

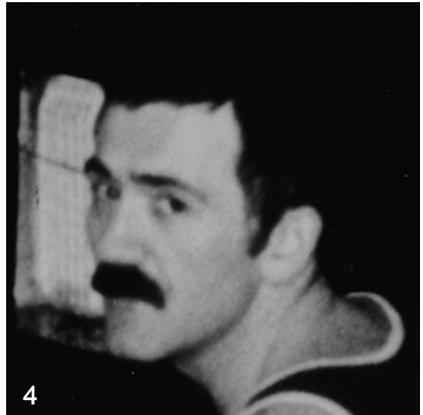
Doing it for Terry

Remembering Terry Higgins and his legacy on his 80th birthday

Foreword by

Dr Rupert Whitaker OBE,
Co-Founder of Terrence Higgins Trust





1. Terry at school, c.1961, **2.** Terry in the Navy, c.1964, **3.** Terry, c.1981, **4.** Terry, three months before his death.



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Foreword by Dr Rupert Whitaker OBE, co-founder of Terrence Higgins Trust

Terrence Lionel Seymour Higgins, known to his friends as **Terry**, was born on 10 June 1945 and was one of the first people in the UK to die of an AIDS-related illness on 4 July 1982, aged just 37.

When I co-founded Terrence Higgins Trust with Martyn Butler OBE, along with Tony Calvert, Len Robinson, and Chris Peel, we **Did it for Terry** – my then-partner. We loved him deeply and channelled our grief into action, determined to fight in his name, and challenge the then-unknown illness that claimed his life, and the lives of many others.

As a commemoration and celebration of what would have been Terry's 80th birthday, I'm proud to introduce this booklet. It tells Terry's story, the impact of his life and death, and how it shaped Terrence Higgins Trust into the leading voice in the fight against HIV transmission and stigma, while providing important support for people living with HIV.

Terry was an ordinary man who stood up against injustice, especially the discrimination faced by the gay community in the 70s and early 80s. His legacy lives on through the work of Terrence Higgins Trust, and his life is commemorated in the Terry Higgins AIDS Memorial Quilt, expertly crafted to mark our 40th anniversary in 2022.

This booklet shares how Terrence Higgins Trust has provided love, care, and vital support for people living with HIV, filling a void in services that once forgot our community.

As you read, I ask you to think of your 'Terry', the person or people you are honouring by supporting Terrence Higgins Trust.

Thank you for helping us create a world where HIV holds no one back.



Warm wishes,

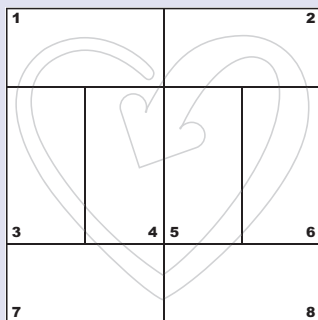
Dr Rupert Whitaker OBE

*Co-Founder and Patron
Terrence Higgins Trust*



In 2022, as part of a year's worth of celebration to mark 40 years since Terry's death in 1982, we worked with The Quilters' Guild to create a brand new eight-panel memorial quilt in his name.

In total, there are eight magnificent panels, some of which feature throughout this booklet and trace Terry's life. When they are all brought together, they feature our heart emblem, which is in our logo and centres love, care and compassion in all that we do.



Read on to find out more about Terry's life, the quilt's different panels, and a brief history of Terrence Higgins Trust and HIV in the UK.



To find out more about the individual panels of the quilt, scan the QR code.

Terry's early life

Terry Higgins was born on 10 June 1945 in Priory Mount Hospital, Pembrokeshire. He grew up in Haverfordwest with his mother Marjorie and attended the local all-boys grammar school from 1956 to 1960.

"Terry was a talented boy," recalls neighbour, Bill Yabsley. ***"He was an accomplished piano player and won the school's long jump competition."***

Terry grew up in a time and place where coming out as gay was risky. ***"I would have thought it would have been dreadfully difficult because there was such a stigma attached,"*** adds Angela, a school friend.

At 18, Terry joined the Royal Navy. After five years of service, he felt it was time to leave. Wanting a quick exit, he informed a senior officer he was gay. The officer replied, ***"If we booted out everyone who was gay, we wouldn't have a Navy left."*** Denied a discharge, Terry painted hammer and sickle motifs on the ship and was formally asked to leave in March 1968.



Panel 4 of the quilt marks his Welsh heritage with a painting in the colours of the Welsh flag, using our 40th anniversary stamp.



Moving to London

Terry lived in Earl's Court and Shepherd's Bush. His flatmate Linda Payan recalls, *"I met him at the Earl's Court Wimpy bar. He was funny, warm, and soon moved in with his boyfriend."*

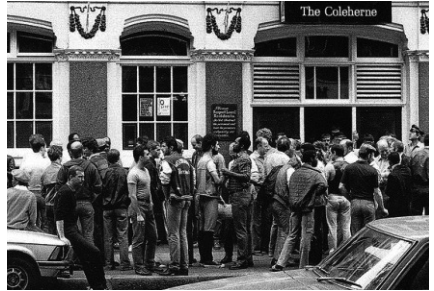
Terry worked at Hansard from 1976. "He typed like the wind," it says on Panel 6. Linda recalls pretending to be his wife at dinners, as being outed could cost him his job. He later worked in the Middle East and as a computer operator for *The Times*.

By night, Terry was part of the gay leather scene. *"Terry took me to clubs like The Coleherne,"* says Linda. *"Saturday nights were never dull."*

In 1979, Heaven nightclub opened, a defining moment for the gay community. *"Heaven was the first space that was ours,"* said one friend. *"Before that, we were just tolerated."* It also became a place where the AIDS epidemic was first noticed.

Julian Hows, an activist and colleague, recalls: *"He was a leather queen in chaps, always stopping by for a chat at the Burger Bar. A friendly, social person."*

Martyn Butler, who met Terry in 1978, said, *"He loved dancing - he had wiggly legs and hips, totally immersed in the music. He danced till we all dropped."*



Source: Les K. Wright



Panel 7 of the quilt celebrates Terry's nightlife and includes some of his favourite tracks - like 'Do You Wanna Funk?' and 'I Feel Love'. A Spotify playlist is available via QR code.

Terry's life, love, and legacy continue to inspire.



“Higgins adored gay culture, American culture, books, movies, music, clothes, clubbing – he was determined to live life for himself.” *The Guardian*

When Martyn Butler arrived in London in 1978, Terry, who was ten years older, took him under his wing.

“He didn’t want anything from me. He showed me the ropes, stood up for me, taught me confidence. He held my hand as I grew up,” Martyn remembers.

At the 1980 London Pride, Terry rode on Heaven’s float – one of the first ever used. When police harassed marchers, Terry leapt off, leather belt in hand, shouting: “How dare you bitches attack my friends.”



Panel 2 of the quilt celebrates Terry’s pride in his identity. The panel features the Pride flag as Terry would have known it, leather to reflect his place in the gay men’s leather scene, and a nod to the hanky code.

In 1981, Terry met Rupert Whitaker at Bang nightclub. They began dating and Rupert travelled back to London from university most weekends to spend time with Terry.

Reflecting on how Terry always brought a smile, Rupert recalls that *“He’d meet me in an outrageous pink sleeveless sweater – he didn’t give a damn.”*

Terry's death and legacy

In 1982, Terry was hospitalised after collapsing at Heaven nightclub. He was unconscious and placed in isolation. When Rupert visited, he wasn't allowed in the room. He asked Terry's consultant if it could be "the American disease," but got no reply.

Terry seemed to recover and discharged himself.

Rupert says, *"He was out having a picnic with friends when [the photo below] was taken. Even though he'd lost so much weight, we had no idea how severe his illness was."*

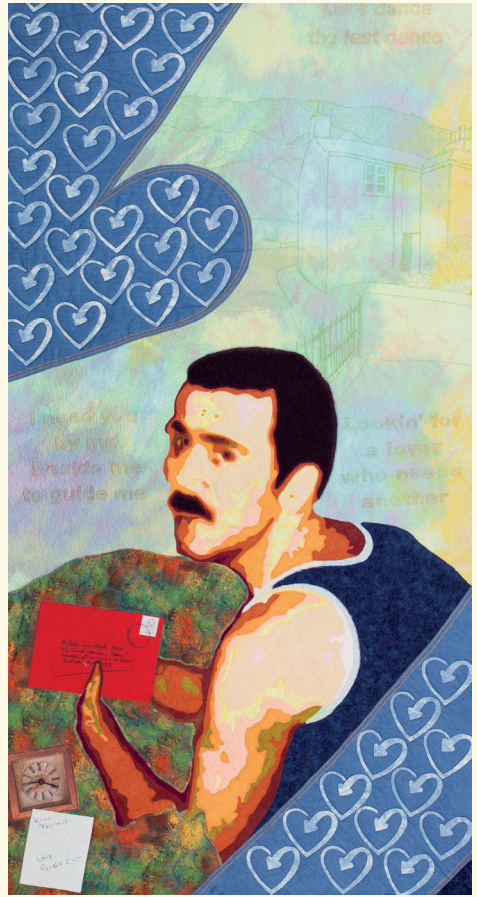
Less than a month later, on 4 July 1982, Terry died, aged just 37.

Within weeks of Terry's funeral, his friends – struggling with grief and desperate to act – gathered in Martyn Butler's front room in Limehouse. **There, Terrence Higgins Trust was born.**

By 1984, the organisation had **gained charitable status** and was providing support to people affected by HIV, becoming the UK's leading HIV organisation.



Terry, pictured on the right



Panel 5 is a tribute from Rupert Whitaker OBE to his then-partner. Rupert, who has lived with HIV for over 40 years, included cherished memories:

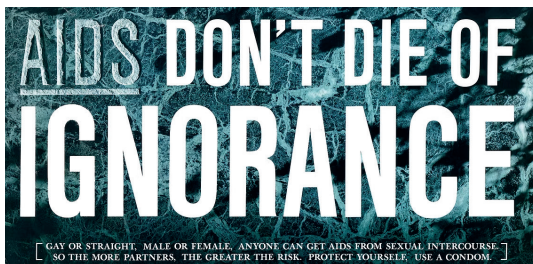
"My favourite photo of him; his letters to me at university; songs we danced to in Heaven; the clock he gave me for Christmas with the note he hid in the back (which still makes me smile); and my grandmother's cottage in Boscastle, where we picked blackberries, made crumble, and where I scattered his ashes the following summer in the Valency river."

Raising awareness and ending stigma

Then

In the 1980s, the AIDS crisis swept through the UK, disproportionately affecting young gay men. Tabloid media used this to further vilify the gay community. Although homosexuality had been partially decriminalised in 1967, LGBT+ people were still treated as second-class citizens.

In 1987, the UK Government launched the ***Don't Die of Ignorance*** campaign - featuring a dark, apocalyptic advert directed by Nic Roeg and voiced by the late John Hurt. While it raised national awareness, it also reinforced the harmful myth that gay men were to blame for HIV.

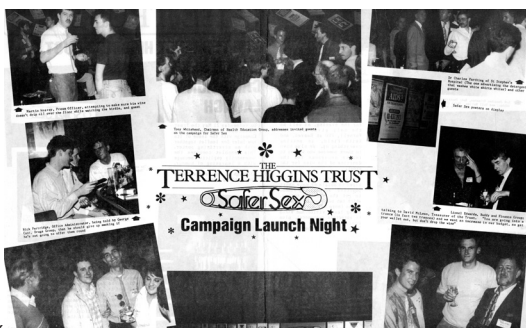


An extract from the *Don't Die of Ignorance* campaign

We were the first UK organisation to publish public information about HTLV-III (an early name for HIV) and AIDS. We understood that **clear, factual education was vital** - not only to prevent transmission, but to combat fear, stigma, and discrimination.

At a time when test results could take weeks or months - and HTLV-III was poorly understood - we took action.

We launched the ***Safer Sex*** campaign at **Heaven nightclub in 1986, with support from celebrities**. Unlike fear-based messaging, it focused on realistic behavioural change, encouraging safer sex practices, not abstinence.



The launch of our *Safer Sex* campaign at Heaven in 1986

Condom use became a central message of the campaign, helping to reduce transmission while also empowering people with knowledge and control over their health.

Our early, bold messaging laid the groundwork for a new era of awareness about HIV and AIDS in the UK.



The logos of our *Safer Sex* campaign and Heaven, which inspired the heart in our own logo

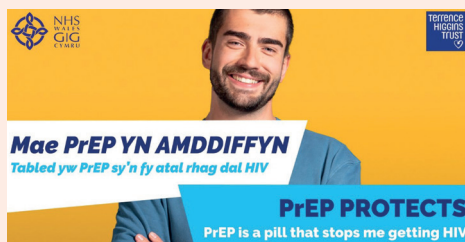
Now

Today, thanks to effective treatment, people living with HIV can't pass it on during sex, a powerful and empowering fact. Yet with **only 23% of people** in the UK aware of this, outdated knowledge continues to fuel HIV-related stigma.

Our **Life Really Changed** campaign tackled stigma by showing how a range of different people overcame the challenges of living with HIV to achieve their life ambitions. In Wales, we worked in partnership with Public Health Wales to deliver **PrEP Protects**, a campaign which explains that PrEP medication stops HIV transmission and where to access it in Wales.



Life Really Changed



PrEP Protects

We're campaigning to raise awareness of **Can't Pass It On** to help eradicate HIV stigma, promote testing, and encourage people living with HIV to stay on treatment and remain well.

Through this campaign, we have the potential to transform the sexual, social, and personal lives of people living with HIV, eradicate stigma, and end new cases of HIV.



One of three different couples depicted in our *Can't Pass It On* campaign



The campaign as seen in Brighton train station

We're Doing it for Terry, and to ensure that HIV holds no one back.

Will you support us in our fight to eradicate HIV stigma?

Always there to answer the call

Then

The Terrence Higgins Trust Helpline launched on 14 February 1984, during a time of fear and uncertainty. **The public, especially gay men, urgently needed information about HIV and AIDS**, as the condition became a tool for homophobic backlash, threatening hard-won freedoms.

Initially staffed completely by volunteers, it was Martin Weaver, an early volunteer and later our Press Officer, who took the very first call.

"In the early days we were getting about five or six calls a night, but sometimes none. The first call was from a gay man who wanted to check his risk following a fling with a friend from America."

As tabloid hostility towards the epidemic and those experiencing it (particularly gay men but also women, people who use drugs, haemophiliacs and migrants) escalated, so did the volume of calls. By 1986, over **7,600 calls** were received. *"If it wasn't for THT Helpline, who would people call?"* Martin asked.

The 1987 *Don't Die of Ignorance* campaign, which sent every household in the country a leaflet with the helpline number included, created a surge in demand. British Telecom feared the Kings Cross Telephone Exchange would collapse. In response, the Department of Health and Social Security funded 15 new telephone lines at a cost of £13,000, and we trained over **50 volunteers - enabling 1,000 calls** to be handled weekly.

By 1991, the Helpline experienced its busiest year since launch, with over 19,000 people calling. While once mainly gay men, 65% of callers were now heterosexual, many spurred by growing public awareness and TV storylines like EastEnders' Mark Fowler contracting HIV, and the death of Freddie Mercury, the lead singer of Queen.



Martin Weaver



Sir Nick Partridge, one of the first employees of the charity

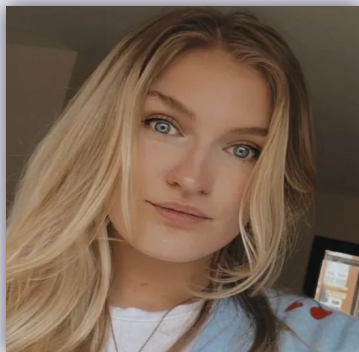
Now

Today, THT Direct is staffed by a team of ten, operates Monday to Friday, and is the gateway to all other HIV support services we offer.

Even with new ways for people to get in touch, like email and live chat, we still receive **thousands of calls every year** from people with questions about HIV. In 2024-25, we received **13,087 enquiries**, with 58% coming via the telephone. The other 42% came from email and our live webchat.

Every year, we receive calls from people newly diagnosed with HIV, like Ellie, as well as many others who are supporting people living with HIV - people like Ellie's mum.

Ellie recalls ***"The day I was diagnosed with HIV, my first call was to my parents. My second was to THT Direct. Unknown to me, my mum spent three hours on the phone with THT Direct and received powerful information on how to support me and what the right things to say were. When we were reunited, her fears were managed and we had a massive hug."***



Ellie



Hamish

The THT Direct Helpline was also a lifeline for Hamish Noah, who was diagnosed in 2020.

"When I was diagnosed, my world just stopped. I really did not believe what I was being told. It was a complete shock," Hamish says.

"In a state of panic, I called the THT Direct Helpline and was put through to Stephan. That call to Stephan was a lifeline for me, when I was at rock bottom."

It was so comforting to know that someone was there for me. Every time I called over the next few days and weeks, Terrence Higgins Trust was there to support me, and I could talk openly and honestly about how I was feeling."

Since 1984, we've been there to respond to the challenges of HIV, and have always been there to talk, listen, and never to judge.

Will you support those who need someone to talk to about HIV, and give a donation to help us be there to answer the call?

Supporting people to live well

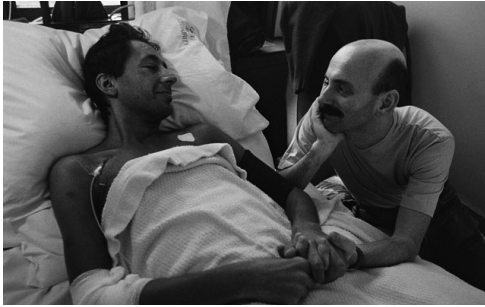
Then

In the early 1980s, before effective treatment or clear information, HIV and AIDS was shrouded in fear and stigma. Many who entered hospital with the condition, mostly young men, but also women, haemophiliacs, and people who use drugs, never left. **The first specialist HIV ward, the Broderip at Middlesex Hospital, opened in 1987**, inaugurated by Diana, Princess of Wales. Other wards followed, including Ealing's Wilmot Ward and St. Stephen's Thomas Macaulay Ward.

Jacqui Elliott, Nurse in Charge at the Broderip, recalled that **"...very often their loneliness was because of isolation from family and friends"**. This is where the Buddy Service came in.



Sir Ian McKellen opens the Wilmot Ward



Source: Gideon Mendel, The Ward.

Janet Green and Nick Partridge were the first employees of the charity. Brought in to run the new services, Janet recalls: **"Some of these guys had become very isolated. They had no family to support them, so we set up the Buddy Service, where volunteers would be matched up with people with AIDS."**

Our **Buddy Service** offered companionship to those living with HIV/AIDS. After seeing an advert, Michelle Clayford, then 21, volunteered. **"It was a really eye-opening experience. I did it for about a year and met such a wide range of people."**

About 40% of Buddies were women. Michelle remembers a woman in her sixties who she was paired with: **"She was terrified of anyone finding out she had HIV. We agreed to never mention why I was there, just in case."**

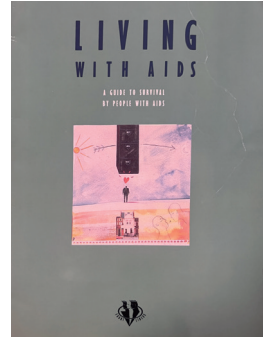


Michelle Clayford as a Buddy

In 1988, we supported Frontliners, the UK's national advocacy and support group for people living with HIV. Led by those with lived experience, they offered peer support and produced 'Living with AIDS: A Guide to Survival by People with AIDS'.

"It may be a difficult read for the newly diagnosed, but it normalised the feelings we all experienced," said one contributor.

Tragically, many contributors died before the guide was published. It became a lasting memorial to their strength and solidarity.



Living With AIDS

Now

As technology evolved, so did the support. In 1996, we launched our first website. In 2011, MyHIV became **the UK's largest online community for people living with HIV.**

During COVID-19, the service grew into THT At Home, offering connection during lockdowns. Over 50,000 posts and 7,000 topics helped shape support services.

In 2024, My Community launched – **a confidential online space** for anyone living with HIV in the UK.

"When I was diagnosed with HIV, it was an emotionally traumatic time and I felt like I was the only one. It was immensely reassuring to be able to connect with others on the online forum. I now volunteer with My Community, which is great for my continued wellbeing." says Vicky, who is now one of our Volunteer Engagement Moderators on My Community.

We've always been there to offer community and companionship to people living with HIV.

Will you do it for all those who have been affected by HIV and help ensure that no one living with HIV has to do it alone?



MyHIV posters



Vicky



This booklet commemorates the life of Terry Higgins, the legacy that he left behind to inspire others to Do it for Terry, and the lives the charity has helped since 1982.

We also remember all those who have lost their lives to HIV and AIDS-related illnesses.

With thanks to:

BBC News

The Guardian Newspaper

Martin Weaver Archives

The Bishopsgate Institute

Terrence Higgins Trust 40th Anniversary Podcasts

The Quilters' Guild



Photo: Candlelit vigil for people who died from AIDS-related illnesses, Trafalgar Square, London 1986.