENIS IN THE ANUS)
• USING NEEDLES TO INJECT DRUGS INTO YOUR BODY
THE VIRUS CAN ALSO PASS THROUGH MENSTRUAL BLOOD AND THROUGH CUTS ON THE BODY.

YOU CAN'T TELL BY LOOKING AT SOMEONE WHETHER THEY HAVE THE VIRUS. THEY CAN BE PERFECTLY HEALTHY

A Positive Woman's Survival Kit

This Kit is dedicated to all HIV positive women in the world.
Each of us is a special human being.
Each of us deserves to be treated with respect and dignity.

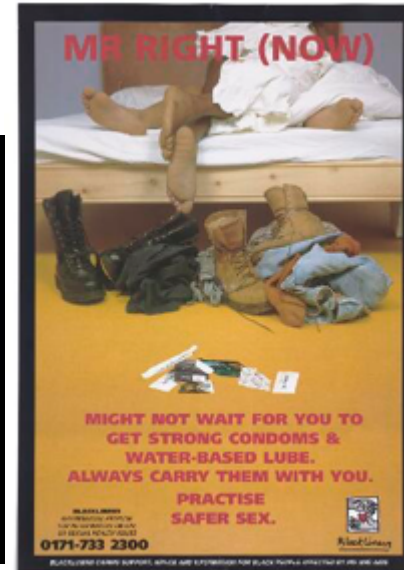


Slide: Jo Manchester and Jane Shepherd

BCAT 1986, Blackliners – 1988

HIV prevention and support for African, Caribbean and Asian communities.

Developed from the Black Communities AIDS Team (BCAT, 1986): mixed group mainly for black and Asian gay/bi men.



Red, Hot and Blue (1990)

Tribute fundraiser, Simon Watney.

Reach Out and Touch (1991)

Community concert – ft Whitney Houston

Largest HIV march and vigil, Vernal Scott.



Photographs: Vernal Scott

Mainliners – 1989

Specialist support for people who inject drugs

MAINLINERS

WORKING WITH AND FOR DRUG USERS
AFFECTED BY HIV

208 STOCKWELL ROAD
LONDON SW9 4JL



ADVICE LINE
071 737 3141

SERVICE
071 738 4656

ADMIN
071 737 7472

REGISTERED CHARITY NUMBER
COMPANY LIMITED BY GUARANTEE
204841

community
MAINLINERS

sids

**THE
WORKS**

Number 1
HIV PREVENTION

USING and HIV



Cleaning Works

2x Bleach

1. Pour 10ml into 50ml water.

2x Water

2. Pour 10ml into 20ml water.

DON'T SHARE NEEDLES OR OTHER
SAFE INJECTION MATERIALS.

You need the needle and
syringe used to inject to be
clean and ready.

Wash 10ml into 100ml of
water.

Don't share needles or syringes.

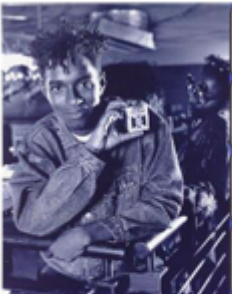
BE VERY CAREFUL WHEN
HANDLING NEEDLES, SYRINGES
AND OTHER INJECTION DRUG MATERIALS.

Dial 100

FREE

Clean

*if you don't have any clean works, then it's easy to make
a used set safer. but remember that **your best bet**
is a new set.*



Smart

*He does. Do you? Remember that you are in
control. Don't let anyone else control you. You are
the only person who can be safe, so every injection should
use a new set.*

100
FREE

100
FREE

100
FREE

100
FREE



Sound

*Even if you feel fine about your
drug use, it's worth knowing about the consequences
you can expect. For free, confidential advice on using your drug
safely, call 100.*

100
FREE

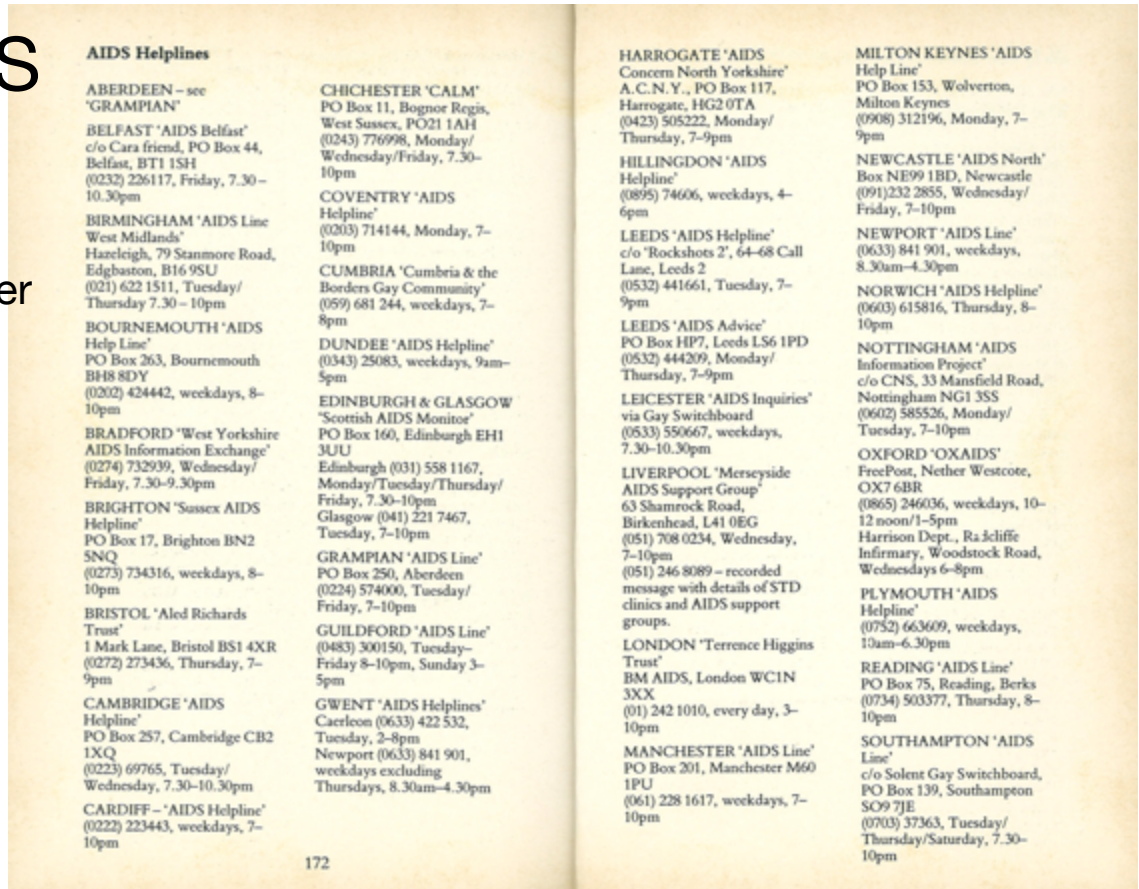
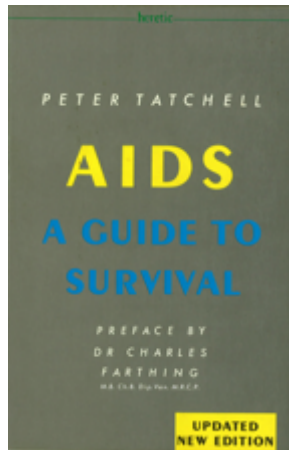
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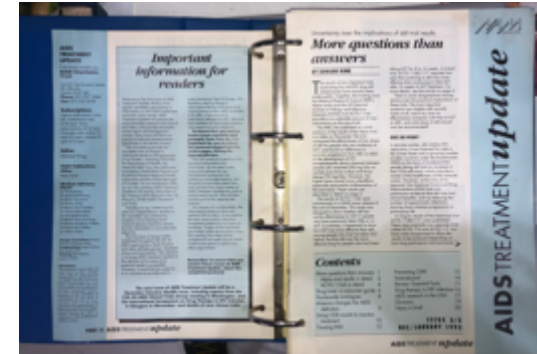
1987: 32 UK AIDS helplines

AIDS: A guide to survival, Peter Tatchell, 1987



Timeline.4 1990s

- 1990 - Black HIV/AIDS Forum (Manchester)
- 1991 – LEAN (London East AIDS Network)
– now Positive East.
- 1992 – Naz foundation & NAM updates
- 1993 – UK Coalition of People Living with HIV
(Published Positive Nation and Back to Work project)
- 1994 - Scottish Voluntary HIV and
AIDS Forum (HIV Scotland)
- 1996 – AIDS Treatment Project (ATP) – Treatment activist
organisation – peer led.
- 1996 - Body & soul.
- Plus numerous African support groups (see next slide).*
- 1997 – First BHIVA guidelines.



African support groups

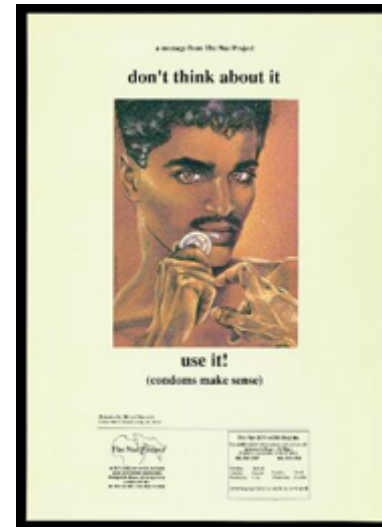
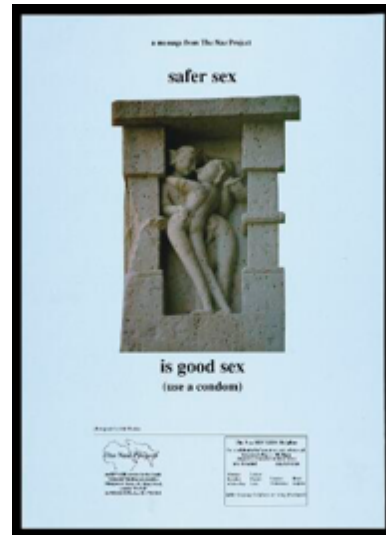
Many African support groups included

- Africa Advocacy Foundation
- African Community Involvement Association (ACIA)
- African HIV Policy Network (AHPN)
- BHAf (Black HIV/AIDS Forum)
- Black Health Agency
- HIV/AIDS Association of Zambia
- Ugandan AIDS Advocacy Foundation
- Uganda Community Relief Association
- Vanguard



Naz – 1992

Support group and services for HIV positive people from BAME communities.



Publications 1996 –



- ATP DrFax #11 – (Nov 1996)
- Body Positive #226 (Sep 1998)
- Positive Nation #40 (March 1999)
- Positive Times #39 (July 1998)

Publications



EQ#11 (John Stevens) 1999, ATU from 1992 , Continuum (Denialist) 1996

ATP 1996

AIDS Treatment Project (ATP)

Peer organisation of people who personally benefited from combination therapy.

DrFax – compilation of latest treatment news faxed to doctors every two weeks.

Volunteer-based treatment information phoneline. Could say treatment worked – at a time when many other HIV organisations were at-best cautious of treatment and at worst were actively hostile.



Summary 1998

By 1998 – when HAART was widely available, hundreds of community organisations had been set up across the UK. Apologies to the many who I have not been able to include.

More than 50 African support groups in London.

More than 30 branches of Body Positive across the UK.

National publications: Positive Nation, Dr Fax, NAM, Body Positive, Positive Treatment News, Positive Times, Equilibrium, Continuum (denialist) many organisation newsletters.

Many of these have no internet history (please keep your archives).

In Memory



Simon Mwendapole,
Uganda AIDS Action
Foundation (UAAF)

and

Paul Blanchard,
Founded the Chapman
Clinic. First editor of
ATP's Dr Fax and
i-Base's HIV Treatment
Bulletin (HTB)

Thanks

Robert James, Hope Mhereza,
Badru Male, Graham McKerrow,
Simon Watney, Ash Kotak, Vernal
Scott, Kate Thompson, Jo
Manchester and Jane Shepherd,
Polly Clayden, UK CAB. Wellcome
Trust (for some images).

Questions...

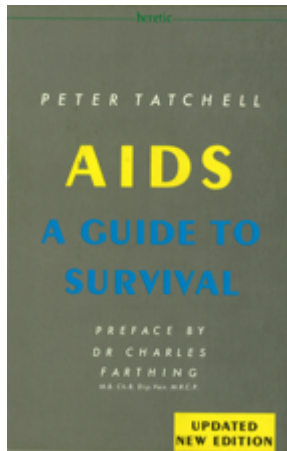


Flyposting 1987, S Collins

Back-up slides

AIDS: A guide to survival,
Peter Tatchell, 1987

Mental imagery: Imagining
sharks chasing infections.



- like to be fit and full of energy.
- 6) Now visualise your body fighting back against AIDS in *symbolic* fantasy form:
- * You could, for example, picture the AIDS viruses/opportunistic infections/cancers as a small group of languid squids and your defender cells as a huge shoal of sharks. Imagine the sharks ferociously devouring *all* the squids and not letting a single one escape. Then picture the sharks swimming away and the sea becoming totally tranquil and crystal clear to reveal an exotic wonderland of filagree corals and tiny multicoloured fish shimmering in the warm aquamarine waters.



- * An alternative symbolism could be based on warfare – ‘AIDS Wars’ – in which the defender cells are represented by huge

Early events

Community activism included getting information from the US (3 years ahead), prevention work in different communities (safer sex) and fundraising events.

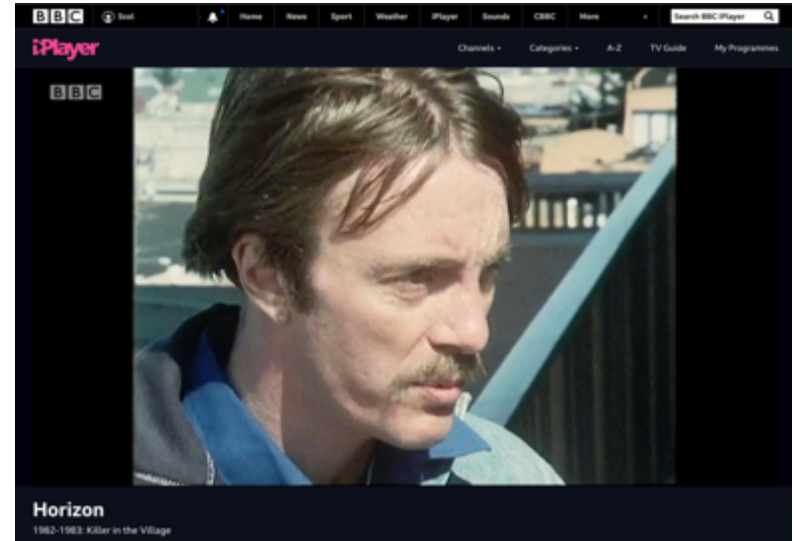
1981 – first cases reported in the US and the UK.

1982 - Terry Higgins died in July.

1983 - AIDS Action Group.

1983 – First THT meeting at Conway Hall,

1983 - Panorama and Horizon “Killer in the village”.



Horizon 1983: Bobbi Campbell, HIV positive nurse, coauthor of Denver Principles

Early safer sex: THT 1984

1. Have sex with fewer men.

2. Avoid anal sex, except possibly with your regular partner.

3. Have sex only with men whom you know to be in good health and who have had few other sexual partners.

4. Avoid sex with men who have been sexually active in North America in the last three years.

5. Since the virus has been found even in saliva, perhaps the only safe sex is mutual masturbation, body rubbing and dry kissing.