

**FROM THE**

**MARGINS**



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**This unique book tells the stories  
of marginalised people, in their  
own words, printed entirely in  
the margins of the pages.**

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**Foreword by  
Professor David Olusoga OBE**

**Afterword by  
Dr Véronique Walsh**

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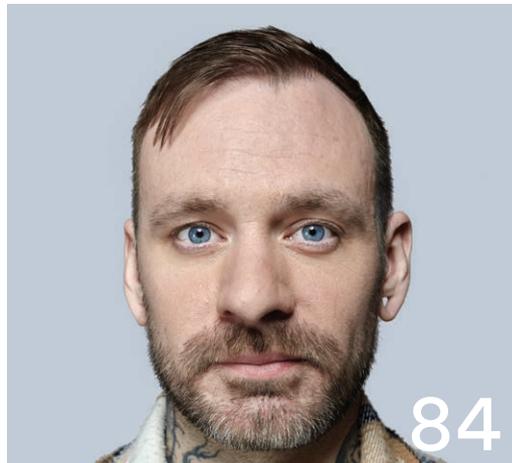


*From the Margins* has been created,  
developed and funded by Gilead Sciences Ltd

UK-UNB-4465  
August 2023

**FROM THE**

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**This book is unique.**

It tells the stories of six marginalised people, in their own words.

Except, their words are printed entirely in the margins of the book.

By design we have sought to make it the most difficult book to read ever published – not only because the words are printed in the margins, but because these words tell stories of hardship, stigmatisation, abuse and marginalisation.

The people featured in this book are remarkable. They have experienced marginalisation and they have overcome it. They have come in from the margins.

There are millions of others out there who have not. Things must change.



# FORE WORD

A portrait of Professor David Olusoga, a man with long, dark, curly hair, wearing black-rimmed glasses, a white shirt, and a dark suit jacket. He has a small nose ring and a goatee. The background is a plain, light color.

PROFESSOR  
DAVID OLUSOGA  
OBE

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**Human societies have always been unequal and human beings have always displayed a tendency to recoil and retreat from illness and disease. The wealthy and the well-connected have always been afforded access to care and treatment that the poor and marginalised have been denied. At times whole communities or ethnic groups have come to be associated with certain disease and conditions.**

Whether pushed to the margins because of their social class, race, ethnicity, sexuality or poverty, they have been trapped within the intersections between disease and social exclusion. As a result, the burden of disease has often disproportionately fallen upon them, leading to and exacerbating health disparities.

As many of the personal testimonies that follow in this volume powerfully demonstrate, these historic patterns have not been consigned to history. They are affecting lives and shaping outcomes in our society right now in the 21st Century. Lives such as that of Stewart, whose own experiences of marginalisation led him to form a charity that seeks to support and advocate for LGBTQ+ people affected by cancer. And Hussein, a Muslim African woman living with HIV, who now helps others through a voluntary community organisation that supports people facing mental health problems, domestic abuse and managing HIV.

Disease can impact the marginalised and disempowered the most severely, which can in turn encourage others to push individuals and even whole communities to the margins. To take an example from the 19th Century, many historians have noted how successive outbreaks of disease came to be associated with successive waves of immigration to the United States. Each new migrant community was in turn both scapegoated and marginalised by civic authorities and opportunist politicians. From the 1840s onwards Irish migrants were seen as carriers of Typhus. Italians were blamed for Polio. The Chinese became linked with tuberculosis and later, in the 1890s, with plague. Jewish migrants from Eastern Europe were at first most strongly associated with cholera, only for them to become linked in the minds of the authorities and the aggressive hyper-nationalist press to Typhus. Legitimate fears of contagion fused with latent racism, religious bigotry and anti-Semitism and powerful strains of political nativism. On occasions Jewish migrants diagnosed with Typhus were not only denied treatment on landing in America but even denied entry. They were returned to the nations from which they had done so much and travelled so far to escape.<sup>1</sup>

The Irish migrants who landed in British cities like Liverpool and Glasgow during the years of the Great Irish Famine in the late 1840s arrived in such vast numbers that they overwhelmed

<sup>1</sup> Emma Grueskin *The Island of Tears: How Quarantine and Medical Inspection at Ellis Island Sought to Define the Eastern European Jewish Immigrant, 1878–1920*, 2017

civic authorities. However, aspects of their treatment and the marginalisation to which they were subjected also reflected centuries of religious division and conflict. Again, fear of disease fused and intersected with older forms of prejudice. Those forces, combined with their poverty and the status of the Irish as new arrivals, meant they were often ushered into the worst housing, the most undesirable jobs and towards the poorest districts.<sup>2</sup>

While some marginalised groups have been scapegoated others have been the focus of unethical medical experimentation, the legacy of which lives on today. As the COVID-19 pandemic tragically demonstrated, the popular memory of medical experiments carried out upon people of African heritage in the 18th, 19th and 20th centuries, often but not always within the context of chattel slavery, is not only a painful historical burden but something that has had direct, devastating and on-going impacts upon the descendent communities.

Research into vaccine hesitancy has demonstrated how, particularly through online forums and social media, the memory of medical experiments such as the infamous Tuskegee Trials became a factor informing attitudes towards COVID-19 vaccines. Between 1932 and 1972, the U.S. Public Health Service used poor African-American men living in Tuskegee Alabama, as guinea pigs in medical experiments into treatments for syphilis. Doctors recorded the progression of the disease, in many cases through to death, when they were well aware that penicillin could have easily treated the condition in the participants in the study.<sup>3</sup> It was the marginalisation and poverty of the African-American community of Tuskegee Alabama that convinced the U.S. Public Health Service that they could be exploited for such an appalling experiment. Today there is anecdotal evidence that the on-line deployment of this history by anti-vaccine individuals and anti-vaccine groups impacted upon vaccine take-up among black Britons during the COVID-19 pandemic.

Indeed, the history of unethical medical experimentation upon communities of African descent stretches back into the 18th century and deep into British imperial history. In the 1760s the British doctor John Quier conducted a series of experiments upon 850 enslaved Africans in what was then the British colony of Jamaica. Quier was seeking an inoculation for smallpox and in his surviving letters he openly admitted that enslaved Africans had been selected for experimentation, because the tests he had devised were, in his own estimation, too risky to be carried out upon free Europeans.

The memory of these practices lingers, not only among descendant communities, but, demonstrably and shockingly within the medical profession itself. In a video clip that was widely

<sup>2</sup> Roger Swift & Sheridan Gilley, *The Irish in Britain, 1815–1939*, 1989

<sup>3</sup> Harriet A. Washington, *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*, 2007

shared in 2020, two medical researchers, were interviewed about how trials for new COVID-19 vaccines might be conducted. In the interview one of the doctors stated, “*If I can be provocative shouldn’t this study be done in Africa where there are no masks, no treatments, no resuscitation? A bit like as it is done elsewhere for some studies on AIDS. In prostitutes, we try things because we know that they are highly exposed and that they do not protect themselves.*”<sup>4</sup> The Director General of The World Health Organization, Tedros Adhanom Ghebreyesus, condemned the comments of the two doctors as a “hangover from the colonial mentality”. Those comments and that mentality is believed to have contributed to vaccine hesitancy in Africa. A study carried out in 15 African countries by Africa Centres for Disease Control and Prevention in 2021 reported that 45% of those who responded, had heard and had believed rumors, then circulating that claimed the new vaccine was being unethically trialled with Africans used as human guinea pigs.<sup>5</sup>

Those marginalised by poverty and social class have similarly been stigmatised and underserved by the medical profession and public authorities. Certain diseases have at various times been regarded as diseases of poverty, incubated in conditions to which the wealthier and better educated are insulated. Contracting such conditions has in itself carried social stigma simply because of the associations with poverty. Such thinking at times encouraged even greater levels of marginalisation and ghettoisation of the poorest and most vulnerable. In the 19th Century the many literary accounts written about the slums of the industrial cities tended to describe the insanitary conditions, the crumbling and inadequate housing and the lack of basic infrastructure. Yet time and again such accounts were simultaneously accounts of the lives and the morals of the slum dwellers – people who were marginalised and physically segregated from wider society by both their poverty and their vulnerability to disease.

In 1859 the writer George Godwin, in his book *Town Swamps and Social Bridges*, described parts of London – then the largest city in the world – as ‘*hotbeds of disease and vice*’.<sup>6</sup> In that statement and others, Godwin – like so many of his contemporaries – unhesitantly linked together language that was medical with language that was moral. If poverty was in part the result of the indolence of the poor – as many believed it was – then so were the diseases that their poverty left them vulnerable to. The belief that certain diseases are the consequence of, or exacerbated by, the moral failings of the poor is not one that was left behind in the Victorian age. Pronouncements made from time to time by politicians about the supposed inability of people living on low incomes to run their household budget, cook nutritious meals or

4 <https://www.thetimes.co.uk/article/china-puts-640-000-in-lockdown-over-new-coronavirus-out-break-sk56gs2dh>

5 CDC Africa COVID-19 Vaccine Perceptions: A 15 Country Study, February 2021

6 George Godwin, *Town Swamps and Social Bridges*, 1859, p 5

understand basic nutrition, are reminders that such ideas are still with us and they contribute to modern health disparities.

However in another, more progressive and forward-looking passage in the same book, George Godwin showed that he like other Victorian reformers was aware of the dangers of marginalising those in need of public health interventions and medical attention. Godwin was writing 30 years after the first of the great cholera epidemics that would punctuate the middle decades of the 19th century, demonstrating to the wealthy and the middle classes that epidemics among the poor often spilled out of the slums and into their elegant suburbs. With this in mind he warned his readers that *'From the cradle to the grave, mankind need the aid of their fellows: we cannot exist without it, – high or low, rich or poor. It is a condition of our being: all who need aid have a right to ask it: none who are able to give it can refuse without danger.'*<sup>7</sup>

Beliefs in links between morality and disease, the long and unhappy history of marginalised groups struggling to access healthcare, were features of life in societies across the world in the latter half of the 20th century when a new disease emerged. Believed to have originated in Africa, and first coming to mass public attention, in the Western context, through its impact upon the Gay community, HIV became the focus for a decades long era of stigma, homophobia, racism and marginalisation. What the advent of HIV demonstrated was that the patterns and the habits of earlier centuries, in which marginalised groups were further ostracised and demonised were not relics of a pre-modern past, but patterns of our own time.

The growing recognition of the intersections between societal marginalisation and health disparity is today building on these lessons from the past. Health disparities among marginalised populations – as it has been shown – are exacerbated by the exclusion of those communities from the medical profession and other professional services. There is in Britain the potential for the hyper-diversity of the National Health Service – despite its own historic and well documented failings on diversity and inclusion – to be harnessed to offer health workers greater insights into marginalised communities, and pathways towards the partnerships that are key to progress. This partnership is needed as there remains – in part due to the histories outlined above – huge levels of mistrust in some communities and their experiences of healthcare often remain very different from the wider populations. Such communities are sometimes tellingly labelled as, 'hard to reach', but they are hardly met, and therefore as we enter the 75th year of the NHS, it requires a new and different approach.

Alongside the bitter struggles over funding and the big societal questions about the future of 'free at the point of use' healthcare, there need also be a debate about the one-size-fits all approaches that have characterised healthcare since the inception of the NHS. It is not possible

<sup>7</sup> George Godwin, *Town Swamps and Social Bridges*, 1859, p 2

for any healthcare system to be truly empathetic to people's needs, nor for patients to be treated with true dignity, and respect, until it is recognised that health needs vary across our highly complex and extraordinarily diverse society.

**Professor David Olusoga OBE**



**JOSH  
HUA'S**

**ST  
ORY**



JOSHUA

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I was born in Sri Lanka and adopted by a British couple when I was five weeks old. My new parents brought me to live in the UK. Two years later, they adopted my sister. She is also Sri Lankan; I'm Sinhalese and she is Tamil. We grew up in Oxfordshire and I went to a private prep school for boys. Childhood was wonderful. Mum ran a business in psychology, so she spent all her time nurturing us and taking us on holidays. My Nan and I were very close. We were a Christian family, and she prayed for me every day! We didn't have electronics back then; play was all about making things, dance, and drawing. We were only allowed to watch TV one hour a week, so we did creative things. I would put on little shows in my bedroom for Mum and Dad. I loved putting on my sister's dresses and all that theatrical stuff. I kind of knew I was gay from a very young age, but my dad's attitude was, "kissing boys is not for boys". Mum took us to concerts. I loved the costumes and set designs. I would make Lego theatre sets and imagine shows that would be performed on them. We went to see

Nutcracker when I was four years old, and I fell in love with dance. I thought, *that's what I want to do when I'm older. I want to be on stage with all the lights.* At prep school I joined the Royal Ballet's Junior Associates programme. I was the only boy that did ballet, but they really nurtured the artist in me and encouraged me to dance at the school Carol Service. At age eleven, I auditioned for the Royal Ballet School, and I got in. I was so young and very homesick. I got bullied a lot for being black. This racism was new to me, and I didn't understand it.

During my teens I began to experience mental health issues. I was a semi-finalist for Young British Dancer of the year 2006. That was an incredible high. A week later my Nan died, and I was just devastated. Looking back, I can see that was the beginning of my bipolar disorder. At the same time the Royal Ballet School taught me discipline and technique. The school was hardcore, but I loved the training. I trained there for five years, and I'm grateful for having that opportunity. From there I went on to do a BA Honours degree at Central School of Ballet. I

studied dance, jazz, and musical theatre. It was at that time that I started going to parties and exploring my sexuality. I was awarded a scholarship to study at the Rock School for Dance Education in Philadelphia. Mum always nurtured my ambitions and let me be myself, but when she took me to the airport, she was a little upset thinking, “Oh my gosh, my baby’s going, I’m never going to see him again”. After completing my year of study in the USA, I did return. I started touring with incredible dance companies: English National Ballet, Murley

Dance, Neo Ballet, Royal Ballet, Kirov Opera, and the Vienna Festival Ballet. I got my first critic review. I was doing what I loved but trying to make it as an artist also started to seriously affect my mental health. Experiencing depressions and highs became an unmanageable battle and I had to see a psychiatrist. I decided to take a six-year break and got a normal job. At that point I lost my ambition, and I began to lose myself. I got into partying, drugs, bad boyfriends, nightclubs, group sex. It was all a bit of a

wash. I grew up in a Christian family with a sense of community, friends, and loving people. Church was a big thing. But when I was still a student, the church turned against me. They said, “You can’t be confirmed, because you can’t have sex with men”. That also triggered me to go off the rails a little bit. I rebelled against anything religious. All I ever really wanted was to be loved, to be appreciated, to have a sense of belonging, and to just make my family happier. But I was looking for love in all the wrong places –Grindr

for instance. It was just sex, sex, sex. Those situations never gave me the chance to meet someone and get to know them before sleeping with them. Men just wanted to get me high and use me for a minute’s pleasure. Over the years I lost my self-worth. Of course, if someone listed themselves as HIV positive on Grindr, it was immediately: block, block, block! Dating apps are not a safe place, there’s a lot of stigmatising there. I’d understood the importance of sexual health from a young age, so I had always been for regular check-ups. Even now, when my life

was so adrift, I would go for testing at 56 Dean Street in Soho. It's an accessible, confidential clinic that provides all sorts of services, support, and education. Most important of all, everyone there is really friendly and caring. One day I received a call from them, "You need to come to the clinic now". I replied, "Well, I'm on the bus", and they said, "It's okay, get off the bus and come into the clinic. We can wait for you", and I thought, *this is not good*. They were waiting for me at the entrance and walked me inside. Someone asked if I'd like a cup of tea. "No, I don't want a cup of tea", I replied. They sat me down and my whole body started to shake. Then I heard the words I had secretly been dreading, "you have been diagnosed with HIV". My immediate thought was, *that's the end of my life, I'm going to die*. Then came feelings of shame and guilt and regret. *What am I going to tell my family? They're not going to accept me, they're going to disown me, they're going to think I am a diseased, filthy, incapable, vagabond*. My walls caved in. But the people at the clinic said, "don't worry, we're here to support you". The way they spoke to me was so caring and loving. Even though I had been regularly going for testing, when it came down to it, I really didn't know all that much about HIV. Sex education at school was not good. All we got was, "use a condom" and, "don't have sex until you're married". That kind of stuff. They didn't teach us anything about gay sex. So, my understanding was, pretty much, HIV is a disease that gays get, and then you die. My knowledge was minimal, and my family knew nothing at all. My mum wanted to know if she had to wear gloves to shake my hand. My sister said I shouldn't share the same glass as my dad. Mum asked why I had brought this on myself, on the whole family. It was heat of the moment stuff – looking back, I understand that my mum was terrified for me, and confused. I see that she was really saying, "you're my child and I'm scared, and I don't want anything bad to happen to you, ever". But at that time, I believed I had brought shame on my family. I had a temperature and was sweating all the time,



“

I lived in fear of HIV.  
Now that I've got it, I know  
there's nothing to fear.”



and I only had a few weeks to live anyway. I had no future, no motivation, no goals. I thought, *I might as well just get high and die*. It was a very dark period. I didn't die. Instead, I started to educate myself. I watched documentaries and dramas. Shows like 'Pose' and 'It's a Sin' are wonderful and I'd truly recommend anyone in my position or with a friend or family member going through an HIV diagnosis to watch those. Mostly, I got my information from the people at 56 Dean Street. But it was lonely. Only one friend, Denzil, came to be with me. He was the one person I trusted and could talk to about everything. We went through the journey together, just being there for each other. His friendship, I feel, got me through that major transition in life. Denzil and I researched and read articles. I tried to share what I learned with my family. I would tell my mum things like, "if my viral load goes down to the level where it's undetectable, that means the HIV is untransmittable". She didn't get that at first. My family did support me, they wanted to be there for me, but there was a dinner and drinks in Soho," she said, "just go, and see how it is". So, I thought, *okay, I may as well go*. And it was just a dinner. We cooked together and chatted and ate. I started to build a connection with people. I began going out regularly with this community of church people who didn't want to give me drugs or sleep with me. Slowly I got weaved in and then I went to a church service, for the first time in many years. I still hadn't disclosed my HIV status, but I was meeting people and networking through the church, trying to find a circle of friends

lot they didn't understand. At the same time, they were talking to other people who were often very judgemental. There was a lot I didn't understand too. Sometimes I didn't feel I could talk to my family, because I thought I'd brought shame on them. My main priority was to find a community of people who would accept me. In spite of her confusion, my mum always loved me. One day she said, "Josh, you need to get your shit together". Well, she didn't say exactly that, but pretty much. Mum suggested I go to a church gathering. "It's a

who had been through the same thing. That was how I came across House of Rainbow. There I met Jide Macaulay who's a priest in the Anglican Church. That man really inspired me to just be myself. I met a lot of people through House of Rainbow, and together, me and Denzil started to go to HIV events. I began to feel part of an HIV community that is all over London, all over the UK. We come together to support each other and to educate others. I started to drop all the shame, guilt, and regret and to gain strength, to feel comfortable with myself again. I

was ready to come out about my HIV status and to go out there and educate others through activism. That was in 2020. Also in 2020, Covid arrived. Being immunocompromised, I was strictly at home on the sofa. I asked myself, *what can I do that's creative, that will bring all my life experience, and tell my HIV story?* What I came up with was an online event with artists each creating their own show at home – dance, drag, poetry, music, videography. I named the event The Naked Truth –

on dates. We got to know one another. From the start, I told him that I was HIV positive. Instead of rejecting me, he was open minded and supportive. Some of his friends also live with HIV, so he is educated. He knows that I can't transmit the virus, but he gets checked up regularly for sexual health reasons. We both do. On Mother's Day, mum said to me, "Joshua, you've never had a real boyfriend until now", and I was like, "Mum, it's true. It's so different to have someone who appreciates me and cares for me like he does". The same year I met my

because for me, coming out as HIV positive was exactly that. And then we live streamed it on World AIDS Day. That was something special. The show touched on many hard core themes, like stigma and drug addiction, but often with joy. It was thought-provoking, and it touched a lot of hearts. We raised a lot of money for the Terrence Higgins Trust, I got praise heaped on me, but most of all it was so much fun. In the past, my only experience with relationships was sex. Then I met my boyfriend in 2022. We went

boyfriend, I achieved my teaching diploma with the Royal Academy of Dance. I've gone on to teach classes with wonderful young people at Primrose School of Dance, Portobello Dance School, London Boys Ballet School, and other amazing places. This year I will be Guest Judge at the Industry Dance Championships. I'm now working at a nursery, where I've just been promoted to teacher. I've always loved children. I've got a niece and four nephews, and I do want my own children one day. I enjoy their little conversations, their cuddles, and watching

their daily  
p r o g r e s s .

Children are my  
passion. Being  
around them  
keeps me alive.

It's taken me a  
long time to talk  
about how I feel  
and what I want  
to achieve in life  
again, but now I

have regained  
confidence to  
go on with life  
without feeling  
low and

ashamed. With  
all I've been  
through I realise

I have  
something to  
give back. The  
first thing I

would say to  
anyone just  
diagnosed is  
that you're not

alone. Everyone  
needs someone  
to talk to and a  
sense of

c o m m u n i t y .

There are  
people out there

for you – go and  
find them. I'm

HIV to the mix. That stigma often means people don't get checked. Then you've also got the reality that many ethnic minority men are in the closet – they're married with kids, not openly gay. You are their bit on the side, and then they go home and have sex with their female partners and pass the virus on to them. And that's another important message: HIV is not a gay man's disease – women can get it too. There's a lot of down-low men out there who don't get tested. Because they are undercover, they don't want to take the risk of being seen

now at the stage  
where I feel able  
to go out and do  
talks, peer  
support, and  
a c t i v i s m .

Through these I  
share my story  
and hope to  
educate others.

I have noticed  
that many HIV  
a w a r e n e s s  
campaigns and  
p u b l i c i t y

materials are  
v e r y  
whitewashed.

Being a man of  
colour, I think  
it's important to  
stand up and be  
heard. Racism

definitely plays  
a part in making  
the situation  
more difficult. I

think in many  
white people's  
minds being  
black or Asian

equates to being  
lower class, less  
important, and  
even somehow

dirty. That's  
before you add

going into a clinic. That's why home testing is so important – you order a kit online and it comes to your house, so testing is accessible to everyone, even those on the down-low. For all these reasons, we need men of colour to come forward and tell their stories. That is what, for example, Billy Porter has done. I have a great deal of respect for him. I'm not demanding that everyone speaks out. Diagnosis can be very painful and private. I'm just saying that I have chosen to come out publicly, and I don't regret it. I don't know what my future holds, but I have ambitions.

The Naked Truth is a little baby that I want to grow. I would like to make it a live event held every year in London. And I've always wanted to set up a charity for children in Sri Lanka – it would be a nurturing place to build a better future for them; a place where they could do dance workshops and have fun on the beach. Of course, these things need funding, but I have passion, and we all start somewhere. If there was anything I could say to my younger self it would be, *you don't have to follow the crowd.*

*It's okay to say no*

Disneyland. It was magical. My parents have been on a journey too, and they've learned so much. They are really supportive now. My mum and dad are my best friends. They mean the world to me. I eat well, I sleep well, my boyfriend and I go for walks, we cook meals, and go to the theatre. Now I'm taking the sobriety route – I gave up drugs a year ago and this year I've given up alcohol. I think I'm maturing, like cheese. I lived in fear of HIV. Now that I've got it, I know there's nothing to fear.



*and just be yourself.* But I don't regret anything that's happened in my life, because it's made me who I am today. At the beginning it was me and Denzil just working it out for ourselves. This journey through HIV, and my involvement with the church, has brought a circle of real friends that will always be there for me. I have a loving relationship with my boyfriend. We now live together. For our one-year anniversary we went to Paris; we watched The Lion King, saw the Eiffel Tower all lit up at night, and visited



**HUSSE  
INNA'S**

**ST  
ORY**

A portrait of a woman with a warm, gentle expression. She is wearing a dark red headscarf with thin gold stripes. Her top is a vibrant red and gold patterned garment with intricate floral and geometric designs. The background is a plain, light grey. The name 'HUSSEINA' is printed in white, bold, sans-serif capital letters across the lower part of her chest, with a thin red horizontal line underneath it.

HUSSEINA

As an African woman living in the UK, I have always felt marginalised. My family is from East Africa. At age 17, my father arranged for me to be married to one of my cousins. I can't say that was a good marriage. It was abusive. I survived it for 20 years. Eventually, we got divorced. He took my five children away from me. He took everything. I had to struggle to survive. Then in 2001, I came to the UK. In England, I did not understand the culture. I knew only basic words like "yes", "no", and a few more. I faced a lot of challenges trying to integrate and fit in. I lived with a family from the Muslim community who supported me while I waited for my immigration status. At that time, I started to have some health issues. I would shiver and get high temperatures. I thought, *you just came from Africa and it's cold here. Maybe the weather is having an impact on your health.* I went to see a GP. She did a lot of tests, and they all came back normal. But she was a good GP and she kept looking after me, kind of monitoring my health. Then I started to go through very heavy menstrual cycles, and very frequently. My GP did more tests. Again, everything was normal – but my health issues went round and round. One day, she asked me, "would you like to do a HIV test?" And it's funny enough, I didn't think twice, straight out I just said "yes". I went home without even thinking about it. After three weeks, I received a phone call from my GP, "Can you book appointment to come and see me?" I went. My appointment was at 10 o'clock and I sat, waiting, waiting, waiting. That made me worry. At half-past 12 I was called in. The GP said, "we have good news and bad news". I said, "okay, can you give me the bad news first?" "The bad news," she said, "... I don't know if it is bad news... but I just want to tell you that you are HIV positive. The good news is, you are in a country where you can get treatment, and you can live like an HIV negative person". I think I was there, but my mind was not there. Maybe my ear was listening, but everything froze, I went numb. *Is this the end of my life?* What I heard was just, "HIV positive", clicking around and around. I

did not hear that there is treatment. And my thoughts went, *okay, I am going to die in this country without seeing my children*. I had experienced losing three family members with AIDS. Because of the stigma, the family didn't actually disclose why those people died, but I suspected it. The last one was my cousin. She lost the baby and after that she was sick for two or three years. I was holding her when she passed away. So, the only thing I knew about HIV was dying. My GP said, "I can refer you to the best hospital who can look after you". She booked appointments for me to go to King's College Hospital the following day. And I said, "yes, thank you so much". I left the building, but it was not Husseina. It was a ghost of Husseina. I went home with a lot of questions rolling in my head. *Do I share this with the family I'm living with? Or do I keep quiet? If I tell them, will they not allow me to stay here anymore? If I don't tell them and I die, how will they understand the cause of my death? How will my family know what has happened?* To all these questions there was no

provide something for others during the thirty days of Ramadan, and they can fast on your behalf. But I still hadn't told the family I was living with about my diagnosis, so I had to fast. I would take my medication before sunrise, and then again late at night after breaking my fast. It took maybe one year for the medication to fit with my body. I was so fortunate to have such a good and understanding GP. I don't know if I will ever find another one like her. With little English, navigating the health system was a big challenge. The hospital consultant

answer. And I didn't go to the hospital. I did not take that appointment. I was diagnosed in August, and I didn't tell anybody, not one word. I spent three months struggling with denial, just dying by myself in silence. It wasn't until October that I came to accept – *if this is happening, I am ready to take it, whatever angle is coming to me*. I went back to my GP. I went to the hospital, and I started treatment. I suffered a lot because, when I started treatment, it was the month of Ramadan. As a Muslim, if you are sick, you can

was a Muslim. He helped me a lot. I was able to ask him lots of questions and he was accepting of me. That helped build my confidence. Then, through the hospital, I met a peer mentor from an organisation called Positive Place. They were doing outreach, meeting patients in the hospital and directing them to support groups. Positive Place was a big organisation that ran a lot of different support groups: women's groups, mother and child groups, LGBTQ groups. I joined an African specific group. Through that, I started to learn about myself and my situation. Quite quickly, I developed a sense of mission – firstly, to get knowledge and understanding, but also to be a role model and support others who are coming behind me. I engaged myself to be a volunteer peer mentor. Even though I did not speak good English, I took that chance. Maybe my personality helped. I like talking – that gave me a good connection with people. About two more months after starting treatment, I felt the courage to tell the lady whose house I was living in. That lady is a

doctor herself. I did lie – I said that I had just received a phone call from my GP that day. I pretended that I had an appointment and then came back and told her that I had been diagnosed with HIV. And she said, “That is good, it is better you know than you don't know”. That lady accepted me. It was such a big relief. In the Muslim community, it is believed that if you have HIV, it is because you have been promiscuous, sleeping around, and that is a sin. At the same time, I did not feel completely accepted by non-Muslims.

Even at Positive Place, I would sometimes hear people talking behind my back, saying, “Hey, Muslim is in the house” and such things. I wanted to take my work outside Positive Place and explore with others, especially in the Muslim community. My peer mentor referred me to another organisation called Naz Project where they were running a Muslim support group. I joined that. Naz Project got involved with a conference for HIV women all over the world. The people there asked, “Husseina, would you like you to speak from the perspective of a

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Who is Husseina? She is  
someone to be recognised.  
I will leave that legacy  
behind, even when I die.”





Muslim person? Others in the group don't want to talk. Are you ready?" I said, "Yes, but my English is not good". They said, "You just go and speak. Whatever you have to say, they will understand you". That was the first time I opened up as a Muslim living with HIV. But I had to be selective about who I told, especially in my community. Mostly I decided to do my work by educating about HIV, not coming out and saying that I am living with it. People can take this knowledge or not take it. The reality is that many people believe there is no such thing as a Muslim with HIV. I experienced that at the mosque. One Friday, the Imam announced, "We are doing some fundraising for women with HIV in Africa". I was so excited thinking, *wow, my Imam is talking about HIV in the mosque!* As the contribution was passed, I grabbed a lady and said, "Can I talk to you? The Imam has said something very, very important, and this is not happening only in Africa, but here in the UK also". She turned to me and said, "There are no Muslims here with HIV". That lady was a

counsellor! I shut my mouth. I did not go further. I also began volunteering at another organisation called African Advocacy Foundation. That was a good thing for me because the people there spoke Swahili. At AAF I was involved with a project called Treat Me Right, aimed at educating doctors to build better relationships with their patients. That is so important. I was very fortunate to have found a GP who cared for me so well at a critical time. But that is not always the case for everybody,

not even for me. After I moved to a new medical practice, I had to see whoever was assigned. One day, I went to the surgery and saw a different GP. Straightaway, the first thing she asked was, "How did you get HIV?" Despite all its good work, Positive Place closed in 2009. By that time, I had become a voluntary support worker, and I was approached by someone involved in commissioning. He said, "we have seen how you engage and interact with people; would you like to apply for funding to start a support group?" All I could think was, *wow,*

*these people are saying this to me? I don't have experience. English is my second language. I am waiting for my immigration. I don't know anything about funding or writing applications.* But I wanted to take the chance. I had built a bond of friendship with some black African, LGBTQ brothers at Positive Place. I spoke to them and said, "guys, we need to do something". And they said, "Okay, let's see how we can do it". One of the members said, "My sister is running a mental health organisation. Let me speak with her. Maybe she can help us". Her sister helped us. We all got together and wrote the application. It was rejected, but that rejection did not put us off. We decided to start the group anyway. My friend offered her house, and I took on the responsibility of cooking – food is so very important. Every Friday, I would cook food and hold the meeting at my friend's house. And that is how I can say I am Co-Founder and Director of Red Ribbon Living Well. Slowly, slowly, slowly, the group started to grow. Red Ribbon is a voluntary community

organisation. We offer support in the areas of mental health, survivor domestic abuse, and those affected and living with HIV. It's here for anyone who needs emotional support; we are non-judgmental and non-discriminating regarding race, gender, sexuality, or religion. As well as peer support we provide education and public events. We started with no funding and, actually, that gave us confidence that we could do something meaningful with just our commitment and passion. Over time we

started to get small, small, amounts of funding – like one or two thousand pounds – first from Lewisham and Greenwich NHS, then Lewisham Council, then Phoenix Community Fund. Each time, the funding pot ran out, or the funding department or organisation was closed. But what mattered most to us was when people came back and said, "thank you, my life has moved forward". That's what kept us going. In July 2022, we apply for National Lottery Awards for All. That was the biggest amount of money we had received so far. The

funding was for six months, and we used it to create a drama production that aims to reduce stigma and discrimination for people living with HIV in the African community. Through performance and singing, it tells the story of a mother and daughter. The mother is a church leader. The daughter is pregnant and staying with her mother – because, in our culture, that is what women do. The daughter goes to the hospital and finds out she has HIV. She goes home and tells her mother. The mother throws her out. But the daughter refuses to be chased away by her mother. Instead, she calls a community member – a peer supporter. Together they educate the mother, and she finally comes to accept her daughter. We did several performances. The biggest one was on World AIDS Day. The people who took part were members of the community and it was a great way for them to raise awareness without coming out openly themselves. Over time, I have become more confident to talk openly about living with HIV. But there are still times when it hurts. A  
S o m a l i a n

W o m e n ' s  
c o m m u n i t y  
group invited me to be guest speaker at one of their events. Beforehand, I was sitting with other women at the venue, and we were talking. I heard someone say, "We have a Muslim woman here with HIV. Actually, she was a prostitute". I felt bad, I felt ashamed. But I went ahead, stood up and said, "I am the person living with HIV", and I told my story. Afterwards, they all came, gave me a hug, and prayed for me. I'm back in touch with my children but I still haven't told them. I don't want to do that

on WhatsApp. I always say to myself, *when I go home, I will tell them*. But every time I go, there's a lot of issues in the family and I think, *now is not the right time*. I haven't found the right time yet to tell my family. My youngest child is 30 now. Maybe they know, but I don't know. My hope is that my little baby, Red Ribbon Living Well, will continue to grow, and that one day I will take it to Africa. There is so much need there. I would like to use what I've learned to support those women and girls in Africa. That is my vision. Living with HIV has not

always been a good journey, but I have a lot of friends and people around me now. If I was not HIV positive, I would probably only have been in touch with people in the Muslim community. Instead, I have explored, learned, engaged, and integrated with a wider world, and that has opened a lot of doors in my life. Now, I can one hundred per-cent say to people: go for a test, know your status, educate yourself and others, and live your life – whatever comes your way. HIV is not a death sentence. I didn't have any degree or diploma, but I can say I am a co-founder of an organisation that helps people and does good. Who is Husseina? She is someone to be recognised. I will leave that legacy behind, even when I die.





**STORY**

**KIER  
ON'S**



KIERON

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My twin sister and I were born to deaf parents. In the 1960s the fact that we signed to communicate at home marked us out as different. Kids at school used that to get at me. They could be cruel. I learned to defend myself with my mouth, and sometimes my fists, at an early age. I was smart, and always in trouble. I achieved nine grade ones at GCSE, without really trying, but school did not interest me. I wanted to be a scally with my mates, go out to Wigan Casino, listen to Northern Soul, go to football matches. I started to get in trouble with the police. Not for violence or burglaries – it was petty, naughty boy stuff. We travelled the country as football hooligans, causing bother. One time I sprayed *Kieron from Haydock* on a motorway sign in Southampton. Later I was pulled up by a policeman. “What’s your name?” he asked, “Kieron” I replied. He said, “Are you from Haydock by any chance?” and I said, “How did you know?” I was arrested. It was silly things like that. Some of my mates started taking drugs. I saw a couple of them injecting.

I didn’t want anything to do with it, so I pulled away from that scene. I met a girl, she got pregnant, we got married, and we had a little boy. I did different jobs; mostly as a sales rep – I had a good line of chat – and my wife worked in a pub. I would pick her up at the end of the night. The pub was frequented by quite a few policemen. I became friendly with them. They would go in for a pint after closing time. That was against the rules, but the police didn’t follow the rules very well in the early ‘80s. One night, there was a big

commotion outside the pub. I went out and saw one of the police getting a kicking. I went to his aid. One thing led to another; I ended up being a witness in court. After the court hearing the Superintendent came to me and suggested that I apply to join the police. I said, “No, no, absolutely not. I’ve got a criminal record” and he said, “Why don’t you apply? I’d not long been married, and with a new baby born. I thought, *the police is a secure career*, so I applied. I flew through the exams and before long I was a beat Bobby walking around the curbs of

Toxteth in a big hat. There were some moments – like the Toxteth riots, with petrol bombs flying about – when I thought, *what the hell am I doing here?* But I was a good Bobby, a fair Bobby. I didn't need to bully people or falsify statements. It was a fulfilling job, and I loved it. I progressed well. I started studying for the sergeant's exam and set my sights on one day joining the Drugs Squad. Then, in my second year of probation, I was knocked off my bike by a disqualified drunk driver. I was hospitalised with a compound fracture of the leg. As things turned out, I stayed in hospital for a long time. I had an operation to try to save my leg. After that, I was laid up. I decided to complete my sergeant's exam, and I passed. But that was pretty much the end of the good news. My wife disappeared with "someone else" and took our son with her. She emptied the house and stopped paying the mortgage. Then my mum, only in her forties, died of liver cancer. I was in hospital and didn't get to see her. Despite all the medical attention, my leg was not getting better.

After about a year, I was retired from the police on grounds of ill-health. They finished me just six weeks short of my entitlement to a full pension. I felt bitter about that. I tried to save my house but, eventually, I had to sell it. One day, an old friend from my Wigan Casino days turned up. By now, he was a scripted addict, receiving methadone ampoules. He said, "Here, try one of these. You'll feel better". I emptied it into a cup of tea and drank it. And I did feel better. In fact, I felt great. I thought to myself, *I'll*

*take these for a few weeks, to get me through this rough patch.* That was the first day of 30 years of addiction. Before I knew it, I was on a methadone script myself, getting those ampoules every day. I met a new girl. We fell in love and got married. She has never been a drug user. I kept my using hidden. I lied to her and, I suppose in some ways, I conned her. I managed to keep it under wraps, at least until after we were married and our first daughter was born, but you can't keep something like that secret for ever. All these years later, we are still

married, and we have two daughters. That is a tribute to her tolerance and compassion. I wanted to stop. I would tell myself that I was going to stop. I just couldn't stop. I loved my wife, but I loved the drugs too. I would stop using one drug, and then start using something else. I told myself that, because I had stopped using methadone, I had "given up". But then I'd start using amphetamines. I began injecting. I thought I was fooling everyone around me, but I was just fooling myself. I was a full-blown addict and my whole world revolved around that. I did different kinds of work to keep my head above water financially. None of it was good, or legitimate. I made money testing drugs for gangsters in Amsterdam. I thought I was the bee's knees, a cut above the other addicts. I was careful, always used clean needles, and definitely looked down on those that had hepatitis C. *Don't go near those dirty buggers* – that was my attitude, that was the culture. All this time, my leg was getting worse. I developed osteomyelitis. It would not heal. Over the course of ten years, I had tests, tests, and more tests. I had so many blood tests, I assumed they checked for everything. Nothing was ever flagged up. In 2013, I had an overdose. It wasn't my first. I woke up back in hospital, having been in a coma for a week. My youngest daughter was sitting on the end of my bed, and she was most upset with me. It turns out she was the one who found me. It occurred to me that I might lose her. I'd already lost the son of my first marriage, all those years ago. I could not let that happen. *Kieron*, I told myself, *it's time to give this up*. I was

had eighteen different operations. The surgeons tried everything. They grafted muscle and bone from different parts of my body into my leg. The bone infection kept coming back. It was very painful and the drugs they gave me did not touch the sides. I was self-medicating; using illicit drugs to fight the pain. Slowly, slowly, the infection travelled. In 1991, the doctors decided to amputate my leg below the knee. Over the course of 30 years, I spent a total of three years in hospital. On every occasion I

fifty-six years old. I went to a drug service called Addaction. They took me in and suggested I go to a Narcotics Anonymous group. I attended some meetings while the people at Addaction helped me to get funding to go into a rehab. I was among one of the last people to get a funded place. I wanted to get far away from people and places associated with my drug use, so chose a rehab in Cornwall. Before I was admitted, I had to do a finger prick test for blood borne viruses. I told them that I'd had every test under the sun in hospital and I was fine,

but they said,

“Kieron, we

need to do it

anyway”. I

thought no

more of it and

travelled down

to Cornwall. I'd

been at the

rehab two days

when I received

a phone call. I

had to go to an

office to take

the call. There

was a worker in

the room who I

hadn't met

before. He

asked if he

could stay in the

room with me. I

said, “Yeah”,

then I picked up

the receiver and

was told, over

the phone, that

my test was

positive, I had

hepatitis C. I

was a s

gobsmacked.

All I knew about

hepatitis C was

this: it was

death sentence.

In the past, I'd

need to learn anything about hepatitis C. I didn't have it; why would I bother? Obviously, that changed as soon as I found out I had got it.

I was very fortunate to be in a safe place with workers who understood all about the implications. They knew how to talk to me and handle

my emotions. We had sessions each week about blood borne viruses and their effects. I started to learn about what hepatitis C is and what

it does to you. I learned that it is virtually symptom-free, there's nothing that gives it away. There's no big C on your forehead or anything

avoided anyone

who had it. I felt

nasty. I felt

horrible. It

turns out, that's

why the worker

was in the room

with me; this

man had been

treated for

hepatitis C. So

he was able to

talk me through

what was going

to happen next.

I assumed I

must have

passed it on to

my wife. I had

to tell her. Gosh,

that was the

hardest thing. I

didn't have the

courage to do it

over the phone.

I took the soft

way out and

wrote her a

letter. Just a bit

of a wimp really.

Fortunately, the

first thing she

did was get

tested herself.

She was

negative. I'd

never felt the

like that. Often the only noticeable symptoms are fatigue and low moods. Bloody hell, low moods was one of the things that perpetuated my drug use. I'd feel down, I'd take drugs, feel better, need more drugs. I learned that, although it can be transmitted sexually, it's very rare to get it through regular heterosexual sex. So, I understood why my wife didn't have it and I was grateful for that. I learned that it mainly affects your liver and can lead to cancer. That was a shock. My mum died from liver cancer. At that point I felt it was written in the stars that I would die this way. I was resigned to my doom. Then I learned that there are treatments. I couldn't sign up for the treatment quick enough. I wanted to be treated that day! I started on the interferon treatment pathway in Cornwall. When I left the rehab, I continued treatment back home in Liverpool. Interferon was awful. I've been told it's similar to chemotherapy. I wouldn't know about that, but it was horrible. You wouldn't think it was something that could make you over and asked if she'd like a lift. She got in and said, "Kieron, I have not seen you for a long time. Are you well?" So, I said, "Oh yeah, I've just been to the doctor's". She said, "Why? Are you not so good?" I said, "Well, I've got hep C". I couldn't believe the reaction. She recoiled away from me in the passenger seat. I just stopped the car and said, "Would you like to get out?" She said, "Yes, I've got to go" and started making all these excuses. She couldn't get away from me quickly enough. All my old circle of friends were associated with drugs, one way better. After three months I became so ill they took me off it. I returned to the NA meetings. A lot of people there had been affected by hepatitis C, gone through interferon, and knew what it was like. It was good to have people to talk to. I thank God for that because out in the wider world there was so much stigma. My wife didn't want me to tell anybody. I didn't understand her attitude. Then one day I was driving through town. It was throwing down rain. I saw a lady that I used to know standing at a bus stop; pulled



“

There is a life after drugs.  
There is a cure for hep C.  
You can stop yourself dying –  
but you can also start living.  
You don't have to suffer.”



or another. I was back home from rehab, clean and full of good intentions; *I don't use drugs anymore*. But it's not that simple. Drugs are only an arm's reach away at any time. There is an old saying: if you sit in a barber's chair long enough, you're going to get your haircut. If you're around drug users long enough, you're going to use drugs. I had to stay away from those people. I started to do voluntary work at the drug service. That way, I could be there every day, surrounded by people who understood. I loved the volunteering, realised I was good at it. The

v o l u n t e e r  
manager at  
A d d a c t i o n  
introduced me  
to the Hep C  
Trust. Back in  
2014, it was a  
s m a l l  
organisation  
that had started  
in London. Now  
they were  
coming up to  
the north-west  
to train people.  
T h e y  
understood the  
value of peer  
s u p p o r t ;  
professionals  
can talk to  
addicts all day  
long and  
probably 5% of  
what they say  
will be  
registered, the  
rest will be  
dismissed. But  
people who are  
like them, who  
have been  
through what  
they've been  
through, will be  
listened to. So,  
they were

training up  
people who had  
lived experience  
of hep C. Over  
the years, I'd  
seen people die  
with hep C. I'd  
said unkind  
things about  
those people,  
and I felt bad  
about that. I'd  
thought I was  
one of the lucky  
ones, one of the  
smart ones,  
who'd got away  
with it. All  
those years, the  
disease was  
s p r e a d i n g ,  
attacking my  
liver on a daily  
basis. By the  
time I was  
diagnosed, I had  
fibrosis in my  
liver. If I had it  
been left  
another couple  
of years, it  
probably would  
have developed  
into cirrhosis.  
That meant I  
had been  
carrying it for a

long time, probably since I first started injecting. I may have unknowingly passed it on to other people. Some people may have died as a result of me giving them hepatitis C. I don't know; I never will know. All that history, I wanted to give something back, wanted to educate people. How was I going to do that? I couldn't stand on the bandstand in the park, shouting *the end is nigh, get tested!* I signed up as a volunteer with the Hep C Trust. I progressed from volunteering at Addaction to a "proper job" as a key worker. I also worked for a different

drug service, going into a remand prison. And I was volunteering for the Hep C Trust. I developed a passion for it. At every opportunity, I would talk about hep C, saying, "Get tested, get tested. I was you, get tested". A job came up as a full-time peer-support worker with the Hepatitis C Trust. The role description could have been written for me. I applied and was offered the job. So, here I was nearly 60 years of age, doing what I loved to do, and getting paid for it. *Yeah, I thought, this is fantastic.* While all this was happening, new drugs for hepatitis C were approved and released. I was very lucky to be one of the ones who was given that treatment early. Within six weeks I realised that I wasn't so tired anymore. I would get up in the morning full of zip, looking forward to my day. I didn't feel low and depressed all the time. The treatment worked! That redoubled my passion, *come on people, this is great.* The World Health Organisation stated an aim to eradicate hepatitis C by 2030. I thought, *I can be part of this. I can contribute.* I've been with the Hep C Trust five years now.

In that time – we keep records – my team and I have got almost 1,000 people onto treatment pathways. I consider that potentially 1,000 lives saved. I meet with professionals and professors - I am so proud of what I do. I'm now the peer program manager for Merseyside and Cheshire with lots of people working for me. We go into drugs services, hospitals, homeless shelters – anywhere that vulnerable people are likely to be. We have a team that works solely in prisons. It's a responsible job, but I handle it.

Whatever happens, I plan to keep doing what I do; talking to people, educating, encouraging them to get tested and treated. Onwards and upwards. I was a very cynical person. I believed that I was going to die using drugs. That was my life, and I couldn't see any way out. If you'd asked me if I believed in an afterlife, or that things go on out in the ether, I'd have said, "Don't talk daft". I've got different beliefs now. So many things have happened that have changed my outlook on life. I go to music festivals like Underworld and Leftfield. I love to dance

on the disabled access stage. Yesterday I came back from Lanzarote. I'm the oldest swinger in town – with one leg. My life is a million miles away from what I envisaged. But I'm not special. It's available to anyone who wants it. There is a life after drugs. There is a cure for hep C. You can stop yourself dying – but you can also start living. You don't have to suffer. I will be 66 this year. My mum died in her forties. I feel so fortunate that I've been able to find a professional pathway that enables me to help stop the progression of hepatitis C – if you get rid of the hep C, you reduce the likelihood of liver cancer. I often say a little prayer. I talk to my mum and say, "I'm doing alright". I believe she is looking down, and she is proud of me.







LEAN  
ZEN'S

STORY



LEANNE

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I was born in London. When I was nine months old, my parents separated. Mum had five children and we moved to Thetford, a small town in Norfolk, to be nearer her parents. It was rural, and very white. We were one of the only black families in the town. My mum is mixed race, and most of her family are white. The town was tinged with racism. I was singled out and bullied. My memories of living in Norfolk are not the nicest, I must admit. By the time I was nine, Mum had two more children, so there were seven of us. She saw that we all needed to be somewhere that would give us more opportunity and acceptance, so we moved to London, right in the middle of Peckham. Thetford and Peckham were galaxies apart. In Norfolk, I was bullied for being black. Now, I was bullied for being different; black, but different. I struggled a lot with my identity. It was difficult for me to know who I was. Things changed when I got to secondary school. My rural upbringing gave me an outlook on life that was different to the inner-city kids. My individuality shone, and I was popular at school. I started going to dance class. Dance involves a lot of self-discovery. It gave me a sense of cultural identity, as well as helping me to develop team building and friendship skills. At thirteen, I was able to speak out and reveal that a family friend who had been coming to our home had been sexually abusing me since the age of ten. I honestly believe dance helped empower me to do that. It was tough, really tough. At first, I wasn't believed and was told I was making it up. I moved to my estranged father's home. I had to grow up very fast. At the time, I just felt terribly lonely and confused. I thank God that I had dance. That became my safe space. At fifteen, I set up my own dance class at a community centre in Elephant and Castle. I was paid £6 an hour! There was a queue outside to get in. It grew and grew. That is the same company that I still run today, twenty-two years later. I got into a very good dance college. I danced and performed but, as time went on, I also realised that I was experiencing a lot of weird sensations while dancing

and having anxiety attacks. I could not handle the feelings, and I stopped dancing when I was 19. I now recognise that those feelings were expressions of PTSD. I had not received any kind of therapy or listening since my revelations about sexual abuse. I met my childhood sweetheart at seventeen. Ten years later, he wanted us to get married and live together. That prompted huge feelings of, *I'm not good enough, I'm not worthy, I can't do this*. I had a massive outburst; I could not cope with making an important decision about my life. I realised that I

was struggling mentally, and I needed some help. One of the people who was involved in setting up the dance class all those years ago was still my mentor. He helped me find a pathway to access a professional therapist. During three years of intensive therapy, I returned to my childhood and examined the racism, the confusion about identity, the sexual abuse, the drinking habit I developed in my early twenties. It helped to stem a lot of those issues. I wrote and self-published a

book that spoke about all that hurt and pain, as well as running a business at a young age. By the time I was 30, I felt I had reached a new beginning. I started a university course as a mature student. I booked a holiday to Barbados with a friend. I was ready to grab life by both horns. Then my mum was diagnosed with cancer, for the second time. I hadn't known much about my mum's first diagnosis. I was too young. This time I was with her when she got the news. Things moved fast. I went with her for all the

appointments and tests. I was about to cancel my holiday but when Mum's results came back, they said that she was going to be fine, that she would need surgery, but not chemo. So, I went to Barbados. During the holiday, I started to feel unwell, throwing up and very tired. I couldn't do fun holiday things, and I felt I was disappointing my friend. I'd been through a lot with my mum, I told myself, I was run down. I also found a slight lump on my breast. By the time I got back to London I'd perked up a bit. But the lump had got bigger. I went to the

doctor. He said, "Leanne, you're worrying because of what you've experienced with your mum. You are far too young to have cancer.". A couple of weeks later, I was having a massage. The therapist noticed the lump and said, "What's that?". I replied, "Oh, it's just a lump. It's getting bigger, but the doctor says it's near the skin surface so it's fine". And she said, "I had breast cancer last year, and this lump feels like the one I had. So, no, it's not fine. I'm going to need you to go to the doctor tomorrow". The next day she called me and said, "I've got your address. If you don't go, I'm going to drive to your house and take you there myself". I rang the doctor and, amazingly, got an appointment that same day. This time, I saw a female doctor. She said, "I'm not comfortable with that lump. I'm going to refer you to hospital on the fast track". Within fourteen days I was sitting in a room being told I had breast cancer. My little brother and my best friend came with me. I still find that time hard to talk about. I was so convinced that I was too young, it was nothing, and all that. Suddenly I

was receiving life-changing news, followed by an avalanche of information. I quickly learned that because of my mum's history, they would send me for genetic testing. That they had found cancer cells beyond the one lump. That I would have chemotherapy, followed by surgery. That I would have to have a mastectomy. That, because I was so young, I would be offered egg freezing. No human being can process that amount of information. The nurse pulled up a piece of paper with a diagram on it and asked me to describe my anxiety level, with one being low, and ten being the highest possible. I said, "Ten. I don't want to talk to you right now. I want to go home". Then, because I was the driver, I drove us all home. As soon as I got through the front door, I collapsed on the floor. In an instant, my life stopped. I immediately emailed Uni and told them I would need to defer. I cancelled a trip to Scotland where I was due to judge a dance competition. I told my two assistants that they would have to run my dance company for a year. I didn't want to tell

anyone else. I'd always been seen as the person who was strong, and at that moment I could not be strong. When you tell people such news, you then have to manage all their emotions that come with it. I could not deal with that, so I asked my brother to do it. I couldn't sleep, couldn't eat, and started having panic attacks again. My mum came with me to the second appointment. That was helpful. She had already been through it all and knew the drill. The consultant explained everything in a way that was much more human, and it started to sink in. My cancer was primary. I was going to have eight rounds of chemo, over six months. I would have surgery, but I was going to be okay. I went home and was able to eat food for the first time in ten days – a McDonald's Chicken McNuggets meal. I did tell a few people myself. One of them was the long-time mentor who I had known since my school dance class days. That man was like a father figure to me. He had supported me into getting therapy and his guidance had helped pull me through some dark times.

After I told him I had breast cancer, I saw him once, and then he never returned any of my calls or texts after that. To this day, I don't know why. Other people just disappeared from my life too. I get it – people don't know how to deal with it – but, with cancer, you really see people's true colours. By the time I started chemo, I'd already been in and out of the hospital several times for scans, tests, and appointments. Every waiting room was filled with leaflets; none of them contained anyone that looked like me. I

began to wonder, *am I the only young, black girl with cancer?* I'd been well known and embedded in my community for a long time. My family supported me but, as the news started to filter out in Peckham, it became evident that a black person with cancer is not accepted. Everyone had something to say: "It must be the white gene. I've never heard of a black girl getting cancer", "It must be your diet", "You founded your business when you were fifteen, all that stress has caused your cancer", "Tumours are not of God, you need to renounce your sins and pray

it away”, “Chemo was created for white people. It doesn’t agree with us. Get a natural doctor. Go back home, get some sunshine and vitamin D”. I was given enough alternative “cures”, exotic fruits, powders, juices, potions, and diets to make a recipe book. These cultural myths and taboos about illness are deeply ingrained, and very unhelpful. I think they stem from a deep mistrust of white people; that they are against us. Anything that comes from a Western perspective is frowned upon. At first, I took it on board. I cut out sugar, did the juice diet, fasted, and watched all the Y o u T u b e videos. It was stressful. Then I went into the chemo ward and there were all these people hooked up to horrific drugs eating cake, biscuits, and crisps and having a laugh with their friends. Just getting on with it in the best spirits they could muster. I now say to people, “the chemo ward is the happiest place”. As time went along, I met other women of colour who were having treatment. I heard about the things they were going through at home and the reactions from their families and friends. I met a young woman, of a similar age to me, with a twelve-year-old daughter. She was told by her parents, “You didn’t catch that cancer from us, so go back to where you caught it from”. I made friends with a beautiful South Asian woman – sadly she passed away. She said that when she was diagnosed her aunty told her to sleep with a potion under her pillow for thirty days, and the cancer would go. There was a lady who always came into the ward by herself. I asked her, “Do you know you’re allowed to bring up to three people with you?”. She said, “We keep this on the hush. I haven’t told anybody; I don’t want to worry them”. I started to get an insight into how cancer is viewed amongst the black community, and it didn’t sit right with me at all. Lack of acceptance did not come only from my own community. Losing my hair was a massive shock. It happened quickly, about two weeks after starting the chemo. My mum and sisters accompanied me to my hairdresser’s, and I had it all shaved off. That was very emotional but also

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For a very long time I couldn't see a future. Now I allow myself to experience feelings of joy and just be present.”





liberating. I felt like I had taken control of that situation. In the world of cancer, it is important to take control of what you can. The hospital set me up an appointment to have a wig fitted. At the centre, the woman said, “Oh, just to let you know, we’re all out of wigs in the ethnic section”. She handed me a magazine filled with pictures of wigs. There were a couple of pages at the back – the “ethnic section” – with lines through all the pictures. “Wouldn’t you like a new style?” she said, “You can pick a wig from the Caucasian section”. So, I did.

Later, I’d been invited to a Christmas party. I put the wig on and thought, *this looks completely off-key. It might look better if I tong it.* I put the tong through the wig, and it burned. That was the end of the wig. I completed the chemo and then had surgery. That was a bit of a fight because I was determined to have a double mastectomy. The doctors had said that my cancer was primary and so I only needed one breast removed. But they had also said that there was a 67% chance of the cancer recurring in my

lifetime. I did not want that risk. Even before the operation, my brilliant, kind surgeon at St Thomas’s Hospital called me into his room and said, “I just want to give you one more chance. I don’t think you should go ahead with this. I think you should only take off one breast.” But I was adamant. I went ahead and had both breasts removed. I do not regret it. That was the right decision for me. I’d lost friends at a time when I really needed support. On one occasion, my breast care nurse warned

me, “Be careful who you turn to. There will be people who cling to you and offer help; they are not always sincere”. I’m sad to say that the nurse was right – a lot of new friendships turned out to be transactional. As I started to get my life back together, some of those people felt jealous, felt that I was moving past them. Towards the end of my treatment, I went through a period of extreme loneliness and isolation. For cancer patients who are told they are in remission, there can be a weird, grey area of not knowing who to trust and turn to for guidance

and support. There was a cancer support group attached to my hospital. I walked in. There were about twenty women, all of them middle-aged and upwards, and all but one of them white. The facilitator turned and said, "Can I help you?" I said, "I've come to the group". She asked, "Have you come for your mum?" and I said, "No, I've come because I've got breast cancer". It was a lovely group. All the women were wonderful. I just couldn't relate to anything that they were talking about – kids, marriages, intimacy. I was young and single. I wanted to talk about fertility and mobility. I wanted to talk about the shame and guilt associated with my diagnosis that I had gone through in the black community. That wasn't in their experience. Walking out, I spoke to the one other black woman who was at the group. She said, "Yeah, it's like this. There is nothing really for us". I was out in Peckham, and I bumped into one of my former students. I will never forget the look of horror on her face. I realised that I had effectively been in hiding for six months.

the hell?! I started writing blogs and talking to people online. Someone from the charity Breast Cancer Now got in touch to ask if they could publish one of my blogs on their website. It was a blog about friends. "Go ahead" I said. She said they would let me know when it went up. They didn't need to let me know. When the blog was published, I started to receive a flood of emails. There was a woman in Ireland who told me that she had been through similar difficulties with friendships. Another woman who had been banished by her family

On the day of my last chemo, I sat in my bed, posted a photo of myself having chemo on Facebook and wrote *Look, this is what I've been going through.* The response was insane but what I remember most is the people that messaged and told me that they'd had cancer too: "Do you remember when I went missing for months?", "Do you remember when I didn't come to ballet class?" There was this whole hidden community of *people that I knew* who had been through or were going through cancer now, reaching out to me. What

whilst she was having chemo, in case the cancer was catching. A woman who was not allowed to remove her wig in sight of her children. A young woman who was blamed for giving her mother cancer, and her mother's subsequent death. A woman whose husband insisted that they keep normality in the family – so she had to go to chemo on the bus, then pick up her kids from school, go home, cook the dinner, and entertain her husband. A woman who had been told that cancer was a curse for things she'd done in the past and she should work on her forgiveness.

Many stories about keeping it all hush-hush, not being able to let anyone know. The stories were heart-breaking, but I felt outraged. These attitudes need to be highlighted. They're just wrong. Worse than that, they create blame. Blame leads to shame, and shame is very detrimental to a person who is ill. I'd experienced it myself, and it made me feel that I was damaged, that I had done something wrong, that I was being reprimanded, that I was somehow responsible for

my cancer. I said to my mum, "You bake some cakes, I'll bring the kettle and cups from home. Let's just tell all of them to come because I can't keep talking to them individually. We will use my office in Peckham". Eight people turned up, and there wasn't a dry eye in the room. I started doing the meeting every two months. Then it became every month. We had 25 spaces, and every space was taken. Women were coming from Bristol, and Birmingham. I couldn't keep catering for everyone, so

everybody had to bring a dish. We would end up with this huge spread of delights: patties, crisps, Jollof rice. We named the meeting ETC – Eat, Talk, Connect – and it was just beautiful. Five years on, my registered charity, The Leanne Pero Foundation, now houses Black Women Rising – as the project is now called – and we have two full time staff members and two part time workers. The organisation exists to empower women of colour through their cancer diagnoses. Essentially, our aim is to help people live happy lives, to feel joy instead of

sadness, isolation, and fear. That's it! At our heart, we provide peer-to-peer support, help people understand their diagnosis, and make informed choices that are right for them. But we also publish a magazine, organise exhibitions, have a podcast, produce theatre, we even have a photo book coming out soon. It's huge. I'm more interested in empowerment than I am in politics, but the work that we do gives us a seat at the table. We have done research that backs up all we say about how women of colour are unseen and unheard. The statistics on

outcomes for women of colour with cancer further support the need for our work. We tell our stories about the hardships, and people in the industry listen. They want to learn more and to know how they can play a part in shifting that experience. In that way, we influence change. For a very long time I couldn't see a future. Now I allow myself to experience real feelings of joy and just be present. What the future holds, I don't know. But I do know that I feel good and positive about it. That is a huge step forward



from where I was. When a woman turns up at our door saying, "I feel alone, and I don't know who to trust" I totally understand. You don't need to go through this alone. If you find the right support, everything will be okay. You will be okay. Definitely.



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REBECCA

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My early childhood, in a small town in rural County Longford, was idyllic. My mum went off to study at college in Dublin, so my brother and sister and I were mostly raised by Granny. It wasn't until much later that I realised that my dad had left, and my parents had separated. We went to the local convent school. I loved it. It was a mixed school; there wasn't a big emphasis on pushing children into feminine and masculine behaviours. My brother was a boy, my sister was a girl, and I was me. I played with dolls, I put net curtains on my head – like a wig – did Irish dancing in a kilt. Nobody ever told me, “You shouldn't do that”. My biggest fear was going to the barber's. I wanted my hair *long*. Our family was quite middle-class. At age seven, I was sent to an all-boys Catholic boarding school in Dublin. I missed home, missed my granny, missed being able to wear net curtains on my head. At school, I realised for the first time I was officially a boy. Soon after, I started to be sexually abused by two of the *C h r i s t i a n* Brothers. It still hurts to talk about it, even now. That never goes away. I could not tell anybody; if I did, it would be me that got into trouble. On one occasion, one of the Brothers tried to have sex with me in my bum. I was standing there in a pool of blood. I think that even scared him. On Sundays, we went out of school for family visits. At my aunt's house, I could not sit down. I was walking up and down. She laughed and said, “Oh my God, you're doing the seven *c h u r c h e s* pilgrimage”. The part that hurts the most is, you get used to the abuse. I came to believe it was me that was making them do this. It never crossed my seven-year-old mind that such holy people would do something wicked. The abuse went on for five years but, as I got older, it lessened. When I was around 11, going on 12, they stopped abusing me altogether. It had become so much a part of me, I couldn't understand the change. *What have I done wrong? Do they hate me?* I even asked one of them and cried. I was slapped and told, “Get your evil away from me”. By this time, my mum had graduated from catering college and was doing well. We had a lovely

house. At age twelve, I was sent to a private secondary school – a rugby school. Surprisingly, I was never bullied by the other boys there. Back in County Longford, at the convent school, I had always been near the top of my class. But at boarding school, while the other kids had been doing their homework, I was being abused. The school would write to my mum and say that I was “slow”. By the time I got to secondary school, I was behind the other boys, not only academically, but mentally and emotionally as well. I became a wild child. The ‘70s

were just kicking in, so it was a great time to be crazy. At age fifteen, I got myself expelled. Granny said, “He’s always liked hair. Hairdressing will be wonderful”. I went into hairdressing, and I loved it. I was able to get lost in it. I was just seventeen when I won Young Hairdresser of the Year. That came with a one-year scholarship, working at Vidal Sassoon in London. London was a different world: gay people, straight people, drag queens, the lot. At seventeen, I still hadn’t really reached

puberty. I would pretend to shave. I wanted to fit in. I used to mimic my brother, walk like he did, stand like he did, try to talk like he did. I knew that I was making a conscious effort to do this because inside, I wanted to be a girl. I thought like a girl, I felt like a girl. I was gender confused, sexually confused – I liked boys, but I didn’t want to be a boy. I couldn’t find me. At eighteen I got into a relationship. I confided some of my turmoil in my girlfriend. She was kind and accepting of me. A couple of years later,

we got married and we had a daughter. When my daughter was two years old, I finally did come out as gay, and my wife and I separated. Back in the 1980s, the political situation in Ireland meant I had no rights as a father. I was not allowed to see my daughter. That affected me badly because I loved my child with all my heart and soul. I threw myself into work. Before long, I was one of the top hairdressers and make-up artists in Ireland. I could name my price for anything. I started to do modelling as well. The bigger my profile grew, the more

well-known I became, the harder it was to be me. I took on the androgynous, Annie Lennox look: baggy t-shirts, leggings, Doc Martins, tinted moisturiser, lip gloss, and mascara. The press called me a “gender bender”. I was hanging out in the London clubs with the likes of Boy George and Marilyn. I was avant-garde, outrageous, but in that environment, it was safe to be what we now call non-binary, or gender fluid. In the nearly mid-80s, I was on a photoshoot in Berlin. I met two girls and discovered that they were trans girls. The minute I met them, the penny dropped. From that moment I went hell for leather to become Rebecca. That was no straight and easy path. I had to see a psychiatrist and a number of other people, kind of a committee, and jump through all sorts of hoops before I could even get on hormones. Back in London, I started to meet more trans girls, and they would buy hormones on the black market. They would say, “take this for your hair, and this for your skin” – we were doing kind of DIY transitions. I had so many hormones in me

I rattled when I walked. We all did. People were wondering why we were all going doolally crazy. There was no clinical service for us to get our levels checked or anything like that. Our hormones were just off the scale. Eventually, the big committee pronounced, in a very X-Factor way, “we are unanimous, we are unanimous” – long silence – “that you are a woman *trapped* in a man’s body”. After that, I was able to get hormones through a GP. So, things improved a little, and then they didn’t. By that time, I was

running a successful model agency in Dublin. I was at the top of my game; had just done Eurovision. Then the press got hold of the story that I was having a sex change. Within a week, my career went belly-up. Nobody in the industry wanted to work with me. Models left the agency. I lost everything. That was a blow. But it did not deter me. I had my sights set on my future. I thought, *this will all be worth it. I’m going to be Rebecca, then everything will be fine, and I’ll get it all back again.* In 1987, I was finally scheduled for surgery. In the intervening years,

AIDS had kicked off. Before any kind of surgery, you had to have an AIDS test. What I knew about AIDS – nobody talked about HIV in those days – was that you had to come from Africa, or be into crazy, weird, gay sex, or be a junkie, to be at risk. I didn't fit into any of those categories. *Fine*, I thought, *let's have the test*. The results came back. I was positive. The doctor told me I had two years, at most, and that I should talk to my nearest and dearest. I asked if the surgery would still go ahead, and he said, "absolutely not". That was when I lost the will to live. I did tell my family, but I made a decision not to tell anybody else. We were living in a climate of fear. I'd already been victimised and abused for having a sex change. I was hounded in the press. My nieces and nephews were getting bullied at school; "are you going to end up like your uncle, or is it your aunty?" I use the language of that time – there were no kind, affirming terms like *g e n d e r* reassignment. Words were coarse and harsh. I was having a sex change, and now I had AIDS. Even among my

own trans tribe, some would say nasty, cruel things like "AIDS-ridden bitch". If that news had got out to the wider world, I could have been murdered. I was a Catholic, from a Catholic country. My family sent me to a monastery. My poor little aunt, who I love dearly, had to bring me there. I think she hated doing it. The church, having destroyed my innocence at age seven, now failed to exorcise the evil out of me. I did make another *d e c i s i o n* though: I would not die with a penis. I would have my operation and

die as Rebecca. There was no way to go ahead on the NHS. I searched high and low, and finally found a surgeon who would do it privately. But it was going to be expensive; £3,000 for my breasts, and £6,995 exactly for my lower surgery. I did not have the money. I started to do sex work. I did mainly S&M stuff – that would not endanger anyone else, and at the same time it gave me some sense of control. But I hated it all. I mean, none of that was on my 'to-do' list. I'd always been quite an abstemious person; I didn't even have a glass of champagne on

my wedding day. Now I turned to drugs and alcohol to numb myself. I could not afford to feel. The pain of reality was excruciating. It all spiralled. Soon I was using cocaine and heroin. I didn't really sleep, more drifted into a stupor. I never knew when I would open my eyes but, when I did, I felt bad, really bad. I'd need more and I'd have to get more. Not only was I going through my own hell, but I was also watching friends of mine die from AIDS; trans friends being murdered and taking their own lives. Being trans and being infected with HIV/AIDS in those times was like being in the front line of a war. Life was a treadmill of s e e d y nightclubs, bad boyfriends, and being beaten up. I went to Amsterdam and worked running a brothel. I got married in Amsterdam. I came back to London. I just trudged on, like a zombie in a horror movie, driven by my determination that I would not, under any circumstances, die with a penis – even if that meant cutting it off myself, which I attempted to do one time. I had gotten so deep down in that dark hole, I started to believe that I had imagined my former life – being a hair and makeup artist, going to the Eurovision Song Contest, having a nice home. It was easier for me to believe that none of that had ever happened. I lost touch with my family, and I lost touch with myself. On one occasion, I owed three guys £25 for a rock of meth. They took their payment by all raping me. The last one pissed on me and, as he was walking out the door, I asked, “any chance of a pipe before you go?” At that stage, all self-respect was gone. That was my life, for more than a decade. But I did get the money together and I did have my surgery. First my breasts and then, in 1991, I finally had my lower surgery. I had to sign papers; say that I was doing it all at my own risk, accept the chance that I would not survive, blah, blah, blah. I didn't care, I had already hit the fuck-it button. I had been raped, I had been abused, I had been exorcised. I did not fear death, at all. I got my vagina. Hallelujah! Against all the odds, here was justification for all I had been through. Everybody I knew got to see it. It was my badge of



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I have found great  
peace in being me.”



honour. But it was not a magic wand to wave all my nightmares away. My body was complete but, mentally, I was a total mess. And now, as a trans woman, I was even further segregated by society. I had crossed a bridge, and it became clear to all that this was not something that I was going to “grow out of”. In the latter years of the 1980s a new drug was licenced: AZT. I started taking it, but AZT also came with some quite serious down sides. First of all, you had to keep the meds in the fridge, so anyone who came to your house and opened your fridge would know you had AIDS. Then there were some terrible side-effects. Some people said that AZT could give you a hunch back, so there was a lot of fear around that. We used to laugh and say, “if AIDS doesn’t kill you, the meds will”. So, I would take it for a while, my T-cell count would go up, and I’d stop. On, off, on, off. I didn’t end up with any deformities, which a lot of my friends did, but I also didn’t realise I was building up a resistance to the meds. I came very close to the edge of death quite a few times with

AIDS related illnesses. The drink and drugs continued. I didn’t know who I was anymore. I was in and out of hospitals and police cells. I was about five stone in weight, I started to lose my teeth and my hair. But I could not stop. To be honest, I was a nightmare. One day, or night, I woke up on the floor with half a bottle of vodka, a broken hand, and no idea what had happened. I got in touch with AA, and I went there. I still felt so bad though. After about three months, I went home one evening in despair. My plan was to take an

overdose of amitriptyline, drink a bottle of vodka, and be gone. Before I lost consciousness, I managed to text a friend for help. I woke up a couple of days later in Chelsea and Westminster Hospital on a life support machine. The doctors had said to my friend, “If she doesn’t come around this time, you’re going to have to let her go”. As soon as they let me out, I went across to the Tesco on Fulham Road to buy myself another bottle of vodka, go home and do it properly this time. What I did not know was that I was on suicide watch. Two elderly

women dragged me screaming out of Tesco, and I was sectioned. I spent a month in Gordon's Hospital – that was my rock bottom. The staff used to call me “it”. I still had facial hair, so I'd be there with my boobs and my vagina, taking a shower and having to shave, with some man watching me. But my friend would come and collect me every day and take me to AA meetings. I realised, *if this is going to work, I have to surrender*. I got a wonderful sponsor, and on the 3rd of April 2005 I got sober. Little by little, my life started to change. It took a long time.

I was the only trans person in my AA group. I went and listened to other people's stories every day for a year before I felt comfortable enough to share. AA gave me the platform to begin to talk honestly. They have a saying, “who you see here, what you hear here, let it stay here”, so I felt safe. Although not yet safe enough to share that I had HIV. By 2009, I was doing okay. I was living in Carnaby Street in Soho. The girl upstairs was also in recovery. We became best friends. I had lost touch with my family years before, and we

talked about that. Facebook was a new thing, but she suggested I have a look and see if any of my family were on there. I found my sister. I was terrified, but I messaged her. She messaged back and told me that they had been trying to find me; feared I was dead. After some conversation back-and-forth, my sister suggested that I come to Dublin for my birthday. I was delighted. In Dublin I went to meetings, and I bumped into a guy that I'd known from the clubs years ago. He was sober now and about to open a big nightclub in the

city. He asked me if I would stay on for three months to be the face of his club launch. I was dubious about that, but he reassured me and said he would protect me. I worked at the club performing a burlesque show as ‘Lady V’. It was fun and I made good money. One night, one of the girls who worked in the club approached me. “Could you talk to the girl who works part-time in the kiosk with me?”. It didn't take long before I realised that girl was my daughter. I told her my story; why I'd not been able to see her all those years, why I'd had to leave. I

told her how I'd thought about her all the time, how much I had missed her on her birthdays, at the time of her communion and confirmation, every Christmas. How I had wondered what she might look like. She listened, and she believed me. And on that day, she told me something, "I've got news for you as well. You are also a grandparent". I'd come to Dublin to work at the nightclub for three months. When I met my daughter and, eventually, my granddaughter, everything changed. I just wanted to be near them, to get to know them, so I stayed on. I'd

been going to AA meetings, sharing my story. Over time, I told my daughter and my family more about my life. Yet I still was not open and honest about my HIV status. We were living in the 21st Century, but the fear and shame of AIDS had been carved into me since the 1980s. I even wrote a book, *His Name is Rebecca*, that told all about my sexual abuse, working in brothels, addiction, and bad relationships. There is not one mention of HIV in that book. I was making a life in Dublin and, after a while, I ran out

of meds. I'd never liked taking them anyway and, what with my new start and family around me, I'd got myself into a state of denial. *I'm not going to any doctors in Ireland,* I thought, *I'm fine, I'm healthy.* Little health problems began to manifest: infections that would not heal, bad teeth. I would not see that these were AIDS-related symptoms. In 2013, I was hospitalised. I didn't tell anybody; I didn't want anybody to visit. The doctors said I had built up a resistance to the meds and there was

nothing they could do. They gave me eighteen months to live. I thought, *no, no, no, no, no.* Once again, without telling anybody why, I packed my bags and ran. I flew to London and went back to Chelsea and Westminster hospital. They confirmed that I was perilously ill but also told me about a trial of a new drug that was working for people who had built up resistance to HIV medication. I would have to stay in London to join the trial. I signed up. I had packed a suitcase and left Dublin overnight. Here I was in London, very ill, with nowhere to live, and no

job. London is not an easy city for those in reduced circumstances. I ended up homeless, going to food banks. I was having lunch at an HIV shelter when somebody told me about a scheme that was being run by the Terrence Higgins Trust to help people living with HIV get back into the workplace. At the time, I did not even know how to turn on a computer. The Work Positive programme was far outside my comfort zone, but I was determined to give it a go. I turned up, and was taught how to use new technology, the internet, and how to repair

the cavernous  
holes in my CV.

While at the  
centre, I learned  
about another  
initiative called  
Positive Voices.

The idea was  
that people go  
into schools,  
talk about living  
with HIV, and  
encourage  
young people to  
get tested. I  
went along,  
listened to a  
woman tell her  
story and, for  
the first time in  
my life, I  
thought, *I want  
to be that honest.*

I rang my  
daughter and  
told her  
everything. She  
told me she  
loved me. Said,  
“When you  
walk into a  
room, you light  
it up. Go and  
shout it from  
the rooftops”. I  
think that is all I  
ever needed to

hear. I started  
speaking, here  
and there.  
Before I knew  
it, I was in  
Amsterdam  
with two-  
thousand  
people standing  
up, giving me an  
ovation and I  
thought, *Jesus, I  
am only telling  
my story.* After  
that I was  
speaking  
everywhere. At  
a conference in  
Prague, I stood  
up and said, “I  
am the only  
trans person in  
this room. I am  
speaking for a  
minority within  
a minority”.  
That opened  
everybody’s  
eyes. I felt like I  
was becoming  
the Joan of Arc  
of trans HIV.  
Someone at  
Gilead rang and  
asked if I would  
tell my story on  
film. *Yeah, why  
not?* They shot the film, and on the Friday the video was sent to me. It was then that I realised, *oh shit, this is going to be up on the internet.* *What am I going to do?* I managed to copy and post it on my Facebook page that evening. *Send.* That was probably the bravest thing I’ve ever done. I closed the laptop and spent the whole weekend in bed, not looking. On the Monday I dared to check my Facebook. There was a barrage of love and kind wishes from Ireland, from many places. So, that’s how I outed myself to the wider world as living with HIV. My

story is tough, and people ask me if I'd go through it all again. Sexual abuse and addictions are never a choice but, honestly, my life has made me the woman I am today. By sharing, I realised the power of my story. It changed my mind about myself, and I saw that it could help others to not have to go through those same experiences. I started working at 56 Dean Street on the front desk. Then I thought I could probably help some of the trans girls with their hair and makeup. Around ten women came to the first event and, as we talked, I realised how much terrible poverty there is within the trans community. I started inviting other people to come in and help with CV writing, skills training, health and wellbeing support. That was the beginning of #ProjectBoot Camp, a programme that helps trans women find confidence, independence, and become their best selves. I approached Kensington Palace, and they came on board, then Chelsea Football Club. Boot Camp has now come to Dublin, and we are taking a programme to Mexico. It's just

grown and grown. Girls come to Boot Camp and do their homework in a safe space. They don't have to go out and be degraded on the streets. Mums ring me up to talk about their kids – because the mums identify with me. Just being in the room brings trans girls out of isolation. They meet and talk and develop an incredible camaraderie. They support and help one another. Beautiful friendships form, and their confidence and sense of purpose grows. My family are in my life. One of my nephews has been able to

come out as gay, without any problems. Now my granddaughter has turned eighteen, and she wants to be a nurse. I work at Chelsea and Westminster Hospital, the same hospital where I was on life support. I do trans training for all the Royal Palaces. It's mostly about using the right terminology. People are so terrified they might say the wrong thing, they run a mile from it. I tell them to just be honest and say, "I don't know". The complexities of trans and non-binary are tricky to navigate. I get it wrong as well. I think other people are quite

relieved when they hear that from me. I also work with HIV Ireland, coordinating a pilot programme aimed at encouraging trans women take power over their own health by teaching them about PrEP and encouraging them to be tested for HIV. Now, I'm about to become the first trans person in Ireland to have her own television show. *Rebecca's Second Chances* is not about being trans, it's about surviving hard knocks. I've taken eight people from different walks of life that have experienced cancer, being a refugee, prison, addiction. They tell their stories and then we ask how we can help them to have a second chance. We create an individually tailored team to help each participant face and overcome their own challenges. Importantly, each of them is supported throughout, and beyond the filming, with appropriate counselling. I have found great peace in being me. If I had a message to anyone, trans, gay, HIV, or anything else, it is this: "to thine own self be true". Until you get real with yourself, you've got no hope of being anything to anybody else.



female and I've the strength of a woman. No man would have been able to endure what I've been through.

Some people may not like who you are, but it's very hard to argue with honesty. In my mid-sixties, my career is just beginning. I mean, who gets a television show when they're just about to get their pension – especially a woman? Today, I have a lot of respect for myself, and I stand tall for all women. I also realise that most women go through some form of abuse in their life, because we're treated as second class citizens by men. I've been on both sides of the fence, so I should know. I am a woman. I've the soul of a



**STEW**

**ART'S**

**STORY**



STEWART

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My early years were spent in a small village in Sussex. It was just me and my mum. We lived in Social Housing, but life was rural; there was walking in fields, pinching local farmers' vegetables, and deer everywhere. It was a lovely environment but there was an archaic aspect to village life. I was left-handed and at school, that wasn't allowed. It was something that had to be 'corrected'. I've always been headstrong and impatient. At age thirteen I came out. My attitude was, why would I wait, if I already know? Mum and I had a good relationship, but our family is large, quite traditional, and somewhat religious in places. I think she was fearful about how they might react, what risk I might be putting myself into, and how my declaration might affect my life in the future. I was too young and naïve to be afraid. There was no internet. Depictions of queer people on TV weren't great. The UK was still under the censorship of Section 28, a law that prevented schools and councils from "promoting the teaching of the acceptability of homosexuality as a pretended encouraged me to go where the money might be, go with the science. I went on to university to study psychology. Like a lot of students, I went in thinking I wanted to be a clinical psychologist – working in hospitals or with kids. I soon found I had a knack for being inquisitive. I would ask questions that my tutors couldn't answer. One of them said, "you have a future in research". In quick succession I did a BSc, an MSc, and then started on a PhD. The first year of the doctorate was supposed to be just reading and generally settling in. My impatience

family relationship" effectively banning any mention of LGBT+ people. So, it wasn't possible to talk about being gay at school. One of my teachers openly teased me about it, but there was no way to push back. All of that gave me quite a pronounced sense of queer shame at an early age. It took me until my mid-twenties to work through and begin to undo that. I had a good circle of friends though, and I did well in school. After college, I was torn between studying art or psychology. I'm from a poor family - they

came to the fore again. I was so focused on what I was doing, I just wanted to get on with it. As I had time on my hands, other students called on me to flag issues and take them to the higher-ups. My supervisors didn't like that. I felt like I was being pushed back in subtle ways. For example: they'd ask me to bring my notes to a round table, and then not call on me to speak. I started to feel restless. After a while I decided that the academic environment was not for me. Dropping out was a difficult decision, especially after having achieved a fully funded place and done all that work. My mother and my supervisors were frustrated with me, but I had grown disillusioned. I was only 23, I'd just moved to London, and I was having way more fun going out, being silly, and doing things I'd never had a chance to do. Academia didn't align with the way I wanted to be. During my Master's, I had a weekend job in a tattoo parlour. I thought it was something I'd like to do more of. I left psychology and went into tattooing. It was very hard work; in those days, you didn't just pick up a

machine and free style. I started with a two-year formal apprenticeship. That involved learning to make your own needles or build a machine from scratch – thorough stuff. Traditionally, your mentor is supposed to break you down and build you back up again. I found a queer mentor, but that didn't mean that he was any softer than the others. We had a fractious relationship. There's no HR department. If there's an issue between colleagues, you sort it out on the spot. I'd become frustrated with the archaic world of

academia and jumped straight into another hyper-masculine and archaic world. That irony was not lost on me. But when I started, despite all my sense of justice and standing up for myself, I was very conflict averse. People around me would ask, "Why are you putting yourself through this?" My family always had a belief that work doesn't have to be pleasure. Sometimes there is hardship, you pay your dues and it's worthwhile in the end. I don't know if that is a perfect view, but that is where I came from. Tattooing requires you to hold someone's

mood, balance their expectations, and deal with whatever is in front of you, even if things get difficult. It's essential to build yourself into a tenacious person. My apprenticeship and my mentor did that. I did that job for the next ten years, and I loved it. I loved the environment. I loved the creativity. I loved the crazy characters, the conventions, the stories, the travel, and the fun. During that time, I experienced a terrible and violent hate-crime attack. My lung was collapsed, and I had to have open chest surgery. That was a lot to process. It raised old questions in me, and some new ones – less about the attack itself, but more about social justice, how such a trauma affects your life and relationships, and what do you do with all that? I began to feel a bit lost, a bit like I was stagnating. I needed a break, a change. Berlin was LGBT-friendly, I knew a couple of people there, and I thought, *it's close enough; if it's terrible, I can just come back*. So, I made the move to Berlin. I hadn't really planned much about the move, and I didn't speak German, so it was difficult at first. But I found a flat, got a job in a small tattoo shop, and started to settle in and make a home. Soon, I moved to a new job in one of the oldest and most respected tattoo shops in Berlin. I started to build a clientele and some new friendships. I fell in love with Berlin and, after only six months, felt I had begun to build a life there. Around this time, I got food poisoning from a restaurant. I went through all the vomiting and so on, but it didn't really resolve. If I ate anything more than carrot soup, my stomach would play up. That went on for a couple of weeks, and I thought, *I'm paying for health insurance, I might as well go to see a doctor*. That was a good decision. The GP immediately said, "Let's do some blood tests and check what's going on". We did the tests, and I was back at home, playing video games and eating carrot soup when the GP rang. He said, "Your white blood cell count is incredibly high. I need you to go to the hospital right now". I was like, "Which hospital? Should I take anything? What do I do?" He said, "Just get there". I turned up at the hospital and said, "My GP thinks

I'm unwell. Can I get some blood tests?" Each person I spoke to said, "You look fine. I'm sure it's nothing". And I felt fine. Absolutely fine. Then they'd get the blood results and say, "Okay, let's move you on to the next person for more tests". I'd sit in a room, and wait, and then get moved on to another room, and wait some more. At one point some random doctor who I'd never seen before stuck his head in and said, "Just to let you know, when we see results like this it is usually related to cancer. I'm not saying it is, but best to tell you, just in case".

And I said, "Okay". About ten minutes later, someone else came and said, "Your white blood cell count is high, but go home, don't worry about it. You seem fine. Come back for an outpatient appointment." That doctor did quite a bold thing, but it ended up being something of a lifeline because I did not get any further clarity about my condition for another month. I went to the outpatient appointment. They said, "You seem fine. Don't worry. It's probably a viral thing. It will resolve itself". But My GP said, "I don't think

so. Let's try a different hospital". All the time, there was anxiety about health insurance. What did it cover? How could I access it? At the second hospital they put me in a single room. I knew that wasn't covered, but there did not seem to be any multiple-bed rooms available. I had a raft of tests; they were trying to rule different possible conditions out – or in. Then they sent a Social Worker to see me. In the British sense, I thought a Social Worker was someone who would help me. It's not the

same in Germany. The Social Worker said, "This room costs a thousand Euros a night. Can you afford it?" It felt vaguely threatening. I thought, *you put me in here. I'm a bit busy thinking about if I've got cancer or not. What am I supposed to do?* I didn't want to run the risk of running up a bill that I could not afford, so I left the hospital the next day. The doctors urged me to stay but I just said, "please call me when you know the results". They called, and did the whole, "you have to come in" rigmarole, with me saying, "just tell me over the phone, then

I'll come in" and them saying, "No, we can't". So, I knew what was coming. I went to the hospital, and they told me that, at age 29, I have chronic myeloid leukaemia, an incurable blood cancer. And I thought, *fuck's sake*. The doctor found an information sheet in English and printed it off for me. I had an appointment to do a tattoo, so I went back to work. Afterwards my boss came by and said, "Well, you just did a fine tattoo, I'm guessing you must have had good news at the doctor" and I said, "Actually, no. It's cancer". He was kind, in a paternalistic way. He said, "I think you should go home" and I said, "Yeah, I think maybe you're right". Then I was left alone with my thoughts; *I'm alone in this country. I don't speak German. How am I going to tell my family? I'm self-employed. I don't get sick pay. How am I going to pay my rent? How am I going to pay my health insurance?* Everything I knew about cancer was probably from a M a c m i l l a n advert. It's older people. You have surgery or chemo or radiotherapy. You lose your hair. Cancer was something that at some point would be cured or go into remission – that you somehow would move past it. I was told from the outset, *that probably won't be you*. I Googled a bit. Blood cancer is not the same as, "There's a growth and we have to remove it". Instead, it was, "there's a mutation on a chromosome where something has switched that changed the way your blood is produced from the bone marrow". It was hard to understand, I just knew that I had to take medication every day for the rest of my life, or my immune system would fall apart. That was as much as I knew for a long time, to be honest. The medication was expensive. Sometimes thousands of Euros. The local chemist asked, "Do you have the money?" and I replied, "No, I have insurance". But I didn't know how to get the insurance to pay the chemist, and the chemist didn't know either, so I'd have to call my broker and have lots of meetings and argue to get the treatment I needed. I remember being in yet another hospital to see yet another specialist. I looked around; there were all these leaflets, and I couldn't

read any of them. In that waiting room I figured out for the first time what the word ‘cancer’ is in German. I realised that I was going through this quite blindly, and I needed to start to make some decisions, for the sake of my health. About six months after my diagnosis, I decided that it would be easier if I just came home. I had built a nice life that I didn’t want to leave, but in England I could speak the language, I’d be near my family and friends, and I would not have to do all that paperwork. I stayed with my mum for a short while whilst

I figured out what to do next.

Friends said, “Don’t shift back to London, it’s too busy.

Try a slower pace of life”. So,

I moved to Brighton. I’d

already been diagnosed and taking my first line treatment,

a drug called imatinib, for six months. I went

to the NHS with my packs of German notes.

They insisted I go through all the tests again.

It was as if they did not trust

German healthcare.

“You could call them”, I

pleaded. But no, it all had to be done from

scratch, including a

painful and traumatic bone marrow biopsy.

Everything was tested, everything was confirmed, and they kept me on the same medication. I really did not need any of that. My family isn’t super touchy-feely. It was difficult for us to figure out how to relate in this crisis. How do we demonstrate our love for each other when it’s something we’re not very practiced at doing? They didn’t know how to be involved. When you tell people about your health, you’re not really given the opportunity to express it in the way you want. You have to manage other

people’s understanding and expectations of cancer, and their feelings. The way you talk about it with the people around you will differ based on their level of comfort. Some friends take quite a blunt approach; “Okay, so you’re not going to survive this, so here is what we’ll do”. Yet if I tried to have that kind of conversation with other friends, they would be appalled; “Don’t think like that, it’s all going to be fine”. For a long time, I discussed my health in terms of the numbers, not how it was affecting me as a person. If someone asked me how I

was, I wouldn't say, "I'm frightened". I would say, "Well, my numbers are good, my blood counts are up, I'm taking my pills", and that would make them feel better. At the same time, some friends were pushing the most crackpot ideas. "If you go to Italy, you can get someone to inject vitamin C in your bones, that will cure it". I love them, but I cannot be force-fed spirulina. All-in-all, talking to people was weird, and a bit exhausting. I asked my Clinical Nurse Specialist if there was someone else with my condition I could talk to. She would say, "Yes, we will organise that. I have someone in mind", but it just never happened. I was beginning to realise that, because my healthcare had started abroad, a lot of information had been skipped. I didn't know, for example, that I was entitled to free prescriptions. I hadn't had a Holistic Needs Assessment. I didn't know how to get the support I needed, or even what that might look like. I went to the local Macmillan Centre, the Horizon Centre, and asked if they had any L G B T Q +

specific content that might work for me. No, nothing. I asked, "Well, do you have any art groups?" and they said, "That's for old women. You need to take part in the sports activities for young men". By this point, I was using a walking stick, so I thought, *I'm not going to be able to do that*. I was trying to keep up tattooing, but it's a physically demanding job. I had so many health care appointments. I was tired. Then I started to experience quite severe side-effects from the medication. The first line treatment was

failing. I had nobody to talk to. I'd stuck it out in Brighton for a year but – really, I don't like the sea. Despite being the gay capital of the south coast it's not very ethnically diverse, and there are no decent art galleries. I tried it and, oh, my God, it was boring. It turns out I'm just not good at a slower pace of life, even with cancer. I moved back to London. I found a flat in Brixton, transferred to King's College Hospital, and got a job. Being in London allowed me to reconnect with friends. I started to regain a sense of normality that I had been

“

I get that positive affirmation from having built something that, I hope, will always be there for others like me.”





missing for a long time. It felt good. I still could not find specific support for LGBTQ+ people. Macmillan had an online forum that was completely dead. The only other support groups were for prostate cancer only. On the internet I found discussion of how to speak to people like me, but nothing that spoke *to* people like me. There was a research study taking place about LGBTQ+ people with chronic health issues. I signed up, and the researchers interviewed me. That was the first time I'd been given a chance to talk about cancer and being queer at the same time – how one was impacting the other – and I wasn't expected to split myself down the middle. I enjoyed it. It reminded me of my old research days. For a very long time, I had had one foot in my cancer patient space, and the other in my LGBTQ+ space, but there was no space where I could talk about both those things and bring them close to each other. Every doctor and nurse would tell me, “You're young, everything will be fine”. I felt like I was almost leading a double life, presenting to the world

that I was fine, *don't worry about me, I've got it all together.* But I wasn't fine. My health was up and down all the time. I'd been struggling to keep up with work, and then got signed off sick. I had to sell my car to pay the rent. Then my legs got worse, I was walking with a stick and struggling to get up and down the stairs because of the medication. This meant I couldn't get in and out of my home safely and I ended up being put in a halfway house by the Council. I did not have it all together. Talking to the researchers

marked a turning point for me. For the first time it really sunk in, *you've got incurable cancer, this is the new normal. This is your life now.* It triggered a mini-breakdown – a night of extreme crying and purging all the emotions. It was the first time I had cried in the two years since my diagnosis. After that moment, I knew something had to change. It had felt so good just to take part in some research and be able to talk holistically about my life; there must, I thought, be other people out there who want to have that conversation. That thought is what kick-

started my charity work. The people at the Macmillan centres in Brighton, and now London, had always been kind and friendly towards me. I went back there and spoke to Lindsay Farthing, the Cancer Patient Experience Manager. “Do you have anything for LGBTQ+ people?” I knew they didn’t because I had already checked online. But I needed to ask that question. When the answer came, “No, I’m sorry, we don’t” I said, “Would you like to start something?” To my surprise and delight, Lindsay got 100% behind my proposal. Lindsay would ask what was needed, find the resources, open doors, and push from the back. She saw that I had a vision and she allowed me to lead on that, rather than try to own it, as many people tend to do. She helped me organise a focus group with potential attendees. We disseminated a survey asking clinicians how they feel about LGBTQ+ people with cancer. We set up a working group. I went from feeling alone and unheard to being surrounded by a team of people all saying, “Let’s do this!” We started with a peer support group at the Macmillan centre. It was so good to see people connecting. I wanted to expand beyond that hospital, and asked Lindsay if I could take it to an LGBTQ+ community centre. Again, she was fully supportive, “Do what you need to do. Let us know if you’d like a nurse to come along”. I never set out to create a charity. I just wanted to meet people. And I too don’t want to ‘own’ the charity. It’s not named after me. When we started, I was listening to an album by Hole called ‘Live Through This’ and I thought, *yeah, why not?* Live Through This exists to support and advocate for LGBTQ+ people affected by cancer. We do that through four main pillars of action. The first pillar is patients: peer support, carer support, and providing information and direct advocacy when it’s needed. Second is professionals: education and resources aimed at clinicians. Third is policy: working with key bodies in cancer to improve the quality of our care. The last is partnerships: how do we, as a niche organisation, influence the wider cancer sector? EDI –

equity, diversity, and inclusion – is the next big social issue that policy makers and the cancer industry need to tackle. Traditionally, LGBTQ+ health has only been viewed through the lens of sexual health. There is so much that is simply not thought about. For example, trans men who have updated their gender with their GP do not get routine invitations to breast and cervical screening, even if they need them. If policies and procedures are not designed with everyone in mind, they must be retrofitted later which can be costly and difficult.

The concept of bringing LGBTQ+ health and cancer together is still very new for a lot of people, even though there can be so many impacts. The industry is just starting to get to grips with that. Everything we do as a charity is for the people affected. Yes, we educate doctors and nurses, but that's so that patients have a better experience. Yes, we work on policy, that's so treatment pathways improve for everyone. We're not just EDI consultants for the sake of it. Now we are thinking about renaming the

charity. That's because we plan to add palliative care to the 'patients' pillar of our work. Being able to hear people's stories, providing a space where they can be open and vulnerable, is a unique privilege. Sometimes I receive an email out of the blue from someone saying that the charity has changed their life and thanking me. But I'm the one who is grateful; those interactions are what keeps me going. I think back to the time when I was so alone, feeling in that weird British way I didn't want to

be a burden on anyone. Sometimes people I'm speaking to at the charity sort of apologise for telling me their story. I remind them that listening is literally what we're here to do. So, my key message is, you don't have to go through it alone. Don't be afraid to reach out. You may not know what you want or need, but sometimes just having a conversation may help you join the dots. Also, if it's not for you, it's not for you. I always talk about building a patchwork of support. There is no one perfect thing, but you can build your own comfort blanket

with all the different things that work for you. I always want our charity to be available as part of people's patchworks. If you'd told me a few years ago that this is where I'd be today, I'd have said, "Naah, that's crazy talk". There are times when I still think, *what's happening? This is wild!* I have, though, created an unintended difficulty for myself. Because I am CEO of the charity, I can't access the support myself – that would be unethical. So, it hasn't necessarily fixed everything for me, but at least I get that positive affirmation of having built something that, I hope, will always be there for others like me.





**AFTER  
WORD**

A professional headshot of Dr. Véronique Walsh, a woman with short, layered blonde hair, wearing a light-colored blazer and a gold necklace. She is looking directly at the camera with a slight smile.

DR VÉRONIQUE  
WALSH  
GENERAL MANAGER,  
GILEAD SCIENCES  
UK & IRELAND

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**All six stories you have read are inspiring – my heartfelt thanks go out to all the advocates for sharing their personal journeys. They remind us how far we still must go to provide healthcare that is truly equitable, and they highlight the true diversity within our health inequalities. From a Black man living with HIV, to a Muslim woman living with HIV, to a Black woman with breast cancer. These stories, and many more, distinctly show that not all inequalities are the same and we need to hear these marginalised voices, so we start to really support diverse communities.**

Fixing health inequalities requires more than just pouring money into the system. What is needed is a mindset change and to reflect on the historical and social reasons behind entrenched inequalities. Professor Olusoga’s powerful introduction reminds us we have come far but more must be done in tackling inequalities.

The founding principles of the NHS were to create universal access to healthcare for everyone.<sup>1</sup> Health inequalities are complex, and the challenges faced by minority and socially deprived communities are stark. As set out in the NHS Long Term Plan, our health outcomes in the United Kingdom are impacted by where you were born, grow up, live, and work.<sup>2</sup> The NHS Race and Health Observatory report said just last year, “ethnic inequalities in access to, experiences of, and outcomes of healthcare are longstanding problems in the NHS, and are rooted in experiences of structural, institutional and interpersonal racism.”<sup>3</sup> ‘The Marmot review 10 years on’ (2020) unfortunately demonstrates health inequalities have widened over the last decade.<sup>4</sup>

The Margins advocates sought their own personal remedy when the system didn’t offer them a solution. But not everyone can do that, which is why I make three suggestions to tackle health inequalities: hearing and acting on the patient voice, building trust through equitable access to information, and partnership with the NHS.

As the Margins advocates so honestly tell us, attention is placed on treatment with little effort to support individuals more personally – a recent survey revealed “74% of women of colour who use a softie, prosthetic breast or nipple were not offered one to match their skin tone”.<sup>5</sup> Providing choice that is inclusive seems a basic idea, but this is sadly not the experience of many women

1 National Health Service Bill. Official Report of House of Commons (Hansard) 30 April 1946: cols 45–46. <https://api.parliament.uk/historic-hansard/commons/1946/apr/30/national-health-service-bill>

2 <https://www.longtermplan.nhs.uk/online-version/chapter-2-more-nhs-action-on-prevention-and-health-inequalities/stronger-nhs-action-on-health-inequalities/> (paragraph 2.23)

3 [https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report\\_v.7.pdf](https://www.nhsrho.org/wp-content/uploads/2022/02/RHO-Rapid-Review-Final-Report_v.7.pdf) (page 10)

4 <https://www.instituteofhealthequity.org/resources-reports/marmot-review-10-years-on>

5 <https://www.standard.co.uk/news/health/breast-cancer-women-skin-tone-soft-prosthetics-black-history-month-b1030120.html>

receiving treatment in our health system today. Patients should be listened to, respected, and valued as people; this cannot be overstated.

We need to change the way we reach out and share health information with different groups and communities. Culturally appropriate health information and advice that is translated into the right language should be a basic right for everyone. Building trust is key. People will only believe and act on the information they receive if the source is credible to them. This requires engagement with local leaders, communities, services, and patient support groups so that people hear information and advice from those who understand them and whom they trust the most.

This has been shown to work in the partnership with Gilead Sciences and NHS England to eliminate hepatitis C (HCV). We involved charities, and other stakeholders to bring testing, advice, and treatment into the community, where we thought the people living with HCV might be, rather than waiting for them to come to the health system. Peer-to-peer education and support has also been critical. As a result, we are seeing many more people identified and successfully treated and micro elimination is already happening.

This book aims to raise awareness and draw attention to the plight of those in the margins as well as highlight how diverse inequalities can be. Most importantly though, it demonstrates to those unheard that they are not alone and there is a way. The stories of the advocates remind us that to support diverse communities now, we must listen, learn, and change so we can break down barriers to better support distinctive individuals and communities.

I would like to thank the advocates once again for sharing their experiences and expertise, and for reminding us that we all have a part to play – only together can we make a real difference.

**Dr Véronique Walsh**

With thanks to the following people, who shared  
their inspiring stories and made this book possible:

Joshua Royal

Husseina Hamza

Kieron Allen

Leanne Pero MBE

Rebecca Tallon de Havilland

Stewart O'Callaghan

From the Margins has been created,  
developed and funded by Gilead Sciences Ltd

Published in 2023 by Unicorn an imprint of  
Unicorn Publishing Group  
Charleston Studio  
Meadow Business Centre  
Lewes BN8 5RW  
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Designed by Matthew Wilson



