



FIFTY OVER FIFTY

A COLLECTION OF INDIVIDUAL REFLECTIONS
ON GROWING OLDER WITH HIV

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ON GROWING OLDER WITH HIV

The Whole Person Care Partnership*



* The Whole Person Care Partnership is a collaboration between MSD UK and several HIV advocacy, education, and scientific organisations. The partnership has come together to promote and support the needs of people living with HIV in the UK. The contents of this material are the result of collaboration and discussion between MSD UK, the Whole Person Care Partners, and other HIV community groups, with content agreed on an equal basis between all those involved.



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The *Fifty Over 50* project is organised and fully funded by MSD UK and coordinated by communications agency M&F Health with communications support from Jo Josh, communications consultant. The contents of this material are the result of collaboration and discussion between MSD UK and the Whole Person Care Partners.



“We are united in our belief that more work needs to be done in this area, and that the voices of people who are growing older should be central to this.”



FOREWORD

***Fifty Over 50* is a unique listening project focused on people who are growing older with HIV.**

It is 40 years since the first cases of HIV were reported. In the early years of the HIV and AIDS epidemic, an HIV diagnosis was almost always met with fear and terror, and the belief that it was a death sentence. For many people it was. Effective treatment, which began to emerge in 1996, helped some of the people diagnosed in those early years to survive. In the years since, with the development of better treatments, more and more people can live into old age with HIV. Most recently, the advent of U=U (undetectable = untransmittable) means that today people who are on effective treatment cannot pass HIV on to their sexual partners.¹

Thanks to advances in clinical development and management, HIV is now largely considered to be a chronic condition and the average age of people living with a diagnosis of HIV is increasing. While we still have work to do to make sure that people are diagnosed in a timely manner, treatment has come a long way. Yet there is no blueprint for growing older with HIV. The generation that is ageing with HIV is the first to do so. Many uncertainties remain about how HIV interacts with the ageing process, and no generation has before had to face the myriad challenges of ageing with this backstory behind them.

So, what do we do? We need to celebrate the achievements in the fight against HIV and AIDS without believing it is all over. We need to recognise and embrace the challenges that are taking shape in front of us as the picture changes. And more than anything else we need to stop speculating and to start listening to people with HIV themselves. That is what this project is about.

It would be easy to fall into the trap of talking about older people with HIV as one group, but even a cursory

glance at the experiences in this book will highlight the folly in that approach. Not only are our contributors diverse in demographic, but also in their outlook on life. While there are some commonalities of experience, this book will not provide any easy answers via consensus. What we do hope it can provide is signposting to some of the key issues that clearly need more consideration from policy makers and those who can influence the construction and maintenance of services for people living with HIV, and those who provide support services for older people. Initial policy recommendations for further action, which have been developed in response to the experiences shared here, can be found on the [MSD working together website page](#).

Our different organisations are all committed to supporting people who are growing older while living with HIV. We are united in our belief that more work needs to be done in this area, and that the voices of people who are growing older should be central to this.

We intend to continue working together on the priorities we have identified and share a certainty that we will deliver good and meaningful work as a result. This will be built on the foundations of the experiences shared in this book which would not have been possible without the input of each of its contributors. We would like to thank everyone who has taken the time to share their experiences and reflections with us, for their honesty and their bravery. We are aware that for some people this is the first time they have talked about many of the issues they have faced.

There can be challenges in looking forward, and in looking back in time, and thus considering what it really means to grow older with HIV. We hope that readers of this book will appreciate each individual contribution and value the collective community wisdom and richness of experiences captured in these pages.

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1. Aidsmap. What does undetectable = untransmittable (U=U) mean? Available at: <https://www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean> (last accessed May 2022)



WORDS FROM OUR PARTNERS



HIV & AIDS – sharing knowledge, changing lives

Matthew Hodson, Executive Director, NAM aidsmap

“When I was diagnosed with HIV aged 30, I did not believe I would live to celebrate my 50th birthday. Even at that relatively young age I had witnessed my contemporaries sicken and die. Effective antiretroviral therapy had just begun its rollout by the time I was diagnosed but many within the communities most affected remained cautious. Even if an AIDS diagnosis was no longer inevitable, could we really expect to enjoy equal life expectancy? The less refined dosing we had at the time, in addition to the experiences of those whose health had been impacted by earlier attempts at treatment, left many wary of a heavy burden of side effects.

Now, 24 years later, I celebrate that HIV treatment has proved more effective than I then dared hope. When we are able to access and maintain treatment we should enjoy an equal life expectancy. But are the systems in place to support a generation of people who did not expect to get old? As much as we may celebrate that death is no longer considered inevitable, is enough being done to ensure that people living with HIV are able to fully enjoy our lives? Stigma remains a heavy burden. Many still suffer the medical impact of years of untreated infection. Some health conditions associated with ageing are much more likely to impact people with HIV.

I love that *Fifty Over 50* represents both the joys and the challenges of ageing with HIV, drawing on the testimonials of a diverse selection of people with a broad range of experience. Our progress has been extraordinary but we must not dismiss the challenges of ageing with HIV, both medical and social, that persist.”

BASHH



Dr Tristan Barber, BASHH

“Whilst we see so much about the successes in younger gay and bisexual men in urban areas with regard to falling HIV rates, the stories of those who are older with HIV, or who have lived with HIV for a long time, are not heard so frequently. This collaboration brings together a wealth of diverse stories to shine light on all the personal aspects of living with HIV but also as a beacon to show how much individual lives, and struggles, have contributed to the HIV journey to where we are today, and done so much for to help, lead, and support all those affected by HIV.”



Jim Fielder, Head of Living Well, Terrence Higgins Trust

“The *Fifty Over 50* project has given us such a valuable listening ear to the rich diversity of lives, experiences and needs of people growing older with HIV today. Reading through these numerous personal accounts provides many useful insights, ideas and pointers for organisations like Terrence Higgins Trust and others to better equip and support all those ageing with HIV now and into the future. We are pleased to be a partner in an initiative that has produced such a rich portrait of people who often go unrecognised within the HIV community.”



Garry Brough, Peer Learning, Partnerships and Policy Lead, Positively UK

“As a peer-led HIV organisation with half of our staff team being over 50 already, Positively UK enthusiastically welcomes the publication of *Fifty Over 50*. Being able to see our stories and experiences represented and shared is a key way to challenge ignorance and misperceptions. These stories are the testimony that with HIV, it is crucial that we now focus more on the Human experience than on the Virus.”



Cheryl Gowar, Senior Policy and Research Manager, National Aids Trust

“Ever since the start of effective HIV treatment, the welcome challenge of responding to people's needs as they age with HIV has been inching closer. The stories that have come out of the *Fifty Over 50* project bring alive the messy complexity – the positives and opportunities as much as the difficulties – of ageing with HIV in the UK. They show that we must continue to fight for the rights of all people living with HIV, but also that there is much to be hopeful about.”



Alex Sparrowhawk, UK Community Advisory Board Chair

“We are continuing to learn about the needs of our ageing HIV population, and the long-term impact on how HIV affects our health and quality of life as we grow older. *Fifty Over 50* provides us with an opportunity to listen to people share their experiences in their own words, exploring the challenges they've overcome – or accepted – through their diagnosis and how HIV has shaped their lives.”



Denis Onyango, CEO, Africa Advocacy Foundation

“The *Fifty Over 50* project highlights the experiences, resilience, determination and hope amongst black African patients living with HIV in the UK alongside those of their peers. The project provides insights into the life challenges experienced every day and their hopes for better quality of life as they grow older with HIV. It underlines the need for culturally competent, tailored, and inclusive services to ensure no one is left behind.”



Sophie Strachan, CEO, Sophia Forum

“This timely report has captured people's lived experiences beautifully, it has also highlighted the importance of hearing diverse perspectives and how living long term with HIV requires different considerations to those who have been diagnosed in more recent years, yet will grow older. Our bodies differ by our gender so our care also needs to reflect that. Assigning a solely biomedical lens to our care, will not support how we live well, how we develop resilience and hope and how we can as a community support each other through the next chapter of our lives. To hear people living well long term is so important, we also need to remain open to learning how we can always do better which involves collaboration and commitment.”



Parminder Sekhon, CEO, NAZ

“*Fifty Over 50* is a compelling collection of interviews and a must-read resource for anyone involved in providing care and support to people living with HIV. The testimonies captured here highlight the complexity, resilience and evolving needs of people living with HIV that need to be heard and considered when planning services for people over fifty. Effective treatment is one part of the HIV story and accessible peer led psycho-social wellbeing support and advocacy is another. As people age with HIV, experiences widely vary and the toll of place-based health inequalities can often come to bear. To ensure experiences of disadvantage, stigma, and marginalisation are not exacerbated and reinforced in later years, we need to take note now. Naz welcomes this collaboration and commends all the contributors for sharing their deeply personal journeys of aging with HIV.”



Dr Nadi Gupta, BHIVA

“I am absolutely thrilled to have been involved in this highly compelling project. It provides invaluable insight into previously uncharted waters; what it is really like to grow older with HIV. I am truly grateful for the enthusiasm shown and willingness of the contributors to share such deeply personal and unique experiences. This is quite simply a wonderful book. Once you start reading it, it is hard to stop. It's a must-read, not only for people living with HIV, but for everyone, including all healthcare professionals, to enable the provision of high quality care.”



“And as life expectancy has extended, so too has the need to look at how people can age well with HIV.”



INTRODUCTION

Nearly eight years ago, UNAIDS issued a new fast-track strategy to end the AIDS epidemic by 2030.¹ This saw ambitious targets implemented to end new infections, stop preventable HIV related deaths, and eliminate the discrimination and stigma associated with HIV.¹ London was the first global city to exceed the 95-95-95 ambitions through the Fast-Track Cities initiative with 95% of people living with HIV being diagnosed, 98% of those in care on treatment, and 97% of those on treatment having an undetectable viral load.² The whole of the UK has since met the UNAIDS target with over 95% of people living with HIV being diagnosed, 99% of those in care on treatment and 97% of those on treatment having an undetectable viral load.³ However, there is still a long way to go to before we get to zero stigma.

In January 2019, the Health and Social Care Secretary set the goal for England to become one of the first countries to reach HIV elimination by 2030, which ultimately provided the springboard for the establishment of the HIV Commission.⁴ The Commission was established through partnership between the Terrence Higgins Trust, the National AIDS Trust and the Elton John AIDS Foundation, and is spearheaded by a range of high-level stakeholders, and supported by collaboration across the HIV community.⁵ It is tasked with developing a plan for how England can meet its stated ambition to eliminate transmission by 2030.⁴ The Commission's final report was launched on World AIDS Day 2020 and set out three main goals for achieving this vision, including annual reporting to Parliament on the rate of progress achieved.⁶

The recent publication of the new HIV Action Plan by the Department of Health and Social Care on World AIDS Day 2021 has set out in more detail how these ambitions will be delivered in a rapidly evolving NHS environment.⁷ It also sets out a plan to consider primary and social care for people living with HIV, as well as optimising quality of life and addressing stigma through improving knowledge and understanding across the health and care system.⁷

HIV charities and organisations work assiduously to bring the Government recommendations into action by campaigning for better care and treatment, getting to zero transmissions and implementing education and awareness to address stigma.⁸ These campaigns are further developed into more

specific workstreams targeting at-risk populations, minority groups and other high priority areas, such as psychological wellbeing.⁹

Against the backdrop of huge progress, there is now a widely acknowledged requirement to look in more detail at the quality of life of people living with HIV, to consider the needs of people living with HIV who have achieved viral suppression but who still experience significant impact on their day to day lives. The Positive Voices Survey, the national survey of people living with HIV last conducted in 2017, has consistently highlighted poorer quality of life, mental health, and wellbeing outcomes versus the national population.¹⁰

And as life expectancy has extended,¹¹ so too has the need to look at how people can age well with HIV.

People who are fifty and over are the fastest growing group of people living with HIV in the UK. They are more vulnerable to 'multimorbidity' and often experience frailty earlier than the rest of the population.¹² The prevalence of high cholesterol, hypertension, diabetes, and heart conditions is projected to increase significantly in the older HIV population over the next decade.¹¹ They also have a higher than expected risk of developing additional complex needs including social isolation and financial stress, and they still face stigma, all of which can impact on their wellbeing.⁹ There are many unanswered questions about the interplay between HIV and ageing.

The UK advocacy community has recognised the need to collect and analyse lived experience of people growing older with HIV. The Terrence Higgins Trust Uncharted Territory report, published in 2017, was one of the first pieces of work that considered lived experiences.¹³ The report provided particularly interesting insights into the perspectives of a group of older people living with HIV and confirmed an extra level of need and necessities that go beyond the 'standard' experience of ageing.¹² Some of the issues that were highlighted included the availability of treatments, not stereotyping the over-50s as one group, co-ordinating long-term condition management and self-stigma.¹²

Now, five years since the publication of Uncharted Territory, the *Fifty Over 50* project is looking to see what has changed, and to gain an additional valuable layer of lived experience from a diverse group of people aged 50 and above.

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8. National Aids Trust. Strategic Plan 2020-2025. Available at: [National Aids Trust Strategic Plan 2020 - 2025](https://www.natrust.org.uk/files/Strategic-Plan-2020-2025.pdf) (last accessed May 2022)

9. BHIVA. Standards for psychological support for adults living with HIV. Available at: https://www.bhiva.org/file/BbShtfyMFNKCz/Standards_for_psychological_support_for_adults_living_with_HIV.pdf (last accessed May 2022)

10. Kall, M. et al. Positive Voices: The National Survey of People Living with HIV - findings from the 2017 survey. 2020. Public Health England: London.

11. Aidsmap. Life expectancy for people living with HIV. Available at: <https://www.aidsmap.com/about-hiv/life-expectancy-people-living-hiv> (last accessed May 2022)

12. Leake-Date, H. Optimising the health and well-being of older people living with HIV in the United Kingdom. 2017. Available at: <https://www.pharmaceutical-journal.com/research/review-article/optimising-the-health-and-wellbeing-of-older-people-living-with-hiv-in-the-united-kingdom> (last accessed May 2022)

13. Terrence Higgins Trust. Uncharted Territory. A report into the first generation growing older with HIV. 2017. Available at: <https://www.tht.org.uk/sites/default/files/2018-02/Uncharted%20Territory.pdf> (last accessed May 2022)



ABOUT THE FIFTY OVER 50 PROJECT

Fifty Over 50 is a unique listening project. We set out to hear from fifty people, over the age of 50, living with HIV.

The vision for the project was not to conduct scientific research but to seek meaningful, qualitative accounts of experience, to add to the body of evidence and existing insights on HIV and ageing. By providing a platform for people to share their own personal experiences we wanted to help people understand not only what issues may exist, but also how people feel about them.

This project wouldn't have happened without the partnership of the Whole Person Care Partnership who helped shape the vision and mission for the project and who worked tirelessly to help us reach the many people who shared their experience and enabled this e-book to come to life. Through the process, we engaged over 50 people, and many of these agreed to share their experiences within this book. It was crucial to us that as far as possible we had a diverse group of contributors. So, in its preparation and development, we worked collaboratively with each of the partners to ensure that the project was accessible and promoted as widely as possible to all.

We spoke to each contributor for between one and three hours, over three months in the Summer and Autumn of 2021. The key themes we wanted to explore were physical health, mental health and emotional wellbeing, practical circumstances such as finances and housing, relationships and issues around loneliness, and experience of stigma, as seen through the lens of living and ageing with HIV. We wanted to explore how people feel their experience of living with HIV has changed or may change as they get older, how it might impact the choices they make as they age, and how important they think it could be in shaping their later life.

Each conversation was largely directed by the contributor. Our interviewer used a discussion guide to ensure all themes were touched upon (see Appendix 1), but everybody was free to focus on the issues and themes that mattered the most to them and to highlight where issues were less important.

We were keen to ensure we had people from different age groups involved. Our youngest contributors were 50, but we also heard from people in their 60s, and 70s and our oldest contributor was 80. The people we talked to were diagnosed at a range of times, from the 1980s, the 1990s, the 2000s, and most recently in the last decade.

We aimed where possible to ensure a balance of genders, and representation of those from black and ethnic minority backgrounds. There are naturally some limitations: whilst you will notice that there is a spread of regional diversity amongst the contributors, and those

based in cities versus town or country living, most of the people we spoke to were in England. We spoke to just one person who is transgender, and fewer people than we would have liked whose first language was not English. This project should therefore be considered to provide an illustrative, rather than a fully representative sample of experience.

We embarked on this project recognising that not all contributors would have the same experiences, current and future concerns, or the same needs. Some people were very positive about the prospect of ageing with HIV and felt confident that their needs would be well catered for, while others faced a myriad of current and future challenges. Some contributors had just one or two key issues at the forefront of their minds when asked about growing older with HIV whereas others were keen to cover a whole range of different things.

While the focus of this project was to understand how people feel about ageing, many contributors also shared how past experiences have shaped their current life and their likely future.

Through listening, sharing, and understanding the experiences of those living and ageing with HIV, we hope to shine a light on the issues that need addressing and drive action across all levels of society with greater emphasis on the following groups:

- Comfort in hearing these experiences and a sense that together, we can help inform a brighter future for those living with HIV.
- For policy makers, our aim is to signpost to the key issues that clearly need more consideration, so these are front of mind in the construction of services for people living with HIV
- For healthcare professionals, we want to instil a greater understanding of the day-to-day experiences - beyond the clinic - for people growing older with HIV to ensure the wider medical needs and concerns of patients are considered and addressed.

It should be noted that the *Fifty Over 50* project work was completed during 2021, and the first interviews took place not long after the second period of national lockdown as part of the COVID-19 response. We asked people about how the coronavirus pandemic had affected them, but for most people this was a completely separate issue that is not key and front of mind. We have therefore provided commentary on this in a separate section at the end of this document.



GROWING OLDER WITH HIV - A NOTE ON OUR CONTRIBUTORS

Each person we spoke to within *Fifty Over 50* has given us permission to share their interview.

These accounts may sometimes be challenging to read, but we hope they will help people understand some of the key issues that we heard. We hope that it helps to build a picture of the issues and challenges that are causing concern or worry and may be impacting negatively on quality of life. Each of these interviews is highly personal and represents personal perspective and opinion. This project did not aim to alter individual beliefs, opinions, or experience - but instead aimed to provide a space for those who have experience and perspectives to share about their own experiences. We hope that this approach will help to paint a picture of the reflections and observations of a diverse group of people who all happen to have HIV, and five plus decades of life experience, in common.

We would like to say a huge thank you to each and every contributor, for coming on this journey with us. Each interview offers a very personal insight, and we would particularly like to thank people for their openness, for the time spent in the interview, and for their commitment to and belief in this project. Throughout this process we have respected that not all people sharing their experiences are ready to talk about their HIV status publicly and have therefore changed some names to preserve anonymity.

We have been touched by the extraordinary optimism in the face of poor health, negative experiences, and worries about the future. We are sure you will be similarly moved, and enjoy the moments of lightness, humour and wisdom that emerge over the following pages.

Disclaimer

Each interview featured within the *Fifty Over 50* project is the personal view and experience of the individual interviewed and so does not reflect the views and opinions of all living with HIV or held by the Whole Person Care group and MSD. It should be noted that some of the contributors have current or future concerns that may be misinformed. Whilst this book is not intended for educational use, we have provided commentary to address anything we feel is incorrect. Should you, or people you know, have any concerns about HIV treatment, please speak to an HIV consultant, nurse, or pharmacist.

Adverse Events

Within the stories, some contributors refer to unwanted side effects. Any medicine may produce unwanted side effects (also known as adverse drug reactions). Individuals may respond in different ways to the same medicine (and to their HIV infection) so it is very difficult to predict whether a patient will experience any side effects.

If you get any side effects talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the **Yellow Card Scheme** at <https://yellowcard.mhra.gov.uk/>

By reporting side effects, you can help provide more information on the safety of medicines.

* This will take you to a third-party website. We do not review or control the content of any third-party site. We do not endorse and are not responsible for the accuracy, content, practices, or standards of any third-party sources.

Your response to reading

We are aware that some of the accounts may be challenging to read. While we hope that every reader will take something from these personal reflections, we are conscious that many readers may also find elements troubling or upsetting. If anything you have read has worried you, or disturbed you in any way, and you are having negative or unusual thoughts, we would urge you to contact an HIV Charity or the Samaritans on 116 123.

There are always people waiting to give help and support.



INTERVIEW INDEX

You can read each individual interview by clicking directly on the names listed or scrolling through the e-book. Many of the interviews touched upon a number of different themes. If you are interested to find out more about a particular topic, we hope you find the below a useful quick reference to where these themes have been mentioned or referenced by a contributor.

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2 ACCESS TO HEALTHCARE SERVICES 17 , 19 , 23 , 30 , 38 , 42 , 47 , 48	7 FINANCIAL HARDSHIP & INSECURITY 15 , 25 , 47 , 56
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4 LONELINESS & ISOLATION 19 , 24 , 35 , 36 , 41 , 43 , 46 , 56	9 WOMEN & HIV 16 , 26 , 34 , 35 , 41 , 44
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Mary is 55 and lives in London. Originally from Rwanda, she was diagnosed in 1994.	16	H was diagnosed in 2001. She is of Somali heritage, and lives in London.	40
Roland is 63 and lives in Surrey. He was diagnosed in 2006.	17	Samantha lives in Dorset. She is 55 and was diagnosed in 2007.	41
Christine is 61 and lives in Wales.	18	John is 76 and was diagnosed in 1986. He lives in Kent.	42
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Gary is 54 and was diagnosed in 1992. He lives near Brighton.	33	Trevor is 60. He was diagnosed in 1991 and lives in Southwest London.	57
Estelle lives in North London. She is 53 and was diagnosed in 1997.	34	Nick is 53. Originally from Belfast, he now lives in London. He was diagnosed in 1993.	58
Constance is of Malawian heritage. She is 61 and lives in South London. She was diagnosed in 1989.	35		
Simon is 57. He was diagnosed in 2015. He lives in London.	36		



50 OVER 50 INTERVIEWS

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“It is important to keep raising awareness. People need to be realistic about how this has affected us.”

Adrienne, 72

GRAHAM IS 53 AND LIVES IN BRISTOL.
HE WAS DIAGNOSED IN 2000.

“Apart from the care home issue I don’t necessarily think all of my concerns about the future are specific to HIV, but I think HIV brings an extra twist and extra element to all of those usual things that people are concerned about as they get older.”

I think overall my health is very good. I’ve been very lucky in that I haven’t really had any particularly bad side effects, a couple here and there including some sleeplessness problems, but nothing too troubling. I would consider myself to have got off very lightly. I had a very late diagnosis, which came about after I was very ill during a trip abroad, and virtually collapsed when getting off the plane. There was a lot of investigation of my gastro symptoms before anybody thought to do an HIV test. I had a very difficult period following that. I remember at one point walking down the street and having pensioners on Zimmer frames overtaking me.

I still have some gastro problems. More troubling for me is the comorbidity aspect. Lots of the men in my family have had heart problems, and unfortunately there have been many early deaths as a result. I have got early-stage atherosclerosis, and I’m currently the oldest male hanging in there with my family at 53.

Because of the early loss of my father and both of my grandfathers I always thought I’d have a relatively short life, so thoughts around death and dying don’t bother me because I’ve essentially lived with it all my life. So, I suppose I’m quite surprised that I’m still sort of plugging away, still here!

Obviously, the HIV brings a different dimension to that, and I have to think about my health now through the lens of problems with my heart. It seems as though comorbidities are increasingly the thing that everybody talks about, but I find it slightly frustrating as I don’t believe it is actually really tackled. I think there is a lack of research about weight gain for instance, to find out whether it is linked to medications, and I also think there is a lack of support for people to help them deal with comorbidities in their daily life. It feels as though we are at the stage of saying, yes, comorbidities exist, but not actually putting the structures in place to deal with them.

I know that I’m currently overweight. I don’t blame the medication for the weight gain as such, but it has affected my fat distribution. I also wonder if the medications make it harder to shift the weight. I do my best to eat well, and I do a lot of exercise, far more than is typical in my age range. But weight loss is difficult.

Lipodystrophy refers to abnormal changes in the way fat is distributed around the body (either fat accumulation or fat loss). Lipodystrophy has been seen in people living with HIV taking older antiretroviral drugs, although these drugs are no longer widely prescribed.¹

From my point of view with things like cardiovascular risk, I think it would be better for people living with HIV if things like weight gain and general lifestyle could be tackled earlier, rather than waiting for some catastrophic event to take place. But I can’t really point at any information designed specifically for people living with HIV. You know, there is some acknowledgement, you should be exercising, but no tried and tested approaches.

“I can recognise that I’m ageing. There’s a definite physical decline. Ten years ago, I was running far more than I would now. Actually, as I’ve got older, I’ve found I’m less interested in that kind of thing.”

At the moment, because my Mum is getting older and I’m seeing ageing up close, thinking about care is sort of at the forefront of my mind. Looking ahead, I would be worried about living in a care home, because of the stigma. I think you could be in a vulnerable situation in there. Elderly people can be no less spiteful than younger people. I’m sure for most people it will be fine. But you do also worry because care home staff may not have a deep knowledge of HIV, they probably don’t have a deep knowledge of lots of conditions that they don’t see very often. And that’s concerning for somebody who has a disease which needs to be actively managed.

Apart from the care home issue I don’t necessarily think all of my concerns about the future are specific to HIV, but I think HIV brings an extra twist and extra element to all of those usual things that people are concerned about as they get older. So, I anticipate it will be harder to keep fit and well. I think managing my mental health, with which I’ve long struggled, may get harder, and I think it will be harder to stay connected and not get isolated. I think all those things apply to everyone, but with HIV, there is just that added layer of complexity there that is a concern.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

GUY IS 55 AND LIVES IN KENT.
HE WAS DIAGNOSED IN 2002.

I was diagnosed with the blood disorder ITP (low platelets) before I was diagnosed with HIV. It was one of the times when I was very ill with ITP that I found out that I was HIV positive as well – and I had probably been positive for several years. The chronic ITP that was affecting me so badly may have been triggered by my immune system being in overdrive all the time fighting HIV. Although I was considered long-term non-progressive with my HIV, I started HIV medication when my CD4 count was still well above the recommended levels for the time – my medical team suggested that if they controlled the HIV infection with meds, it could take the pressure off my immune system and possibly the chronic ITP would go into remission.

Did you know that HIV treatment guidelines now suggest that if individuals are able to commit to taking antiretroviral therapy, it should be started, regardless of the CD4 count?¹

I’d battled with my health since diagnosis, and this was both physically and emotionally very difficult while I was trying to cope with a stressful full-time job. Ultimately, I got to a point where I was physically doing better than I had for years, but mentally I wasn’t in a good place – I wasn’t very good at recognising it – it was manifesting in all sorts of ways that weren’t great, like aggression, mania, depression and nervous exhaustion.

I worked in publishing as a Designer and Art Director, managing teams, running projects, travelling for business and directing photoshoots, but when I was 50 I was signed-off long term for stress, and then made redundant. In reality, there had been a long process of falling out of love with my job and reaching burnout. I had tried various strategies to lessen the stress, including moving out of London and working from home part of the time, but the way I was working was unsustainable.

The end came after I tried to push myself too hard, driving myself into the ground at work trying to catch-up after a period in hospital for a minor operation.

I realised that after surviving with HIV over 20 years I didn’t want to drop down dead from a heart attack or have a complete nervous breakdown. I just had to let go and step away.

Since leaving full-time work, I try to keep busy with volunteering roles – some HIV related – and local community projects and have dedicated a lot of time to renovating my home.

Now I’m trying to work out what to do about the rest of my “working” life – it’s not too late for me to go back into my former career, but it would not be easy to find opportunities where I now live, and I have to question if I have the energy to commute regularly, or to even start the hunt for work.

I do have worries about my financial security in both the short and longer term. I think one of the reasons I pushed myself so hard at work in the first place is that without a traditional family structure, I’ve always been conscious that I will not have anybody else to look after me in the future.

I spent the first 20 plus years, maybe longer, of my working life believing there was no point in planning ahead or having a pension, as it seemed very unlikely that any of us (sexually active young gay men) were going to get beyond 40 – I lost many friends my age to AIDS in the 80s and 90s and I think my feeling (even before I was diagnosed) was this disease is out there and it’s going to get me. As a result, I don’t have any pension to speak of, and the little I managed to save in the last few years of working is worth almost nothing. I hope to be able to survive on what I have, but it will be a touch and go thing, and I will have to wait and see when I get to pension age whether I have done enough.

I am still undisclosed to quite a number of my friends – and I carry a huge amount of guilt about that. Of the people I have told I’m positive I’ve honestly never had a directly negative reaction, but it can change the dynamic of a relationship, and I have some friendships that I simply don’t want my HIV to be part of.

I’ve been single for 20 years and I can’t imagine having an intimate long-term relationship again – I can’t picture

myself trusting somebody else again. I’ve become so self-sufficient and withdrawn in my emotional needs that I find it almost impossible to imagine a situation where I could allow somebody to come into my life.

I feel incredibly fortunate that by chance I’ve been given this longer life when so many people lost theirs. That brings complicated feelings in itself: it makes you feel that you should be doing something important with it, isn’t that weird? I think it’s a form of survivor’s guilt, involving all sorts of complicated feelings about finding purpose, making the most of the extra time you’ve been given, and feeling as though you are not doing enough with it. There’s this sense of, well, I really need to become a total saint and do good works!

I think people diagnosed before combination therapy became available had a very different experience to many younger people who are diagnosed now. Thankfully they don’t have to contend with those awful years where a positive diagnosis seemed to inevitably lead to death, and they also don’t have to deal with the toxic side effects of some of the early drugs. It is a treatable disease now.

Did you know there is currently no cure for HIV, although antiretroviral treatment can control the virus, meaning that people with HIV can live long and healthy lives.²

And hopefully with PrEP and PEP the numbers are levelling out behind us, it’s sort of as if we are this generation that is just passing through. We are like a little bubble that’s moving through time, getting older. We are the first lot to survive. We were trailblazers then as gay men making our way in the world, and we are trailblazers now too in lots of ways.

1. Lipodystrophy. Available at: <https://www.aidsmap.com/about-hiv/lipodystrophy> (last accessed May 2022)

1. BHIVA. BHIVA guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2015 (2016 interim update). Available at: <https://www.bhiva.org/file/RVYKzFwyxpgil/treatment-guidelines-2016-interim-update.pdf> (last accessed May 2022)
2. NHS. HIV AIDS – Treatment. Available at: <https://www.nhs.uk/conditions/hiv-and-aids/treatment/> (last accessed May 2022)

MARY IS 55 AND LIVES IN LONDON. ORIGINALLY FROM RWANDA, SHE WAS DIAGNOSED IN 1994.

“I am proud to be part of the group that speaks out openly about HIV and I am proud to share my story. I was given one month to live in 2000 but I am still here now after all these years, and I am an older woman. I think it’s worth celebrating. It’s definitely worth celebrating.”

I was diagnosed HIV positive in Uganda having fled there after the war in Rwanda. At the time, if you didn’t die by the gun/ machete, you were given this long lasting, shameful illness. Some of the people doing the genocide, thought that if they cut you, that was instant death, but giving you this disease by raping you, you would die miserably. I don’t know if I contracted it then, through rape, or before, but that is my story. It has just made me a stronger person.

In Uganda I was given treatment, but it wasn’t good. The tablets had a lot of bad side effects. I was told that I could maybe live for six months only, and that I couldn’t have children. There wasn’t much information but the information we were given was painful. There was a lot to come to terms with, given what we had been through, and the diagnosis and what it meant.

When I came to UK, I found out that I could have children despite being HIV positive and I had my son. I was very, very ill when he was born, and I thought I wasn’t going to make it. It took me a year to recover from liver disease. My partner left me at that time, which was the best thing that ever happened to me because if he had stayed, I could have given up on life knowing that my son had a father, but his leaving helped me to fight for my life so that my baby would have a mother.

I’ve had all sorts of types of tablets, and some resistance. But right now, I’m stable. The side effects of the treatment are the only real issue I have. I have kidney problems, and there are issues with the way my body looks. Sometimes I am conscious when I look in the mirror, and I can’t wear the dresses I would like to because of the way the drugs have changed my body shape. I also worry about the long-term side effects of the treatment when I am older. But still, I can’t resent anything. I am still here, and I am still able, and I’m still living. I avoid stress and try to live as positively as I can.

Lipodystrophy refers to abnormal changes in the way fat is distributed around the body, along with resulting metabolic complications. Body fat changes may be stigmatising, which can cause stress and worry amongst people taking HIV treatment.²

of the women I work with have self-stigma which stops them from disclosing their status. They worry too much about people

Did you know that with the right care, women living with HIV can give birth to children without passing on HIV. When considering conceiving, consult with an HIV doctor or nurse. The advice will depend on each individual’s circumstance, their general health, whether they are taking antiretroviral medication, their viral load and whether their partner has HIV.¹

knowing. Some hide tablets so that family members don’t know. I know women who have hidden it from their husbands for many, many years because they are afraid. And they don’t want the GP to know. And particularly they fear the receptionist knowing and gossiping about them in the community.

Personally, I need the doctor to know about my HIV so that I get better treatment. For example, when I had a difficult time with the menopause, and I wanted to take supplements, and I knew I needed to check those with my GP to make sure the supplements were okay alongside my HIV medication. You have to be open to be safe. I had a previous problem with drugs that wouldn’t work with my HIV medication. But now I have a new GP, and she is very good, very aware. She’s from Kenya. So, I think she has experience of it. I feel comfortable discussing anything with her.

With age, obviously, we are vulnerable and may need to depend on other people. I’m hoping that by the time I need care, that there will be more HIV awareness so that carers get to know that people living with HIV are not contagious, so that they won’t treat us differently, by not wanting to touch us and things like that. But that is a worry for many people about the future.

“There aren’t many older women who are confident to speak out. We need to say, “You know what? An HIV diagnosis is not the end of the world, we’ve been there 30 years.”

We need to support and empower other women who have lived for a long time with self-stigma. We could save a lot of mental health issues. I think it is really sad that we have women who are 50 and who are still struggling to cope with the HIV diagnosis. I’m hoping that at 50, we all should be able to live as positively as possible. Reaching a certain age could be a turning point.

I am proud to be part of the group that speaks out openly about HIV and I am proud to share my story. I was given one month to live in 2000 but I am still here now after all these years, and I am an older woman. I think it’s worth celebrating. It’s definitely worth celebrating.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

ROLAND IS 63 AND LIVES IN SURREY. HE WAS DIAGNOSED IN 2006.

“There are advantages to getting older. I feel the ability to speak my mind more. And I have certainly become very good at enjoying the moment.”

Because of my involvement in the community, HIV is a huge part of my life, but for me personally I don’t spend much time thinking about it now. When I was first diagnosed it was the first and last thought every day, but now 16 years later, it’s just not there like that anymore.

This last year I have had a heart attack and a stroke, so I feel out of my nine available lives I must have used about eight so far. Every cloud has a silver lining, because since these events, I’ve made some significant changes. I’ve radically changed my diet. I go out for long walks every day. I’ve lost about 12 kilos in weight, and I feel so much better. I wouldn’t necessarily recommend a heart attack or a stroke as a course of action, but it has changed things for me, and it’s given me a different perspective yet again. I feel that I am incredibly lucky, for whatever reason.

I have experienced first-hand the disconnect between primary care and hospital care and even between specialists within hospitals. A good part of the time I am acting as the go between delivering messages about me. I say, “I assume you will forward these results”. And then when I call, they haven’t got them. So, I go back, and they might email them to me, so then I have to forward them on. It’s exhausting. I’m relatively proactive, but for those people who are not that able to express themselves, or to understand what’s going on, it’s hard. When I was first diagnosed, it was seamless, but it’s very different now.

“I have had plenty of opportunities to think about my own mortality. I’m fatalistic. My big concern about getting older is not dying but losing my partner. If something happened to him before me, I could not imagine being around.”

I have no intention of going into care. I’ve seen my brother in a care institution, and although I have no complaints about the care he received, which was fantastic, I still think it is degrading and humiliating. It is not for me. I don’t want to end up in a home where they don’t understand the need to take the medication at the right time and the right doses. And potentially at that stage, who knows, I may not be capable of communicating my needs around medication. And if there’s nobody else around to advocate on my behalf, what happens? I also think, if I were to have to go into a care home, I would have to hide my sexuality somehow. I imagine that by that stage in my life sex won’t be so important to

me, but it’s part of my DNA, I cannot remove that part of me. I’ve seen recent reports about the potential creation of retirement centres for LGBT people, and I’m in two minds about it. I don’t want to live in a ghetto.

If my partner is still around at that point, I wouldn’t want him to diminish his life in any way by having to look after me. For me, there is no security net of children either, like many gay men my age. So that changes the way you look at old age.

There are advantages to getting older. I feel the ability to speak my mind more. And I have certainly become very good at enjoying the moment. I make the most of the times when I am happy and content. I’m very aware that the days slip by without noticing. All of our days are numbered, we have a finite number, and while I don’t know how many that is, I do know that unless I do something to make each day memorable and remarkable, then it’s a day that’s lost.

“I think older people with HIV fall into two camps. People who were diagnosed a long time ago come with that particular mindset where at the time of diagnosis they were told to prepare for death. People who are more recently diagnosed don’t have that background and have had a different experience.”

I think the two groups find it very difficult to understand each other’s viewpoint, which is sad. I kind of straddle the two groups. I was diagnosed when very effective medication was available, but I was diagnosed very late by which point I was extremely ill. So, I can see both perspectives. Either way, we are all in the same boat.

All the information now seems to target younger people; it’s more about prevention and younger people need that message. But the older generation is the largest group. I think that lack of representation is potentially the reason why many older HIV positive people don’t feel able to disclose or to talk about it. We need people talking about it so that we can reach those older people who have lived a life of isolation because they felt unable to disclose or to reach out and find a supportive community. I would love us to change that. Hopefully this can help a little bit.

1. NHS. Can HIV be passed to an unborn baby in pregnancy or through breastfeeding? Available at: <https://www.nhs.uk/common-health-questions/pregnancy/can-hiv-be-passed-to-an-unborn-baby-in-pregnancy-or-through-breastfeeding/> (last accessed May 2022)

2. Lipodystrophy. Available at: <https://www.aidsmap.com/about-hiv/lipodystrophy> (last accessed May 2022))

CHRISTINE IS 61 AND LIVES IN WALES.

“Generally, though, as I get older, I feel it affects my life less and less. Previously I think I was a bit of a victim to it, but now I feel as though I have more power over it.”

Generally, I would say I’m quite fit and healthy, I have very little time off work. In fact, I’ve probably got the best sickness record in my team at work! I get up early every morning, go for an hour and a half walk. But then I do have other things going on. It’s very difficult to know what’s HIV related and what is just general ageing or genetics or whatever. I have osteoporosis, peripheral neuropathy, and general fatigue. My iron levels are generally quite low, and I’ve got high cholesterol. I don’t know how much these issues are related to my HIV. I used to say to my consultant that I would rather he sorted all these issues out than the HIV. They have more of an impact on my daily life.

I’m not out with my status, sometimes I wish I was, and I am a little bit jealous of people who work in HIV services and can therefore be out. If I wasn’t a parent then maybe I would think differently. It is difficult to know how much stigma is really out there, and how much of it is self-stigmatising. But then it feels very risky, and once the genie is out of the bottle, you can’t put it back in. I think it’s difficult because I live in a small rural community. It’s quite inward looking and everyone knows everyone. I know it will get around very quickly on social media. Even my sister who has been very supportive in general was very protective of her children, understandably. Although she was very welcoming and, you know, we used to go and stay with her and everything, she was always very careful about sharing cutlery and that kind of thing. And so, I only tell people who I trust on a sort of need to know basis. So only people I trust implicitly.

I have had a lot of trauma associated with losses from HIV. And coming to terms with my own diagnosis was a gradual process. The images in the media were how I always assumed that I would end up. I used to make bargains, about being around long enough to see my daughter grow up. First of all to when she was twelve, and then to when she was 20. One day I woke up and thought, I’m not dying. You know, I can get on with my life. And now I know I will probably die of old age rather than an AIDS related or HIV related illness. So, I may not live to 99, but I don’t particularly want to live that long anyway.

“I enjoy life now. When my daughter left home, she went travelling, and that inspired me to start going on backpacking holidays. I’ve been all over and had a fantastic time.”

I take out insurance through an HIV organisation, I take my medication and some extra. Going to Europe is fine, and if I’m going further afield, I get my consultant to write me two letters, one to say, she needs this medication, it’s essential. And then another one saying what it actually is. I’ve never had to use the letters.

ELIJAH IS 54, OF GAMBIAN HERITAGE, AND LIVES IN WEST LONDON. HE WAS DIAGNOSED IN 1990.

“I want to empower myself to see how far I can go with sharing my story. When I have gone to support groups in the past, I wasn’t comfortable talking about my life. I never imagined I would feel that I wanted to. But now I’m preparing myself to do that and to help raise awareness in any way I possibly can.”

My life went very wrong when I was given my diagnosis. That’s when I lost family, that’s when my education was cut off. That’s when I was made homeless. From that point, I was no longer me. Before I was diagnosed, my life and my dream was just set up. But then I lost everything. The consultants told me no good news. It was a death sentence, a matter of time. So, I mentally prepared myself and I was just waiting to die.

I have a brother here, and uncles. I have cousins. But when I was diagnosed, I was basically out of the family circle. They were looking for me to be sent back to my original country, and I was going to be killed or sacrificed for having HIV. Then it was believed that everybody who had HIV must be gay. And they thought I came into this country and then adopted another lifestyle. So, in the eyes of them, with Islam, and with their culture, I wasn’t fit to live. So that’s how the break-up came about. Some of them I know where they would be. But I have moved all over London just to run away from family members. It was painful. It is still painful. But I’m stronger now than then. I have isolated myself for thirty years, keeping myself to myself. My only interactions now are with professionals who are there to support me. I have tried three times to work, but it was too hard. And so, I have stayed alone.

“I’ve seen other people getting older and I’ve seen how the illness made them look over time. You just don’t need to be told that this person is on his last legs, you see how their body changes, how they lose weight, and then how they are just fragile.”

Most of this is maybe ten or fifteen years back when medication was not what it is now. But because of what I’ve seen in the past, I’m struggling to accept that things are different now. I’m saying to myself, regardless, I’ll be ending up just like the people that I have seen in the past. If I am honest that is eating me inside.

My wish has always been to live and die with my secret. But now I am getting older I know that could become impossible at some stage. That is a worry that I keep on thinking about. I worry that if I get very ill then a family member will be contacted. That’s the most worrying aspect of the future for me. I also worry about dementia. I think there is a high possibility that if I get dementia, I may end up sharing about my HIV status when I don’t want to. And then I worry what reaction people would have to that.

I have Type 2 diabetes, and that is difficult to control, and I have my severe depression. I would like to be able to have a discussion with my HIV consultant about all my health issues, but it’s like they only deal with the thing that has taken you there that day. I understand, because for the consultant the whole thing is about the treatment. But when you have all the issues related to the virus itself or a concern like you are worried about something that may happen, or that you have seen happening to other people, I want to be able to discuss it.

“I think to avoid being ill I need to stay active. But it is difficult. Loneliness creates that environment. You are just sitting at home or lying down, just eating. Not doing anything, not exercising, not socialising. So, all this just attracts more ill health.”

Currently, I can go out and about on the bus for instance. But I think, what will happen to me when I cannot do that any longer, when I can’t get around? That worry is motivating me now to try and find some energy to get myself out of the serious depression and create something that is meaningful for my life. At the moment, my hope is high. Sharing my story here for this project, I never imagined I could do that. It gives me hope. I now see possibilities of trying again to volunteer, and then maybe getting a paid job that is part-time or full-time.

I want to empower myself to see how far I can go with sharing my story. When I have gone to support groups in the past, I wasn’t comfortable talking about my life. I never imagined I would feel that I wanted to. But now I’m preparing myself to do that and to help raise awareness in any way I possibly can, however small it is. And even if I manage to save one person the loneliness, that’s good enough for me. I feel I’ve got so much experience, and that can be very useful and helpful to so many people, particularly people who share my cultural and faith background, because I know what is in their minds and how hard it can be in this community.



"I don't want to be patronised because of my age. I still have a lot to offer."

CHRIS LIVES IN LONDON. HE IS 74 AND WAS DIAGNOSED IN 1982.

I was an elite controller, and I didn't start medication for eight years after it was available, because they thought I didn't need to. Now they would start elite controllers on medication earlier because they think HIV is still working away in the body, in the reservoir, but we didn't know that then.

My health is good but because I had a kidney transplant, I take a lot of medication. I take 17 tablets a day because of that, not because of my HIV. In theory my GP should be coordinating my care, but the reality is somewhat different. The GP often makes mistakes and I have to do a lot of chasing and following up, so in essence I am the one doing the coordination. It takes a lot of effort, to be leading your own care, it can be frustrating and annoying. Recently I had to point out to them that they've been getting the medication wrong for a full year. It's the chasing and general craziness of having to follow up so much that drives you mad.

"I am well now, although I am starting to get a little tired sometimes, but probably nothing that you wouldn't expect at my age. I have a very full and busy life."

I began my role representing patients at Mortimer Market when I was 60. Some might say it was quite a late age to be taking on a new career, but I was looking at other new careers at the time this opportunity came up, and I was actually thinking about entering the legal profession, so a late change has never been a problem. I have learned a lot through my role at Mortimer Market, I find I am good at it, and very dedicated to it. I am passionate particularly about education, of the public, of healthcare workers, and of people living with HIV.

If I am at all fearful about the future, it isn't the HIV that I'm afraid of. HIV as a disease is not the problem. The issue for me is people being fearful of handling HIV. There should be no fear, but there really is massive ignorance.

Did you know that a small subset of people living with HIV can spontaneously control the infection without treatment and they are known as elite controllers? If you have any questions or concerns about when best to start HIV treatment, you should speak to an HIV doctor or nurse.¹

Obviously, there is a worry with social care. I shall be heavily reliant on my executor, who is a lawyer, and friends to get something together for me. But I think it is a thought at the forefront when you are getting older, and particularly as a gay man, because of the absence of a traditional family structure.

I think bearing in mind that some people will see stigma and discrimination around every corner where it does not in fact exist, it is definitely still a widespread problem. And self-stigmatisation is a huge problem. A lot of gay men were coming out during the AIDS crisis. Some, like me were coming out before homosexuality was even legal. We are carrying all this weight of history with us. We are carrying forty years of negative media coverage, and malicious rumour, and misinformation. I think the residual stigma, and the internalised stigma, is enormous, and I believe it contributes to people not engaging and becoming lonely.

I strongly believe we need to educate the fifty plus age group so that they can move on from some of the stigma and start to engage so that they can have a better quality of life. But it is difficult to engage that group in the first place, an awful lot of older people are afraid of groups, they are fearful that they might see somebody there. But we need to find a way to do this. Education is vitally important.

For many people, HIV has become a crutch. When it comes to ageing, we have to distinguish between what is due to HIV and what is just part of the normal ageing process. Some people blame HIV medication for everything

and believe that the medication prematurely ages you, but I don't think there is really any evidence for that. I think we have to encourage people to understand ageing.

Disease patterns are complex for those ageing with HIV and clinical research is continuing to help differentiate between the normal ageing process and those on antiretroviral therapy (ART).²

I don't want to be patronised because of my age. I still have a lot to offer. I'm constantly surprised when people ask me to do things, to pick my brain, or to take on a responsibility. But I appreciate that, and it demonstrates that I do have this vast knowledge, and a huge amount of experience working within HIV and representing patients. I've been fortunate to do so much work, speaking at conferences, working with fantastic healthcare professionals. It's certainly nice to use that knowledge. I think having a focus is incredibly important at my age and this is my focus. I remain committed to HIV and convinced that education is the key to supporting us all getting older well.

I am now Education Director of the National HIV Story Trust, a Governor of Central & North West London NHS Foundation Trust, a Trustee of two HIV charities and doing lots of other educational and research projects.

1. Aidsmap. What is an elite controller? Available at: <https://www.aidsmap.com/about-hiv/faq/what-elite-controller> (last accessed May 2022)

2. The Lancet. Future challenges for clinical care of an ageing population infected with HIV: a modelling study. Available at: <https://www.sciencedirect.com/science/article/pii/S1473309915000560> (last accessed May 2022)



MAURICE IS 80 AND LIVES IN STOKE ON TRENT. HE WAS DIAGNOSED IN 1984.

“I am surprisingly busy for an 80-year-old, with lots of commitments and membership of groups. As Chair of an LGBT older people’s group, I have a heavy workload, but this is offset by participation in choral, drama and dance groups.”

I consider myself to be a long term HIV survivor who enjoys a busy, active fulfilling life. Perhaps one should distinguish between two types of older HIV positive people. On the one hand, there is the older person who has lived with HIV for a long time, like me, contrasting with one recently diagnosed. The oldest person I am aware of who is living with HIV, is Miguel who lives in Portugal and is over 100 years old, he falls into the second category. Interestingly, he is just as upbeat about life as I am.

I’m completely open about my HIV status; I feel comfortable speaking out not just to colleagues, friends and relatives, but also to the national press, television and radio. It just seems right to do what I can to combat stigma, prejudice and discrimination. Here in the 21st century, it is heartening to see all the advances made in HIV treatment: there has been such incredible progress. HIV is now not only a manageable long-term condition, but, with an undetectable viral load, you can’t pass on the virus. The disease has changed beyond all recognition, but stigma still appears to have an unwarranted negative impact on many.

When it comes to thinking about the future, I try not to worry too much. Of course, there might be a problem with social care. Will LGBT and HIV positive people have to go back into the closet in order to get the treatment they need from carers who may have prejudiced views and values? There are care homes too that claim to be LGBT and HIV friendly, but, in actual fact, staff stand back when residents express biased, ignorant, or inappropriate opinions. I’m not unduly worried for myself at the moment as I have the confidence to challenge anybody: let’s hope I don’t live to eat my words.

“I think as you get older it is important to stay active. You should follow your interests, whether they be physical exercises or creative activities. Swimming is an excellent pursuit, I used to love it, but now I hardly do it at all, which is a great shame because it is a really good, healthy, physical activity.”

Connecting with nature is also important. I’ve only got a little back garden, but it’s thriving; I even grow vegetables and fruit. I used to enjoy preparing feasts – cooking for one is not the same. Nonetheless, I avoid fast food and prepare healthy meals every day... I even make jam! There’s no doubt in my mind that making things, producing things, is very good for one’s sense of self-confidence and wellbeing.

HIV positive or not, creativity is a hugely important tool in ageing well. I’ve been involved in lots of projects and

benefitted from all of them. Dance in particular, helped me with my ARV drugs related peripheral neuropathy. Dancing helps with balance and strength, which of course are very useful assets as you get older. One shouldn’t be put off by ill-informed opinions about what older people should and shouldn’t do. Ignore them: take risks, explore, engage and don’t be afraid to dream big.

“It is vital to stay engaged with all your established communities: apart from the obvious social benefits, active involvement boosts one’s self-esteem, especially when you feel wanted and useful.”

I work as a church organist which is beneficial on more than one level: it is a source of income, but more than that, I am surrounded by lots of people to whom I can respond and feel that I’m doing something useful. More generally, connection with others is key to good mental health and wellbeing.

I am surprisingly busy for an 80-year-old, with lots of commitments and membership of groups. As Chair of an LGBT older people’s group, I have a heavy workload, but this is offset by participation in choral, drama and dance groups. Of course, once a group’s funded project is underway, I too benefit from its wide range of creative activities, just like everyone else.

You might be amazed that I consider ageing with HIV to be an unexpected privilege. But it’s true. So many of the fabulous things I’ve achieved came after my HIV diagnosis: a career in professional theatre, two honours degrees, lots of global adventures, reputation as an activist...the list goes on. Ageing, in my view, is a natural process to be appreciated and cherished. Because of the advances in modern medicine and other technologies we are able to have much longer lives. Sadly, for some people, this does not hold true: impaired by disease and ill health, for these individuals the ‘extra years’ are more like a drawn-out extension of death. Personally, I subscribe to the view that what matters most is not adding years to life, but rather of adding life to years.

‘Undetectable = Untransmittable’ (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.’

1. Aidsmap. What does undetectable = untransmittable (U=U) mean? Available at: <https://www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean> (last accessed May 2022)



ALAN IS 66 AND LIVES IN EAST SUSSEX. HE WAS DIAGNOSED IN 2003.

“But now I’m somebody who is aware of the needs of other people. I get real satisfaction being able to help people through my work, helping them with issues like housing, navigating the benefits system, with mental health problems.”

Well, given my age, and the number of years I’ve been living with HIV, I would say that my general health is actually better than the rest of my age group who are not living with HIV. Not all of them, obviously. But generally, when I see people of my age and about, I consider myself to be much fitter and healthier than the majority of them.

“It’s an irony certainly, that I may outlive some of my relatives who did not have HIV to contend with. I can’t live forever, but I know I’m pretty healthy right now.”

I actually do attribute some of my good health to my HIV status. I’m monitored, which I’m hugely grateful for. Shortly after I was diagnosed, I stopped smoking. I was never really a heavy drinker, but I moderated my drinking, and actually over the years it’s dropped to virtually none. I also started eating sensibly and became pescatarian.

Had I not become positive all those years ago, I suspect I would have been vastly overweight. I had a really good job and earned a lot of money, and I was dining out in fancy restaurants all the time. I hadn’t actually found my way into any kind of recreational drugs, but I think I would have done eventually, and then I probably would have done it to excess. I suspect I would have been on course for an early heart attack. I’d certainly be heading for one about now, if not. But now, instead, I am really focused on my health.

I knew at the point of my diagnosis it wasn’t likely to kill me, although I wasn’t aware of the long-term chronic illnesses that go with it. To start with though I didn’t think about my health at all, because my mental health was a bit of a mess. I hid away. At that time, I just didn’t want anybody to know, or ask after me, or see me. It took me a long time to be able to talk about it [HIV diagnosis], but eventually I found my way to speaking out, which helped me come to terms with it. I became a peer mentor and was surprised to find I was actually quite good at it. It was very good to be able to sit down with people who had been diagnosed for maybe three days and tell them that they were going to be okay. I became very involved in campaigning around stigma. And then two or three years ago a job came up as an HIV case worker. I didn’t think I was qualified, but I got the job and have been doing that ever since. Over that time, it’s become less and less about my own HIV, and more about other people. So, HIV is a huge part of my life, but it’s not my HIV that is the focus.

At work, I see a lot of older people really struggling with their GPs. They have multiple comorbidities and just getting an appointment just to talk to the GP is difficult, then they’re only allowed to talk about one thing in one appointment. It’s ridiculous. It just doesn’t work with HIV. It just doesn’t even come close. I sit in on multidisciplinary meetings for some patients. So, there is one chap who is struggling with taking his mental health medication. We have multidisciplinary meetings, with the lead nurse practitioner from the HIV centre, plus his consultant, plus his probation officer, and his housing officer, and me. But what’s the chance of a GP joining into one of those meetings? Zero.

Before the diagnosis, I would never have described myself as an empathetic person. I think I was actually developing a certain arrogance. But now I’m somebody who is aware of the needs of other people. I think I used to be more of a ‘pull your socks up’, type person, and that’s not me anymore. I get real satisfaction being able to help people through my work, helping them with issues like housing, navigating the benefits system, with mental health problems. I like being able to sit down and tackle things together. I am pleased that at my age, I really do feel like a useful member of society, much more so than when I was a young man and doing other, corporate jobs. I was meant to do this.

“I am aware that it changed the course of my life financially. Diagnosis killed my career, it terminated with an enormous bump, there was just no way that I could continue with the impact it had on my emotional health.”

So, any thoughts of collecting a big fat pension went straightaway. But it seems churlish to complain, compared to many of my clients I am very fortunate.

So, for my own future, really the only background worry is that we don’t know what will happen after being on these medications for the long-term. But apart from that, I feel good doing what I am doing, and I’m happy where I have got to, where my own HIV doesn’t matter anymore. But HIV in general, where it affects others, really matters to me and always will.

JOSEPH LIVES IN NORTH YORKSHIRE. HE IS 68 AND WAS DIAGNOSED IN 2000.

At the time I started medication it wasn't as good as it is now. It was effective in terms of controlling the virus and very quickly got me better. But the side effects were pretty miserable, and taking it was quite a challenge. I also developed resistance to quite a few of the drugs. So, I experienced the whole gamut of side effects going from one drug to the other. Those early years, maybe about eight years, were really debilitating because you didn't dare leave home. You had to know where the nearest loo was.

Phase 4 trials are also referred to as post marketing surveillance and as the name suggests, it is conducted after the drug is already marketed and available to the general public. The main objective of the phase 4 trial is to check the drug's performance in real life scenarios.¹

Some long-term side effects have been insidious. I mean, the drugs are tested in clinical trials for efficacy and immediate side effects, but quite a lot of things don't come out of the woodwork until they're used in clinical practice. So, things like lipodystrophy, things like peripheral neuropathy, they started to manifest years later. And I've developed kidney disease.

But it can be a really complicated picture. It's easy to say, "Oh it's the HIV", or "Oh it's the drugs". But it may not be, it may just be something to do with ageing. But whatever the cause, you've got all these things going on, and there are going to be issues with polypharmacy. You've got to think about how all these medicines interact. At the moment, for me, I'm in control. If I get prescribed something I go to the Liverpool database and check

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

it out. That way I have control. I've had to prompt my GP to do those checks in the past. And he now says, "You're better placed than I am, you check it out". That's all fine and I don't mind doing that. But if, God forbid, there came a point where I was no longer able to do that, who would do that on my behalf if the GP doesn't feel comfortable doing it?

I'm living on my own. I don't have immediate family to support me, and I wouldn't want to involve them anyway as they've got their own lives to live. If another serious health condition were to crop up that meant I just didn't have the energy or the capacity to manage my own health in the way that I do currently with my HIV, I do worry about where that holistic management of my health would come from. I certainly don't feel it's going to come from my GP. And other clinical disciplines don't always know how to deal with HIV.

I actually live a very solitary life. When I got HIV, I just didn't want to engage in any social activity, and I became almost reclusive. I guess I haven't really broken out of that shell. Peer support networks have been very important though.

I'm much more relaxed now about people finding out about my status. I think back in the early 2000s I was very conscious about stigma, but also just the thought of passing it on to someone else was overwhelming. The advent of U=U lifted a huge burden off my shoulders. I no longer felt that I was a risk to other people and in a way that removes a lot of the concerns that other people might have about me. If I'm not a risk, then what's the problem? But although I now feel more comfortable around other people, I've noticed it becomes harder to make friends as you get older. The longer you are solitary, the harder it is to change.

I know that I'm very fortunate. I had a good job; I've got a reasonable pension. I'm financially comfortable. And I know

that's not the case for a lot of people who are living with HIV. So, I think that is a real big plus, because that means for pretty much anything that I want to do now, HIV isn't holding me back like it did in the first seven or eight years when I was dealing with the side effects of some of the medications. Now I can travel, I can do what I want to do. HIV is not a problem for me. Not at the moment, at any rate. It's just under the surface though; I know that if I stop taking my medication, it reverts back to an incurable disease with one outcome. And I become "unclean" again.

Did you know there is currently no cure for HIV, although antiretroviral treatment can control the virus, meaning that people with HIV can live long and healthy lives.²

My view is that getting older is okay as long as you are fit. I try and look after myself. I'm active, and I go to the gym. I'm keeping an eye on the newer medications and what's happening there. There are now other side effects like weight gain, which might lead to diabetes or prediabetes. And if you're going to be taking medication for ten, twenty, thirty years, then that is a concern as I don't think there are many medicines that you would normally take for that length of time. So, we are guinea pigs really, but my view is that I'm a very grateful guinea pig. I wouldn't be here otherwise.

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You can visit the University of Liverpool HIV drug interaction checker here:
[Liverpool HIV Interactions \(hiv-druginteractions.org\)*](https://liverpool-hiv-interactions.org)

* This will take you to a third-party website. We do not review or control the content of any third-party site. We do not endorse and are not responsible for the accuracy, content, practices, or standards of any third-party sources.

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1. NHS. Clinical trials. Available at: <https://www.nhs.uk/conditions/clinical-trials/> (last accessed May 2022)

2. NHS. Treatment - HIV and AIDS. Available at: <https://www.nhs.uk/conditions/hiv-and-aids/treatment/> (last accessed May 2022)

3. Aidsmap. What does undetectable = untransmittable (U=U) mean? Available at: <https://www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean> (last accessed May 2022)

EMMA IS 52 AND LIVES IN LONDON. SHE WAS DIAGNOSED IN 1991.

"I try and put myself forward for every bit of research I can, as I think long-term female survivors should be studied. We have different issues to men, going through the menopause obviously, but also potentially higher rates of osteoporosis in older positive women than in older positive men."

I truly wish I had believed, in the first five years, in the first decade post my diagnosis, that long-term survival was possible. In the early nineties nobody really talked about long term survival. For me, when I look at facing older age it's financial security that is probably front of mind. I've worked from the time I was diagnosed, I've never not been employed, yet I never put a pension plan in place. My first employer told me I couldn't join the company pension because of my condition, which I found out later was wrong. And so subsequently, I never paid into a pension because I didn't expect to live this long. Even when I got to my twenty-year anniversary, I still wasn't thinking I'm going to have another decade, even at that point, so I still didn't do anything. And now I'm suddenly 52 and pensionable age could potentially be a reality. But I have no plans in place to deal with that. And that for me, is a huge concern.

"I would say my health is 90% good. I do have what I call niggly issues that are all under investigation and being sort of addressed, but I would say I'm in pretty good shape right now for my age and for being a long-term survivor."

But my general health has gone downhill since I turned 50. It was almost like my body recognised I was turning fifty and everything suddenly kicked in. So now I've got to have all these different doctors, a rheumatology consultant, a haematology consultant, a menopause doctor. Suddenly there's all these issues that, quite frankly, I wasn't expecting to live to have to deal with. I have a very good relationship with my HIV consultant, and now I just try and make sure all my doctors are talking to each other.

I try and put myself forward for every bit of research I can, as I think long-term female survivors should be studied. We have different issues to men, going through the menopause obviously, but also potentially higher rates of osteoporosis in older positive women than in older positive men. I personally think once we reach 50, we should get a DEXA scan every year and things like that. And we really should be studied to the nth degree because we're going to be the blueprint for the next generation of women this age.

Your perspective changes as you get older. It was all consuming in the early months and years. Every sniff I had I thought it was the start of PCP. Whereas thirty years in

I've got a much better perspective on everything. Reaching fifty was a massive milestone. I'm living a happy life. I have a partner. I'd actually decided at that point I probably wouldn't find another long-term relationship, being positive and middle aged. I thought dating at my age and with HIV in the mix wasn't going to be easy. So, in a sense, I'd made peace with myself that I was going to be single. But then the universe did its magic.

It is strange getting old. I'm never going to be upset by the ageing process. Essentially every wrinkle, and every grey hair is a testament to my survival. So, I'm not going to see it as a negative thing because this is a place I never, ever expected to be. But I do tend to think that us older women are invisible, and the specific challenges we face aren't fully acknowledged.

I do find some of the younger generation, the activists, have no concept of what HIV was like in those early years. I think there is a gulf between us long-term survivors and people who have been diagnosed in the era of U=U. You just think, God, how lucky you are. I went nearly 25 years thinking I was a leper. As I get older it is becoming more important to me that the voices of long-term survivors are still heard. The early years were so difficult. I had planned my own funeral. I even bought my own coffin. And here I am all these years later. I've kept the coffin, it now sits in my living room as a storage chest as I get on with my life, incredibly grateful that I'm getting old!

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MANDY IS 54 AND LIVES IN PORTSMOUTH.
SHE WAS DIAGNOSED IN 2002.

“HIV doesn’t define me, it’s a part of me, but really it’s just another experience. For me I want to use that experience, maybe try and change things for people. I want other people to know that yes, it’s bad, but you can get through it, and get on with all the other things in life.”

I feel that my health is probably very good. With everything that happened to me, and all my body went through, I have to think that really it isn’t so bad. As I had a late diagnosis, a lot of damage had already been done by that point. So, when I think about what my body has had to cope with, when you add up the years since my diagnosis, and the years before that, there is a lot that has happened. After my diagnosis I was a physical wreck. I was in a wheelchair, and I had to learn to walk again. A lot of damage was done.

I remember going to a conference not long after my diagnosis when I was back on my feet. At that point it was the most important thing in my life, and I was completely focused on taking my medication on time and making sure I didn’t forget anything. And I saw all these people that had been living with HIV for a few years, and I was like, “Wow, it doesn’t seem to affect them, they’re laughing, it’s not the centre of their life.” It just seemed to me that all these people had just somehow moved on and were getting on with their lives which seemed extraordinary. I got chatting to somebody who told me that once you’ve been living with it for a long time, they call you a dinosaur. So, I thought, right I’m going to be a dinosaur too!

“And it’s true, over the years, I’ve done what they’ve done and got on with life. It’s become less and less of a focus. I don’t really think about it day to day now. I probably think about it when I take my tablets first thing in the morning. Other than that, it doesn’t really cross my mind.”

I am a bit of control freak. And I can’t control my illness, obviously, the HIV is in control there. But I can control my lifestyle. So, I eat well, I don’t smoke, I don’t drink alcohol. I’m quite healthy in that way. But I just have to accept a degree of physical disability.

But I do have certain limitations. I’ve got a lot of physical restrictions; I am basically disabled. I’ve got very painful osteoarthritis in my feet and in my knees, and peripheral neuropathy, and back pain. I fall over a lot, and the last time I fell I was on my own and it really hurt, but I got back up, and I haven’t let it scare me.

You can always look at other people and recognise they’re probably worse off than you are. And I think that’s the best thing to do, to count your blessings. There are definitely people with

HIV who are my age who are much worse off. I’m very lucky, I feel very privileged. I’ve got a roof over my head, and I’ve got food for my cupboard. I’ve got good friends and good interests – I’m getting out and about, we go out litter picking which is great for my mind and for my body and keeps me busy.

In a way there’s less to be scared of for me in getting old. I’m hardly going to become old and dodderly; it doesn’t quite apply to me as I’ve been dodderly for years anyway! Healthcare professionals told me once a long time ago that I had the body of an eighty-year old woman already. So that was a bit scary. I think the menopause is a challenge as well and there’s not enough support for that.

“I like that quote where they say, “Getting old is a privilege denied to many.” It’s something you’ve got to appreciate because so many people don’t get there. I think I’m very lucky. And I think I need to recognise that I get to represent all the people that did die. I’m very privileged.”

I’m lucky that I’m an artist. I have always created things, ever since childhood, I would create things and disappear into my own world to play. I have a lot of art I want to do. I’ve done a lot of art about HIV before and now I want to do a big collaborative HIV installation, but I also love my artwork that is focused on other things. I have a big project celebrating some amazing women that I’m working on at the moment. It’s important to me that it is not all about HIV. I feel like I’ve got too much work to do. I’ve got a book I’m going to write as well! I may be getting older but there is a lot to do!

HIV doesn’t define me, it’s a part of me, but really it’s just another experience. For me I want to use that experience, maybe try and change things for people. I want other people to know that yes, it’s bad, but you can get through it, and get on with all the other things in life.

MINA IS OF SOUTH ASIAN HERITAGE AND LIVES IN LONDON.
SHE IS 52, AND WAS DIAGNOSED IN 2003.

“If you’re lucky like me with a good clinic, they’ll give you the right guidance, but also you have to empower yourself to go out and get that information too.”

Well, age is just a perception, isn’t it? Obviously, things do change. But I think what I’ve realised is that mindset is powerful around how you see yourself and how you perceive age.

I think we are lacking good news stories about getting older. I think we don’t hear the positives aspects of ageing in this society. I mean, getting older can make life better. Of course, everybody goes through their own journey, but I do think life gets better when you get older.

I don’t worry about the small stuff anymore. I can turn a worry around quite quickly now. My spiritual approach to life has enabled me to teach a lot of self-resilience. So, I can overcome hurdles quicker. I’m more at peace with myself. I really don’t care what people think anymore. You care less about what other people think as you get older. You’re like, “You know what? I don’t give a monkey’s; I’m going to do what I like.” It’s kind of like, “Been there, done that, got the T-shirt.” You let yourself off the hook.

“And once you’ve fought your way through menopause and all that stuff as well, you feel a bit stronger. Menopause was extremely tough. So, when it passed, it was like, emancipation! So, this new post-menopausal world, it’s a new lease of life for me.”

I think it’s about how you deal with old age because stuff will happen. It’s about knowing where your support systems are. It’s knowing where you can go and get information and support as things happen. With health issues, it is about knowing that you can go to your clinicians and ask for support. But I’ve been really fortunate turning 50 with a good clinic. They are being really thorough, not just thinking directly about the menopause but also checking out the strength of my bones, doing body scans, on the lookout for signs of osteoporosis. That’s very reassuring that they are on the case, recognising that my body is getting older and being proactive.

If you’re lucky like me with a good clinic, they’ll give you the right guidance, but also you have to empower yourself to go out and get that information too. There is definitely a gap in signposting, clinical services could be much better at signposting to support services.

I do some work in the South Asian community and we know that people are being diagnosed late, passing it on to their partners, and there is a lot of secrecy. There’s a lot of work to be done to shape a new narrative, to help people realise in this community realise that it’s not a death sentence. But there’s not much funding focused on South Asian community. We are a minority within a minority.

I think it’s critical that you are empowered. It’s about promoting your own wellbeing and taking personal responsibility as well. You’ve got to think about what matters to you and what’s important to you and prioritise that. I think having a passion, interest, hobbies, and actually reinventing yourself, are really important as you get older. It worries me that we are living in a world where youth and beauty are so highly prized. It’s far more important to be comfortable with yourself. For me, growing old gracefully means in a way that you are content and happy with where you are.

“I’ve become an expert in self-love and I’m very purposeful about helping other people realise that they are more than their identity and more than their HIV diagnosis. I’m doing a lot of writing about it and for me that helps me fulfil my own goals and fulfil my own purpose.”

There are one or two considerations – not limitations – but considerations that HIV brings. I always used to think I would end up living abroad. But if I wanted to move abroad, I’d need to think about what the support services would be. It’s a big consideration as I’ve got to recognise that treatment is free here and I get amazing care. I’m starting to plan for the future though, and I have exciting plans. I want to live off grid, I want to live sustainably in an eco-village. Again, I will need to think about access to care, but I intend to create the life I want.

I don’t have any worries about getting older, and certainly no worries about dying because I’ve been so close to that already. Life is for living, and I won’t spend it living in worry. I’m grateful and happy that at this age I actually feel more vibrant and more alive than I’ve ever done.



"I tell people about it when I trust them: good friends, and sometimes new friends if it feels right and I feel I can trust them with that information."



MOJI IS 60 AND LIVES IN LONDON. SHE WAS DIAGNOSED IN 2009.

People always say to me, "Gosh you don't look 60!" And I say, "Well I can assure you; I may not look like 60, but actually my body feels like it's 70." People can't see, but I have diabetes, and high cholesterol. I think it is all connected somewhere to the HIV.

I feel sluggish now. I was always someone who was a really fast mover, but I'm definitely not moving as fast as I used to, physically. I always used to be bam, bam, bam, bam, bam, you know? But now everything is slowly, slowly. I just can't get myself moving in the way I used to. And that's the same mentally too. For years I've worked on the local elections as Presiding Officer, now everything to do with that I am slower. The admin tasks, the packing up. Something that used to take me 15 minutes now takes me an hour. I've done it for 30 years but I think it is too hard now. I think it might not be helped by living alone. I sometimes have students in, but mostly I live alone, and I think maybe that slows me down.

It's also not ideal because I'm not as sharp as I was, and I'm not as strong as I was, I'm starting to need to have people around to help. I've got problems with my hands, so household things like opening jars, fixing things etc. I struggle on my own.

That all makes me sound very old! Other times I feel quite young. I've got lots of younger friends who I get on with really well. And you know I remember my mother's generation, when they were my age, they were dressing in an old lady way, and that seems so strange to me, I'd never dress that way! I'm very spontaneous and good at having fun. I've got great friends, I'm not lonely.

I've got three grown boys, and two grandchildren. My sons were obviously very sad when they first found out, but I reassured them, told them that I would be fine because of the medication. And you know when I'm tested, I normally come up as undetectable. They don't really talk about it anymore; it doesn't come up now.

I tell people about it when I trust them: good friends, and sometimes new friends if it feels right and I feel I can trust them with that information. So, it's not like it's all under cover, but it does hold me back from having a relationship, definitely. I'd love to have someone but I'm afraid of rejection because of my status.

I've come a long way. When I was first diagnosed, I was absolutely devastated. When they told me, I was on the floor, I just collapsed. My sister and friend had to come and literally pick me up. I spent a lot of time after my diagnosis still trying to work out where I had got this from, and a bit of regret. I didn't anticipate being here now certainly. It's thanks to the medication. I wasn't great with the drugs to start with, I was always missing it or whatever. But I know that without it things wouldn't be good. I tell everyone, it's my life-saving medication. That's what it is quite literally.

When I look ahead the first thought is, I would very much like not to be a burden to my children. My mother had a stroke and was paralysed, she couldn't talk or do anything. I say to the kids, if we get to that point you've got to let me go, I don't want that. Obviously, I've got sons, but people say they aren't as good as daughters at looking after you!

If I hadn't had HIV, I think I would probably have had a partner to go into old age with. That's the biggest way this has affected me. It's my biggest regret.

Don't get me wrong, I definitely don't need a man, but now at this age, I would like a companion. And I think the HIV is a block to that. It's probably more that than my health that worries me. I mean, let's face it, I'm more likely to die of cancer than I am of HIV. I think 60 is a good old age, but when I think about my dad reaching his 90's, I think I could have a bit of time left yet!



JO IS 55 AND LIVES IN THE EAST OF ENGLAND. SHE WAS DIAGNOSED IN 1986.

“There is an assumption that living with HIV today is straightforward and it's great that people diagnosed early can have a normal life expectancy but for those of us who have been living with HIV for almost four decades, we don't know what our future holds as we age.”

When I was first diagnosed, I was told I had five years to live and I got very fixated on that, counting down the months and years. I was a student, and I could only think three months ahead, to the end of each term. I was living in the short-term and couldn't imagine graduating, having a career, a relationship, a family and definitely not old age. As a result, I didn't follow a typical career path or do any financial planning. I didn't start paying into a pension until very late.

I was very open about my HIV status for a long time as a co-founder of an HIV advocacy organisation. Living openly as a positive woman took its toll, but it was also very liberating. When I moved away from London in 2002 and had children, I went back into the closet because until we'd told them, I didn't want them finding out another way. Now that they are older and know my status, I've started telling friends that I've had HIV for over 15 years. This feels strange and I realise that I held back from forming close friendships as I couldn't tell them my whole story.

“I live with complications from the early antiretroviral therapy that I started in 1996. My first drug cocktails were difficult to take, with awful side effects, and then ultimately, they caused long-term side-effects which are still challenging today.”

As long-term survivors of HIV, we've been at the front-line. I think it could be more difficult for us to stay healthy and mobile and I think we need more support around that and certainly more psycho-social support as we get older.

There are other concerns. From a practical point of view, my clinic is in London but that's not where I live. It takes me two hours to get there on public transport. As I get older, if my mobility is restricted, will I even be able to get to my clinic or will I become more and more dependent on primary care? My GP usually assumes that all symptoms are HIV-related and refers me back to the hospital, whereas the HIV clinicians encourage me to go to the GP. I continue to fall between the two and this could be hard to manage in old age. Sometimes I wonder, what if I get to the point where I can't manage my antiretroviral medication myself? If I am living alone, who will remind me? Who will make sure I'm taking it? Maybe injectable ART will be the answer if we get more forgetful?

The menopause was particularly hard for me and seriously affected my quality of life and it was difficult to get the support I needed. There's more information about HIV and menopause available now but for me that came too late. I

did my own research and decided I wanted to try HRT but was refused as I wasn't having hot flushes. Finally, five years later I have just started HRT but it has been a battle.

“I imagine as we get older, people with HIV could face more stigma unless there is a change in public awareness. Older women with HIV are not visible and we no longer have the voice that we fought to find as young women, but we are still here.”

There is an assumption that living with HIV today is straightforward and it's great that people diagnosed early can have a normal life expectancy but for those of us who have been living with HIV for almost four decades, we don't know what our future holds as we age. What will be the impact of surviving AIDS-defining illnesses, early treatment and the damage caused to our immune systems all those years ago?

Sadly, there's still stigma, discrimination and lack of understanding and I worry that as I get older, I will experience this again but in different settings. I would turn to peer support to help cope with that, but there isn't anything available where I live.

I couldn't imagine being 25, never mind 55 and I'm very grateful. Many of my friends died at a young age and I was lucky. But things change as you age, and you need support of different kinds. We need to be talking about this. I feel very strongly that it is important to listen to older people, from a medical perspective, from a societal perspective, from a psychological perspective and to develop services that meet our needs, wherever we live.



ELLE LIVES IN LANCASHIRE. SHE IS 53 AND WAS DIAGNOSED IN 2016.

“HIV is a lifelong condition that you have to learn how to live with. In some ways it has to become your best buddy. You need to pay attention to yourself and make sure you are being kind to yourself in all ways not just physical, but also with your emotional and mental health too.”

HIV is a part of my life but doesn't define who I am. I actually feel quite blessed as there is medication to help suppress this virus. I could have been diagnosed with another life limiting condition for which there are no meds that can help you have a near normal life. Yes, I've been diagnosed with HIV, but I'm otherwise in good health.

I have a grown-up family whom I still haven't disclosed to. I'm protective of their future given there is still quite a lot of stigma to address. However, I do think the stigma is generated more from my generation rather than younger people. It's education and removing fears that we lived through during the 1980s that need to be addressed.

Stigma in the health service can still be a concern, mainly around classing people with HIV as an infection risk, when in fact people with HIV can't pass on this virus if they are undetectable. If people in the medical profession are uneducated about this, then what hope can we have for the general population being educated enough to remove their fears and stigma about this virus.

“I do have thoughts around dementia in my future, particularly around continuing to maintain an undetectable viral load, which doesn't just maintain my health, but also protects others if they are needing to provide any support for me.”

HIV is a lifelong condition that you have to learn how to live with. In some ways it has to become your best buddy. You need to pay attention to yourself and make sure you are being kind to yourself in all ways not just physical, but also with your emotional and mental health too.

Right now, as of today, I'm in a good place. I've learnt to listen to myself and pay attention to what I need to keep me healthy, happy and living this life that I am so blessed to have!

“Yes, I have HIV. But I don't look back on my diagnosis with regret. It's not a full stop in my life. It was another page in my life, and the future is a chapter that is in the process of being written.”

‘Undetectable = Untransmittable’ (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.¹

1. Aidsmap. What does undetectable = untransmittable (U=U) mean? Available at: <https://www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean> (last accessed May 2022)



PETER IS 80 AND WAS DIAGNOSED IN 1990. HE LIVES IN CENTRAL LONDON.

“Anything I want to do I am able to do. I have a house in central London that I am very lucky to have and which I am very happy in. I am a very sociable person.”

It's been over 30 years since I was diagnosed. I feel very fortunate. Things have gone extremely well for me since my diagnosis. Considering this was something which at first, I thought I was not going to survive, life since has been extraordinary.

I was a GP, and funnily enough a GP with a special interest in sexual health. So, I came to this with some knowledge. I didn't really make any changes initially, I went on working as long as I could, until my consultant suggested that I should probably retire. At that time I think he was less optimistic than I was, and was expecting things to go downhill rapidly. So I was medically retired on the basis that I had less than six months left. Of course, when I did retire, it was a huge relief, I had really been under a great deal of stress. I was actually extremely ill at that time.

Clearly, I recovered. I gradually began to realise that what I had expected wasn't happening. So, I thought I would have a few more years, and then those few years that I was anticipating extended and extended, and then eventually I began to be able to visualise a normal lifespan.

And here we are! All that now seems like a very long time ago. I have been undetectable for years on treatment. We've changed the treatments occasionally, as I became resistant to some groups. I have some health problems, I would say I am fairly disabled with breathlessness, and I have difficulties with back pain which has been a lifelong problem that is worsening now. I think it is fair to say that I now have restricted mobility but then I think many people my age do.

“But overall, the HIV is not really having a very significant effect on my quality of life, and I suspect it's not going to have a very significant effect on my longevity either.”

I am very fortunate financially. I didn't cash in my insurance and blow my money on a final fling or anything like that which many people did. And I received some money when I retired. And of course, that has all been of great benefit, and I am now very comfortable. In 2012 my partner at the time encouraged me to think about retraining as a ceramicist. So, I went to college for four years and then on to do a BA at University. That has provided me with a second, wonderful life.

I know I have been very fortunate in life. Anything I want to do I am able to do. I have a house in central London that I am very lucky to have and which I am very happy in. I am a very sociable person, and most of my friends are younger than

me. I enjoy the company of younger people. My partner is 22 years younger than me, and we have been together for 26 years now.

I have experienced loss of course; I lost my partner. It was 30 years ago, and we had enjoyed 16 years together. The person that I got it from, he was to die soon too. There was a lot of loss and of course we look back on those people with great affection, but we must go on living.

“I have been involved in advocacy work. I was very involved in the early days of Stonewall. I consider myself very lucky because I have never been on the receiving end of significant stigma, either about my sexuality or my positive status. I am very happily out and clear about who I am in both regards.”

Just in the last few months, I have had to start to get some help. I've looked after my garden for 40 years, but I'm now very happy to accept some help there. I do now often think when I'm doing jobs, will I be able to do this in a year's time? I have to adapt a bit. But then I think you would expect anybody who is approaching 80 to be thinking like that. And actually, regardless of the HIV I think I do better than most people my age. Many people don't even get to this age.

I suppose I don't really think ageing applies to me; I rather think that the fact that I am approaching 80 must be a joke of some kind! I don't spend my time thinking a great deal about the HIV. There are other things to think about and life is there to be enjoyed.



GARY IS 54 AND WAS DIAGNOSED IN 1992. HE LIVES NEAR BRIGHTON.

“I do think friendships are going to be important. Personally, I've always had quite a small friendship group, but very strong friends. That closeness is important to me. I've currently got some good friends.”

My health has been managed well; medication has worked extremely well for me. I have some minor ailments, including some bone problems which seem to be HIV early onset bone deterioration. I do have some back problems, I live with some pain, and I suppose I may have a slight background worry about mobility as I get older. But beyond that, my health is quite good considering how long it is since my diagnosis. HIV itself doesn't really preoccupy me now.

If I think about anything to do with my health it tends to be about things like the fact I used to be a smoker, and the impact that might have had on my health, so general health concerns. Having seen cancer close up I'm probably much more fearful of that than I now am of the HIV. It seems to me to be less manageable, really.

I think the most significant things that have affected me have been the losses of three long-term partners, two to HIV, one to cancer. That's been very hard, and I think in particular the compounded nature of the grief over time, as it all happened within 14 years. I was fortunate to be diagnosed at a time when there was still good mental health support, and good availability to that support for people with HIV. I was able to access support at the time and consistently throughout that period of loss. I have gained strength and resilience as a result of my long connection with the mental health service, and I've even been lucky enough to have the same practitioner for many years. The losses are the defining part of my life really, more than the HIV itself.

“Although I have recently moved away, I've been very fortunate to live for the most part in Brighton and being in that environment has shaped my experience of living with HIV. We've got very enlightened GPs and the HIV service is excellent, so I have never had any worries about my care.”

I have also been able to be part of a community which is very accepting and therefore I have just got on with my life.

Stigma is still an issue and I think particularly when it comes to relationships for older people. I have a partner right now but when you're single, and you're meeting people, and you might be expecting or hoping for a friendship or some kind of relationship, you mention the HIV, and the conversation just sort of tails off or takes on a different slant. You can walk away from that, but you still have that moment of it feeling damaging and hurtful. So, I understand people not seeking out relationships because as you get older you just want less of that damage in your life, don't you? So, you have more people ending up single.

I do think friendships are going to be important. Personally, I've always had quite a small friendship group, but very strong friends. That closeness is important to me. I've currently got some good friends, and there's good potential to make new friends, but my pool of potential friends has been limited by my HIV status. Many of my friends are positive. I would hope that as I grow older, I will be able to have a broader mix of people in my friendship group. For me, it's really important to kind of have that diversity, including gender, because most of my friends are men.

“I am fortunate in that I am financially comfortable. I gave up work soon after diagnosis, I was caring for my partner who had dementia. But I started to volunteer in the HIV community and began running a lunch club which grew and grew, and now I have paid employment within that.”

I think like many people my career path followed my HIV life experience. I would like to be able to retire in my early 60's, and I would very much like to travel, as I think I lost out on that opportunity earlier in my life because of my HIV.

I've changed many of my opinions as I have got older, which I think is the nature of ageing. 10 years ago, talk of normalisation of HIV would have irritated me, we all kind of felt very different from other people and I think needed to be seen as different to get the care we needed. But now, I'm all for normalisation, I think it leads to better care and better treatment. I know some people are very against this and I understand that, but I also think it is sad when people become stuck in their HIV and can't move beyond it. Living with HIV has shown me that it is possible to draw strength and resilience from negative and harmful experiences and move beyond them. I've definitely done that, and I know it's not necessarily the case for everybody, but I believe it can be done.

ESTELLE LIVES IN NORTH LONDON. SHE IS 53 AND WAS DIAGNOSED IN 1997.

“I do worry a lot. I’m always thinking, I hope I’m not going to die on my own, now the kids have left home. It would be nice to have a companion. But my past choices of partner have not been very good, so I shield myself from that a bit.”

My health is good at the moment. I’ve been undetectable for many years now and definitely think of my health as good apart from living with neuropathy, which is difficult and often causes me real problems at night. Sometimes when it’s very hot at night, my feet are burning up. I have to wake up at night and cool my legs, perhaps go and get an ice bucket. Anything just to get them cool. They can feel like they are really on fire. That’s been happening forever. So, it’s something I learned to live with. I’ve tried lots of things, but it’s a problem that isn’t going away.

I also have to take medication for high blood pressure. And it’s been picked up recently that I am borderline with my blood sugar, so I need to keep an eye on that and I’m trying my best with diet and exercise.

I’ve changed both my GP and my consultant now but there was lack of communication with my former GP and former consultant that affected my care. We used to get all our care from the HIV team. So, when we went to the GP, the GP was so clueless. There were some mistakes, lack of communication and that really affects the patient.

“I’m a peer mentor, which I love. I’m a Mummy Mentor. I help women who are pregnant and positive. My son was born positive, and later on, I had a daughter who is negative. Both of my children are wonderful, and united in their support and understanding of HIV.”

My son has now moved away which is difficult because I still worry about him. I try and call him and remind him of things for his own health, he tells me off! He reminds me that he is not a child anymore, but it is hard as you are a mother forever!

I do worry a lot. I’m always thinking, I hope I’m not going to die on my own, now the kids have left home. It would be nice to have a companion. But my past choices of partner have not been very good, so I shield myself from that a bit. I’ve never been comfortable with disclosing, so I think the thought of that is keeping me away from relationships. I have made peace with it but then I worry about being alone. I struggle to be in the house on my own, I’m almost afraid of being here on my own, which is an embarrassing problem that I can’t tell anyone about. I think peer support can help you get from a bad place to a good place. And I think it is more important as you get older, we will have more problems and challenges in common to discuss and share and support each other with. I now feel the need to connect with people my own age more.

I am getting some psychological help to cope with some of the things that upset me. I think we lived through a dark time and unfortunately in my African community, there is an assumption that if you were diagnosed at that time, you were either a prostitute or you slept around and, you know, you weren’t nice. There is gossip, and if somebody finds out they will tell somebody you are dating for instance. People are still pointing fingers.

“I never thought I would be here. I wouldn’t have believed it because I was so ill. But you can go from a very dark place, to now in the present being good. I want to share that message of hope. I’m hopeful for my future.”

I will keep on with the therapy, I will give up smoking, I’m doing mindfulness and intermittent fasting. I’m focusing on just living healthily. I will keep on with the mentoring because I feel responsible for these women. There are people who need me so I need to stay strong so that I can be there. I want to see my son live a healthy life too, hopefully with even better treatment. And I can’t wait for grandbabies!

“But ageing does scare me, and I get very depressed about it sometimes. I don’t want to reach the final chapter in my book. It can be a bit scary if sometimes you ask yourself, “What have I done? I still want to do this, I want to achieve this, have I achieved enough? Am I done? Am I ready to get to that chapter?”

But then I also feel that I’m still young at heart, maybe my age in my head is 40! Inside I’m still the young person who would go out and wear a nice pair of boots, so in my head I have my 40 boots! Yes, I may be getting older but I’m definitely going to try and keep my 40 boots attitude!

CONSTANCE IS OF MALAWIAN HERITAGE. SHE IS 61 AND LIVES IN SOUTH LONDON. SHE WAS DIAGNOSED IN 1989.

“Women do face different issues, one of the big issues for me is thinking about research, and making sure women are included and doing that. And funding for women’s groups, and making sure women have access to funding.”

I was diagnosed a year after my husband. We were told we only had about 10 years to live and that we should prepare in that time. We were given the early drugs, which of course gave us a lot of problems. When the side effects became too much, then you would change to a different one. We lived through really, really bad diarrhoea, stomach problems, nausea, insomnia. And I think a lot of my problems today are because of the side effects of medication.

Lipodystrophy refers to abnormal changes in the way fat is distributed around the body (either fat accumulation or fat loss). Lipodystrophy has been seen in people living with HIV taking older antiretroviral drugs, although these drugs are no longer widely prescribed.¹

The medication changed the whole shape of my body and changed my whole physical appearance. My muscles disappeared; I got a very pointy belly. In those early days I would not look in a mirror. Over time, I’ve got used to it of course, but it still bothers you on some level. I have pains all over my body, in different joints, and I struggle with pain in my feet. I also have high blood pressure. Sometimes I’m not sure what is causing what. But my feet are a problem because of getting around and struggling with footwear. There was one medication that I was on that made me gain weight overall which has been very difficult. I went up several sizes. So, I stopped eating, I cut right back on meals. We have changed the medication, but I am still struggling to shift the weight.

“So, I’ve had lots of problems with side effects. But if it wasn’t for the medication I wouldn’t be here. I wouldn’t have seen my children grow; I wouldn’t have met my baby granddaughter. I am grateful for this. I had hope and I embraced it.”

I tried to give my husband hope, but that message didn’t resonate with him like it did with me, and he died in 1994. After he died, I had to start thinking about me, and think about my life. I never thought I would be here now, at this age. I have so much gratitude to the powers that be that have kept me here.

Now I’m just hoping that I live long enough, not just to meet my grandchildren, but to be able to talk to my grandchildren as they grow up, to have real conversations and debates with them! To be able to see them grow up would be wonderful.

I do have worries about practical things as I get older. My children, they live abroad, so they cannot look after me in practical ways. I have nobody near me really. I live a secluded life by choice, I feel safe at home. I am not unhappy now, but I think perhaps I will become more isolated as I get older. I don’t think there are many people who would check on me when I am older. Ideally, I’d like to live in sheltered housing or somewhere where there is always somebody around. Companionship is probably more important as you get older.

But although I am mostly alone, I am happy if I am busy. I am doing my university studies, and that is important to me. I have always loved learning and have done so much studying. I am fortunate that I can do a lot from home. My philosophy is just to keep going, keep doing things, keep busy with learning or whatever. When you stop, you die, that’s what I think. Also, I think learning keeps my memory working, it keeps my brain alive. You hear about HIV dementia, and I don’t know if it is really a thing or not, but as I sometimes struggle with my memory, I think the studying is good for me.

I know I wouldn’t be able to hold down a full-time job because of my mobility problems, travelling to an office, it would be difficult. So, I do the learning and I keep going with advocacy work.

I’ve always worked with women, we work together on the issues that are important, and for a long time we have been saying ‘nothing about us, without us’. Women do face different issues, one of the big issues for me is thinking about research, and making sure women are included and doing that. And funding for women’s groups, and making sure women have access to funding.

I am now getting involved in services for refugees and women in Africa and I am learning about the struggles they face. I have done significant advocacy work over the years, and it is very important to me. I think it is important that women my age are still active in this, we have many things to say. We need to pass the torch on to the next generation of women with HIV.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

1. Aidsmap. Lipodystrophy. Available at: <https://www.aidsmap.com/about-hiv/lipodystrophy> (last accessed May 2022)



“There is still a long way to go with public education. We’ve got to get the message out there, we’ve got to talk about it.”

SIMON IS 57. HE WAS DIAGNOSED IN 2015. HE LIVES IN LONDON.

My HIV diagnosis was never an issue to me. I knew it wasn't the same as it was in the 1980's & 90's. I started antiretroviral medication straight away and within a month I had an undetectable viral load. Which I have maintained to the present day. Once I was stable, they could deal with the Hepatitis C that I had at that time.

So, as I said HIV itself is not a big issue. But it's everything else. For me, chronic pain, neuropathy, carpal tunnel syndrome, ulcerative colitis, I'm on my way to having osteoporosis. I've got multiple things wrong with me. I do find the pain difficult to manage. With pain medication, I don't see the point sometimes. I'm already on 22 medications a day for various things so that's a lot. Most of these are inflammatory health issues that could be linked to HIV, but nobody has ever definitively said the HIV was a direct cause.

I was also worried about Parkinson's Disease. There is a family history of Parkinson's, my grandmother had it. I actually moved into her flat until she had become so sick that she had to go into a care home where she could get 24/7 nursing care. Now my mother has Parkinson's disease, so I've seen it up close and it scares me. I feel like I've beaten HIV, I've beaten Hepatitis C, but that's different for me. When I think about illnesses that might happen, dementia, or anything that brings dementia, I think I can handle that bit because when you're gone in your head you're gone, but it's the journey with Parkinson's, that slow train. That would be a different matter.

My mental health goes up and down. I hit a crisis point at Christmas 2015. It wasn't the HIV; it was triggered when I was made redundant shortly followed by losing my home. My 13-year relationship with a nine-year Civil Partnership ended. I was arrested while I was sofa surfing at a friend's place. Now anybody can find themselves homeless. I'd had good jobs, a place in society, but you can lose

it all very quickly. Housing is actually terrible in this country. In my opinion, as a single man you do not get housing, you can forget it. Actually, the first time I slept on the streets of Camden was the day I was diagnosed as HIV positive and HepC positive. I was sofa surfing as best I could, but then trying anything I could to find somewhere to sleep. This all came to a head when I was called into a meeting with the Housing Officer. But after months and months where I hadn't received any support for housing, I snapped. I told the Housing Officer I was going to bite him, kill myself and name him in my suicide note (he knew I had HIV positive and HepC positive, but he didn't know that I couldn't infect him through a bite). The next thing I knew was two huge bouncers escorted me out of the Council Offices. It was at this point the Mental Health Crisis Outreach Team jumped in. I was given a temporary place in their Mental Health Crisis Hostel (usually two weeks but due to the fact it was Christmas and the New Year period I was given four weeks accommodation). Whilst I was staying there, I received mental health support. Once I left the Crisis Hostel, I was placed in a homeless hostel in the east end of London. After nine months in the hostel, The Council's Housing Office still couldn't offer me accommodation from their Social Housing stock. They directed me to one property from a private landlord that they deemed would be suitable for me. You have to take the place they offer you, wherever it is, because then they've done their due diligence. And if I didn't accept it, there would be no other assistance offered.

But now that I am on the road to recovery. I know that I don't want to kill myself, now I want to actually stick around for quite a long time. So, then you have to think about the future. That's partly why I do the campaigning, to try and make things better for the future for me and for everyone else. I volunteer with a number of the national HIV Charities and Support Groups. This has been in various forms, including launching a report looking at the first generation growing older with HIV titled: "Uncharted Territory". I have also given training to Care Home staff to help educate them about the facts and to bust the myths surrounding HIV. The problem

you've got is that the people who come to something like that are the people that are engaged already. They're not really the ones you need to reach. Campaigning is frustrating in that way, you have ups, and you have downs. There's a long way to go. But it is satisfying, and I also partly do it to give a voice to people who are silent, who have all kinds of problems that stop them having a voice of their own.

There is still a long way to go with public education. Younger people, they're brilliant. The generation that didn't see the tombstones, they get it. But anyone that was around to see that, it sticks in their mind. I think that campaign was the right thing to do, but it has definitely stuck. For me, telling the world that I am undetectable and untransmittable, that's an important political act. It's become second nature to me to talk about that. I do my bit on social media talking about it, I wear the badge. We've got to get the message out there, we've got to talk about it.

I worry a little bit about loneliness and mobility as I get older. But really, I'm hugely privileged that I didn't get HIV until later, until there were good medications that allowed me to become undetectable, and not be made ill by the medications themselves. We lost so many people from the generation before mine. Also, if I hadn't had HIV I may not even be here now. Most 50 something guys don't go to the doctors. It was being able to access HIV support services that helped me discover the various underlying health conditions I had, both physical and mental.

You've got to stay engaged, stay busy. I try to do something every day, but don't beat myself up now if I don't manage it. I love doing charity fundraising, fun runs, shaving my head, that kind of thing. I want to keep volunteering because you can make a difference to somebody's life by just saying one reassuring thing, or making one phone call, and helping others is the source of real happiness for me. I look at the positives. And whatever getting older brings I much prefer it to the alternative!

If you need to talk to someone please call the Samaritans for free on 116 123.

Did you know, the precise risk of HIV and Hep C transmission through a bite is unknown but it likely to be negligible? In the first instance seek expert health advice from a doctor or nurse for an individual risk assessment to be carried out.¹

1. Aidsmap. HIV cannot be transmitted by spitting, and risk from biting is negligible. Available at: <https://www.aidsmap.com/news/may-2018/hiv-cannot-be-transmitted-spitting-and-risk-biting-negligible-says-detailed-case> (last accessed May 2022)

GORDON IS 54 AND WAS DIAGNOSED IN 2004. HE LIVES IN WEST LONDON.

“The self-management principles that I learned when I was newly diagnosed with HIV have been so useful with the HIV. I implement them without thinking about them when dealing with my HIV.”

My health is the worst that’s ever been as I have cancer, and things have been extremely difficult. I’ve had a very, very hard journey with the cancer and I’m now on maintenance chemotherapy. There’s not going to be a cure, so I’m getting used to the idea of the chemo now being the situation for life. It is fairly clear now that I will die with HIV and not from HIV.

Ageing in itself is hard, and then it’s harder with HIV, and then it’s harder still with cancer. The cancer takes up a lot of my brain space right now. And actually, HIV hasn’t taken up a lot of my brain space in terms of my own personal health for quite a long time. I think HIV has become a really manageable condition for most people in the western world. Certainly, it is my personal experience that it’s a condition where I take one pill a day and I get on with my life.

When I got the cancer diagnosis I just thought, “Right, I’ve been through this HIV journey and that should help me here.” It didn’t cross my mind that the tools wouldn’t work. I thought, I know what to do, I’m ready, I’ve got everything that I need, so let’s go. But it didn’t work.

The self-management principles that I learned when I was newly diagnosed with HIV have been so useful with the HIV. I implement them without thinking about them when dealing with my HIV. But they just haven’t worked with the cancer because I can’t coordinate things in the same way. I can’t get the doctors to work together. I try and link them up, and try and act as the link, but there is resistance, and I think they find that really difficult. In the early stages of my chemo treatment, I was having really horrible side effects, and I was asking about interactions between the drugs and they just weren’t prepared to look at it like that. Getting them to talk to each other was impossible and that’s even considering that I’m fortunate enough to get my cancer care and HIV care not only in the same hospital, but actually in the same unit.

I’ve also met doctors who I don’t think are comfortable with me taking an expert patient approach. In actual fact, in all the years since I was diagnosed with HIV, I haven’t felt quite as disempowered as I have this last 12 or 18 months. It makes you realise that if you then get all the other stuff that comes with ageing that you may have real problems getting your doctors to work together.

It has occurred to me that the HIV might become an issue at some point. My CD4 count has dropped, and I’m not certain that the doctors fully understand the link. There could be a point where they tell me that my HIV is no longer managed and I think I would find that really quite difficult to hear because it’s so far in the background that if it were to be brought forward, I think I would feel completely overwhelmed.

I have had some tricky times. As part of this cancer journey, I had a transplant three years ago, and I nearly died then. But I had also done a lot of reading about death and dying in preparation for the transplant operation. Not that I was particularly worried I didn’t think, but I had nonetheless done the reading. I found it really helpful. I work a lot on mindfulness and meditation practice, not looking ahead and being really mindful of the fact that I’ve only got today, or this moment. That has been very helpful to me.

Discrimination is still a problem. If I felt like having sex right now and wanted to go out and try and negotiate having sex, I’d still come up against discrimination. All the usual stuff, maybe not as often 15 or 20 years ago, but it’s still there. But if you’re living with HIV, you have a choice, really, to get on with that just being the landscape, I guess, and whether you let it bother you or not.

I hear people saying every day’s a bonus. And I remember my grandfather saying to me years ago that he was still surprised when he woke up in the morning like: “Oh, I’ve got another day.” So, because of everything that I have been through and that I’ve got going on right now, I am really grateful to be here, I do really appreciate it. I’ve had a few things that have nearly taken me out, and they haven’t yet, so I’ll just kind of keep going on, trying to take care of myself the best way I can.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

VANESSA IS 57 AND LIVES IN OXFORD. SHE WAS DIAGNOSED IN 2014.

“Also, having to live with that stigma for all those years might have been quite damaging. If I’d had all of that it might have affected me. I might not be the person I am now who is able to be outspoken and speak up for people that can’t speak up and fight the fight.”

I had quite an unusual experience as I wasn’t diagnosed for a long time after contracting HIV. Despite living with all the symptoms for a very long time, and being continuously, horribly ill, nobody thought to do an HIV test. Looking back now, everything added up to that, but at the time nobody thought of it. I was being investigated for lymphoma and all sorts of things. Clearly it was an enormous shock. I didn’t anticipate that I could possibly have HIV. Working back from my eventual diagnosis, we have established that I had probably become infected 30 years earlier when I was 19. And, of course, it all made sense.

Did you know that with the right care, women living with HIV can give birth to children without passing on HIV. When considering conceiving, consult with an HIV doctor or nurse. The advice will depend on each individual’s circumstance, their general health, whether they are taking antiretroviral medication, their viral load and whether their partner has HIV.¹

I am quite angry at a personal level about the failure to diagnose me, and all the years of ill health I endured. I kept saying, “Is there something underlying?” I was so ill for such a long time, and it affected everything, my parenting, you know. On the other hand I know I was also quite lucky in some ways. I’ve had conversations with women who were diagnosed before me who were told not to have children. I had my two children by the time I was diagnosed, in fact they were young adults by that point. By pure chance, both were born by C-section, and I’d been unable to breastfeed. All pure luck. But both were healthy. It seems like a miracle really, but it was as if everything had aligned to make that happen. I’d lived all those years with it, and I hadn’t infected them, or anyone.

Women living with HIV who wish to breastfeed should speak to their HIV doctor or nurse first.²

I also know that had I been diagnosed in 1983 I would have likely been given the original drugs that proved to be pretty toxic. I know long term survivors now who are still suffering the effects of having those.

Also, having to live with that stigma for all those years might have been quite damaging. If I’d had all of that it might have affected me. I might not be the person I am now who is able to be outspoken and speak up for people that can’t speak up and fight the fight.

As it is, my health is very good. I have some blood pressure problems. I am probably more worried about my weight than my HIV to be honest. My HIV, nowadays, takes up very little space in my head in terms of how it affects me. I take

Did you know there is currently no cure for HIV, although antiretroviral treatment can control the virus, meaning that people with HIV can live long and healthy lives.³

my tablets and that is it. I definitely could do with sorting my weight, cutting back on alcohol etc. I try and do the best I can, I do a lot of walking.

I hate the idea of getting older in general. I mean when I look in the mirror, I think that’s not me, where did all the time go? But you can’t stop the ageing process, so you may as well embrace it. I am happy, I’m lucky with my children, I enjoy my job. I love travelling, that makes me happy when I can do it. My children think I should be saving for my future and despair at my lack of financial astuteness, but I have to do it my way. I am probably a bit of a spendaholic, not on material things, but on things that matter. I live for experiences.

I think HIV has made me a stronger person, and it has without doubt broadened my horizons. I think my life’s fuller. I certainly appreciate life more. I think I’m more empathic, less judgmental, and more tolerant. I’ve met so many wonderful people through this and made friendships that I would not otherwise have made, with fantastic gay men and other brilliant women. It’s enriched my life.

But it is an opportunity to educate people and speak up. I think I’ve always been quite an outspoken person. I was brought up to stand up and be counted for what’s right by my parents and I think that’s always been the type of person I am. You know, if you see something, you say something.

I think dating is one of the trickiest areas for stigma. If you’re trying to enter into a new relationship, this idea that you have to be up front immediately, even put it on your dating profile, why would you do that? You wouldn’t put on your dating profile: “I’ve got diabetes.” And if you can’t pass it on to somebody, why do you have to tell them? That’s my feeling. If you do tell somebody, they’re absolutely horrified. Terrified. They run a mile, you know, unless they’re one of a very small minority that is educated. When I was first diagnosed U=U wasn’t really a thing, so of course that’s been hugely liberating for most people. But I still think there is a lot of stigma, and self-stigmatisation within the HIV community itself. It’s a throwback. The idea that you somehow deserve this. That it’s a dirty thing still. That self-stigmatisation is one of the most damaging things.

‘Undetectable = Untransmittable’ (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.⁴

1. NHS. Can HIV be passed to an unborn baby in pregnancy or through breastfeeding? Available at: <https://www.nhs.uk/common-health-questions/pregnancy/can-hiv-be-passed-to-an-unborn-baby-in-pregnancy-or-through-breastfeeding/> (last accessed May 2022)
2. BHIVA. HIV and breastfeeding your baby. Available at: <https://www.bhiva.org/file/5bfd3080d2027/BF-Leaflet-1.pdf> (last accessed May 2022)
3. NHS. Treatment. Available at: <https://www.nhs.uk/conditions/hiv-and-aids/treatment/> (last accessed May 2022)
4. Aidsmap. What does undetectable = untransmittable (U=U) mean? Available at: <https://www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean> (last accessed May 2022)

H WAS DIAGNOSED IN 2001. SHE IS OF SOMALI HERITAGE, AND LIVES IN LONDON.

“Working with the support group, I had a mission to build my skills and my knowledge. It gave me an opportunity to interact with and engage with other people like me.”

I was diagnosed not long after I’d arrived in this country. My GP was very nice when she told me, she gave me lots of information. But it took me a long time to get my head around it. The first time I tried to visit the hospital, my mind wasn’t there, and I walked out. My immigration status was still uncertain, I had left all my family back home. And of course, all I knew about HIV was from back home, where most people who had it died. I had lost many family members. So, I was very distressed, just thinking about my children and how I was going to die in this country, separated from them. I couldn’t go through with the appointment.

It took me three months I think to come to terms with it. I had to live with it and observe it. I am a Muslim, and my religion is important to me. I did a lot of praying in those three months. And that gave me strength. I gradually realised that I needed to take the medication, and that I could live with it. I had to think through everything about how I was going to live with it and manage the stigma. I went back to the hospital and saw a Muslim consultant, and that really helped me. He explained everything and that was the start of things getting better. From there I had the strength to get involved with a support group. I met people who had been living with HIV for 10 years, for 20 years. I knew that I could get the knowledge and skills to cope there. Once I started to get involved. I haven’t looked back from then really.

Working with the support group, I had a mission to build my skills and my knowledge. It gave me an opportunity to interact with and engage with other people like me. I became a volunteer after a while. I gained confidence through that, I went to college, and got my life on track.

“Now, I have some mobility issues, I have arthritis. The way I see it, my body is just not the same. I just don’t have the same energy. And it is difficult to live with pain.”

When you have health problems as you get older, it is difficult, you don’t know if it is just because you are older, or whether it is the HIV, or the medication. It can be very stressful.

I think it can be particularly hard for older black African women to access information. Many people do not want to come out and ask for information, because of the stigma. Many women I know have not disclosed to their GP. For many African people they don’t know who to turn to and how to find the right words, in English, to ask for help. It gets harder when you get older, especially as now you have to book many appointments online, I think it is hard for people

to think how they can describe what the problem is, they think, how can I explain? I think that is hard for many people but if you have HIV as well that is very difficult, worrying about stigma, worrying about finding the right words.

And many people are very isolated and don’t have help. They only get help when they get very ill and go into hospital. I think support networks are needed there to help support that person, to talk to the hospital, to talk to the clinician.

“For me, I still have worries for myself. I worry about care homes. I think, will I be treated as a normal person? I realise that the confidentiality I have now, I will not have there, because they need to give me certain medications.”

It is quite likely that the staff won’t want to come into your room. It is difficult in my culture to think about being in a care home, I should be with my kids. They would look after me because they are my blood. We look after our relatives, but my children are back in Africa. There are a lot of issues around that, the system is difficult for immigration, and for benefits, which is another worry and stress. The benefits system is hard, and then it is harder if you have HIV because the people who manage it don’t have knowledge or understanding. And there is stigma there too.

But I enjoy my work as a volunteer, it makes me happy when I can support other people, to get them help, to find solutions for them. I think being in a support space with older women, where you trust other people and you feel free to speak up is very important. Somewhere different to where you live, somewhere you can retreat to and be able to talk, to share experiences. That is so important. We have this issue in common, and if people feel free with people the same age, all women, we can help people find their voices and say anything they want to say without fear. There are a lot of issues, and we have a lot to say.

SAMANTHA LIVES IN DORSET. SHE IS 55 AND WAS DIAGNOSED IN 2007.

“I feel like I’ve got a lot in common with other women living with HIV. It was meeting other positive women that helped me come to terms with my diagnosis.”

Now that I’m older, there’s a lot of reflection happening, a lot of looking back. I was a slow progressor when I was diagnosed, so I thought, “Okay I’m dying, but I’m dying slower than everyone else.” It was hard to get my head around. It was five years before I was given medication, as my CD4 was OK, and my viral load was never higher than 5,000 but actually in that time I was really quite ill. The worst was a brain virus. I actually think that those five years probably did age me quicker than it should have done. I think maybe if I had been given medication, maybe I wouldn’t have aged so quickly. I know that sounds a bit off, but that’s what it feels like.

I think my metabolism has slowed down as I feel really fat at the moment. And I think that side of ageing is a bit of a problem for me. My Mum always had such a negative opinion on getting older. So even though I try to fight that negativity, it just kind of gets to you a little bit, you kind of think, well, you know, she’s thinking like that, so is the rest of society thinking like that?

I have considerable mental health problems, and that’s been an issue since diagnosis. When I was diagnosed, I had an eating disorder, and I developed Generalised Anxiety Disorder, which to this day is an absolute nightmare. I always think that to think far ahead into the future provokes my anxiety, so I always try to live a day at a time. But then when I think about it, I can see that the future issues are there in my head in the background anyway, so then I think I ought to confront them.

Because my relationship with my children is complicated, I feel quite alone, and I worry about that. My parents are my biggest source of support, but I’m getting older, and they are old already. So, I worry what will happen when I’m getting a bit older, and they aren’t here anymore. Mum talks about when she’s not going to be here anymore and I get upset and say, “You can’t leave me.”

“I reckon getting older is actually a background thought more than I sometimes realise. When I moved into this flat, I noticed that the woman who lived here before me had a stairlift. I think I thought on some level: “Yes this place will be okay for when I get older.”

I think I know that I need to make some changes. I’ve been trying to give up smoking, and I think that’s because I know that I need to because of my health. Also, I’m saving the money I would normally spend on cigarettes, and seeing it build up is quite good. And it inspired me to start looking at banking and savings accounts. So, I am obviously looking forward in a way that I don’t always realise. Then there’s the worry of will there be the right medication for me when I’m older?

I’m also slowly starting to do some self-care which is really hard because my anxiety gets in the way. And it’s all a little bit late with me, but I suppose it’s never too late. I’m thinking if I don’t look after myself, I could age even quicker and then it’s going to be even harder.

I feel like I’ve got a lot in common with other women living with HIV. It was meeting other positive women that helped me come to terms with my diagnosis. I remember that was a turning point, almost an awakening, an epiphany.

I walked into this room. There were all these women, and they were like or different ages, some with children, some who were grandparents, just so many amazing stories. And, you know, beautiful, beautiful women. So, it kind of made you feel a bit more normal if that makes sense. That started me on my journey to get involved and support others.

It’s so great that we’re looking towards the end of transmission by 2030, but we still have many women living with HIV. There are issues that are specific to women, retiring age is different, we have the menopause.

“I think women supporting women is important. I like finding women who are positive about the future, and who I can age disgracefully with!”

1. BHIVA. BHIVA guidelines for the treatment of HIV-1-positive adults with antiretroviral therapy 2015 (2016 interim update). Available at: <https://www.bhiva.org/file/RVYKzFwyxpjil/tareatment-guidelines-2016-interim-update.pdf> (last accessed May 2022)

JOHN IS 76 AND WAS DIAGNOSED IN 1986. HE LIVES IN KENT.

“I’ve always been very athletic; I was a keen cyclist and a very good runner. I’ve run since the age of 11, and I was doing marathons and all sorts even at that point when I was undiagnosed. I only actually stopped running six years ago on my 71st birthday.”

When I was diagnosed there was an option for the early drugs, but my consultant suggested we hang fire, and wait for something else to come along. The downside was that longer wait resulted in shingles that happened just as I was finally about to start treatment. It was very, very bad, it went into my brain and that can be very serious. I was off work for six months. But on the upside, I had waited for the better treatment, and I haven’t looked back since starting treatment. Once I became undetectable, I have been undetectable ever since, I’ve always had it well controlled.

Did you know there are now several effective treatment options that enable most people with the virus to live a long and healthy life. An HIV consultant or nurse will be able to discuss commencing treatment.1

I have neurocognitive impairment which appears to be related to the shingles. I also had bad liver damage caused by one medication, but I was a bit limited in my choice of medications due to resistance so actually had to continue with that medication at the time despite those problems. I was very fortunate to have that damage treated very well and my function is now back to normal after a lot of work. I was also diagnosed with Type 2 diabetes five years ago. I found I couldn’t tolerate any of the diabetes medications alongside my HIV medication, so I tried diet and exercise and have now got my diabetes under control. One of my observations from my diabetes experience is that there seems to be a real lack of knowledge about the relationship between HIV and diabetes.

Staying fit is extremely important to me. I actually think staying fit has been what’s protected me at times when I’ve been ill and I also think it was what protected me for the 10 years that I was positive but undiagnosed.

I walk on average around 40 miles a week. I joke to the grandchildren, “I don’t mind if I lose my marbles, but if I lose my mobility, I want you to shoot me!” I’m not sure I could cope with not being mobile. I have seen dementia of course; I know it is very difficult. But for me, I think I would be aware of a loss of mobility and that would be hard. I also think if I lost my mobility, I would probably lose my mind anyway.

I’ve always been very athletic; I was a keen cyclist and a very good runner. I’ve run since the age of 11, and I was doing marathons and all sorts even at that point when I was undiagnosed. I only actually stopped running six years ago on my 71st birthday. It wasn’t that I couldn’t run anymore, I just took a whole load of things into account like the difficulty in the future of getting replacement hips and knees and things. I just thought, “Let me quit while I’m ahead”. I’d ideally like to shuffle off without having had to get bits and pieces replaced! So, for now I’m concentrating on the gym and walking which

keeps me physically fit but is also very important for mental wellbeing too.

I lost my wife a number of years ago. Although we were in a platonic marriage, she was my soulmate, and it was a terrible loss. She was the only person who knew my status. A few years after she died, I had an accident and needed surgery, and decided that the time had come to tell my daughter and grandchildren, as I needed them to know for the future. They have been marvellous and support me emotionally and have taken it in their stride. They also accept my sexuality. I am close to them all, and actually live with my granddaughter.

I also have a close male friend. It’s a relationship of affection, support, and companionship. I value that relationship greatly. I think that companionship, alongside family, is the most important thing going into your old age. I am fortunate to have always worked, so I am financially comfortable, so I have security.

15, 20 years ago, we would never have dreamed we would be able to have a conversation about ageing with HIV. That’s the nice bit. The less nice bit is tackling everything that comes with ageing. We are a patient cohort growing older and we don’t know if the comorbidities are going to be much worse for us.

But you do have to accept there comes a time with ageing where it is about managing decline rather than improving health. Any sensible person does that. And any sensible person also needs to come to terms with their attitude to death. I think anybody of my age who hasn’t come to terms with their own mortality is making a big mistake. But I think perhaps that might be what HIV has done for me. Like anybody else, I don’t know how long I’ve got left, but however much time it is I’m going to make the absolute most of it.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

RUTH IS OF UGANDAN HERITAGE AND LIVES IN LONDON. SHE IS 53 AND WAS DIAGNOSED IN 2010.

“ I think we need to be looked after as we get older. We need more help. We need more attention. I think we need GPs that are better at looking after people with HIV.”

Before I was diagnosed, nothing worried me. I was studying at the Metropolitan University. I had a job at an events ticketing company. When I got the call back after the blood test, they explained it to me. There was no good news. I was so, so devastated. I shut down. I did finish my course, I graduated, but things were very hard emotionally.

In 2013 I went back home. I wasn’t feeling good, but I didn’t tell anybody back home. I felt so bad about it, and I felt very lonely.

It was when I came back to this country in 2014 that I had a stroke. I finally felt I had to tell my brother, who was also living here at the time. Because of the stroke, because I was ill in hospital, I felt I might need him to support me. I am lucky to have him. He understood. I told him that he was the only person I had told, and he understood that. I remember him telling me that it would be okay, he told me that I should remain calm. And he tried to reassure me. He agreed with me taking medication, he knows like me that many people back in Uganda have died because of lack of medication and told me that it is good to be here and to have access to that.

Then I started to have problems with my mental health. I was eventually admitted to hospital. I was out of hospital for a while and then I came back in last year. And now I’m living in a home, in a supported living situation. I think I will be here for some time.

I am taking medication for my mental health which stabilises me. I don’t mind that. And I am very happy here. It is calm. The staff understand my HIV and help me with any hospital appointments and with anything that goes wrong with my health. I feel supported by them.

“Also, when I came here, I found I had access to organisations that were able to support me in talking about my HIV. So, we sit together, and we talk about ourselves and what we are feeling, and that is good.”

I find that very helpful. It has been a very positive thing in my life. We talk as a group; I have a lot in common with other people in my age group who also have HIV. Of course, we talk about the HIV, but we also talk about other things.

I feel safe in that group and able to talk about it. But I can’t talk too much. I don’t know what happened, but after my stroke I cannot talk as much. It has affected my communication

in every way because I cannot talk as much, and I cannot write very well. Handwriting is a problem for me, my handwriting just goes off down the page. And I struggle to do my signature. Although I’ve been told that if I practice, I might be okay. It has also affected my memory. And I cannot read as well, which is sad because I enjoy books and have enjoyed being in a book club.

I think we need to be looked after as we get older. We need more help. We need more attention. I think we need GPs that are better at looking after people with HIV.’

In some ways though I would rather have HIV than cancer. HIV is not a death sentence. We can live with the medication, and we have great choices of medication in this country. But I think maybe it is harder for women who have children. They may take all your energy and then your health will suffer. I have no children, so I am able to put all my energy into being well.

I do wish we could all talk more openly about HIV. And I wish we could talk to the young people and tell them to be more careful. Even though the disease isn’t too much of a problem for me, I wouldn’t want other people to have it. It changes your life, it changes what you can do with studying, with working. But life goes on. And I think we cannot do anything about it, so life must go on.

1. Aidsmap. Starting HIV treatment. Available at: <https://www.aidsmap.com/about-hiv/starting-hiv-treatment> (last accessed May 2022)



"I began speaking out when I started to get angry about the fact that because of stigma, women living with HIV were being forced to live invisible lives."

ADRIENNE IS 72 AND LIVES IN BLACKBURN. SHE WAS DIAGNOSED IN 2002.

I must have been positive for about two years before I was diagnosed. I had all the signs and the symptoms, but nobody thought of testing for HIV, probably because I was a heterosexual middle aged, white woman, I didn't 'fit'. Luckily, I was diagnosed by a homeopathic doctor in Spain (after having nearly died from PCP otherwise I would not have been here now. When the test came back positive, I was absolutely horrified. I was really sick by that stage with virtually no immune system because I had been living with the virus unknowingly for so long. I'd suffered from all the classic signs, constant oral thrush, rashes all over my body, loss of voice, chronic fatigue. I was on antibiotics countless times, and I just couldn't work out why I was so ill all the time. But I had very little knowledge back then of HIV.

My mother was the first person I told, and she looked after me through the early stages and helped me to cope with the toxic medications, some of which were hallucinogenic. I was 50 when I was diagnosed and my mum was in her 80's, so she needed supporting too. We looked after each other in those early days and my sister supported us both from afar. From the very start I've been well looked after by my HIV team in the UK.

The side effects of the toxic medication obviously have had an impact on me over time. Some younger people say now that having HIV doesn't affect their life at all. I hope they can say the same when they've been taking medication for 20 years, although the drugs have progressed and are much kinder to the system nowadays.

HIV related stigma is one of the worst things about living with this disease, even now 20 years on. My GP doesn't really understand. He says it's no different to any other chronic illness giving diabetes as an example. I argued there is no way you can compare the two things. Diabetes doesn't affect your sexual relationships.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

When you get older, regardless of HIV, you have to take other tablets. I'm on statins now and blood pressure pills. I don't really feel in control of my body anymore. I feel like I haven't been myself for the 19 years that I've been taking medication. Firstly, I was controlled by the virus, and now

I'm controlled by the things that are controlling the virus. So, I feel like I've never really been me for many years. I do feel quite low from a mental health perspective, but I'm fighting not to be that person that ends up with somebody having to look after them. In a care home for example where the stigma would probably be rife. I try to do chair yoga, and Tai Chi to build up my muscle strength and balance. I believe that mental attitude can make a huge difference as you get older.

"Talking to other positive women really helps."

Talking to other positive women really helps. The first time I spoke to another positive woman she told me to think of my tablets like little soldiers inside my body, doing their job. And that image has stayed with me! It was the first positive interaction I'd had with another woman who was living with HIV, and it was very powerful.

I began speaking out when I started to get angry about the fact that because of stigma, women living with HIV were being forced to live invisible lives. It took me about three years to start speaking out under my own name, and then I went on to do lots of advocacy work which has been wonderful.

I do notice that as I get older, some of the female voices have disappeared. If you've been on medication for many years, you may not be well enough to do it, or maybe you just don't feel like what you've got to say is so important. The 'old woman syndrome' of feeling as though you're no longer necessary. Also, it's hard to keep up with things, things just move too fast. And you think, I've done this now, I've spoken out, I'm out of energy, and now I just want to go back into my shell. But I think it is important to keep raising awareness, so I try to make myself do something in advocacy every year.

People need to be realistic about how this has affected us. How I feel is, yes, you can still live your life, you are still alive, but it does still take your life, it's still in control of who you are. Even if it is undetectable, it is still there. I think most women put a brave face on and there is this classic line, we say: "Because of HIV I've met so many wonderful people. In some ways it's really changed my life for the better." We've all said it. I've said it, but it's not really that simple.



MERCY IS 55 AND LIVES IN NORTH LONDON. SHE WAS DIAGNOSED IN 2001.

“I’ve tried different careers since the nursing, but I now have a new job, which I want to do well, and to try and be sociable there. I have other things I want to do. I want to travel; I want to go further than Europe.”

When I was first diagnosed, I told my mother, and her reaction was really, really bad. I had my young daughter at the time, and she didn’t treat her the way she did her other grandchildren. She didn’t want me to tell my father, which I think was a mistake, I think things could have been different for me if I had told him. Her reaction made me think, well if your own mother can’t protect you, nobody else will. I just shut down completely, I didn’t want to make any friends. So, at work for instance, I just kept to myself. It set a pattern of being reclusive, and I’m still reclusive now. I think I have been depressed since I was diagnosed to be honest.

My body is changing as I get older. I have a very big belly now, much bigger than when I was pregnant. I have asked the doctor about it, but I have never really had a proper answer. Sometimes I won’t eat for a day because I think all my stomach will go down. But it doesn’t happen. That’s only happened since I turned 50 and it bothers me, both from a health perspective and from the way it looks. I’ve seen this with a lot of other people who have HIV and are on medication. I also have a lot of joint pains, in my back, in my knees, and my arms. I’ve never discussed it with my medical team. I just feel like if they can’t sort the problem with my stomach what’s the point of me going to them with this?

I worry about getting old and needing a walking stick, and I think how would I manage getting to hospital when I need a stick, it’s hard to imagine dealing with public transport when you are old like that. I would like it if my GP could do my bloods and keep it local. I mean can you imagine being 85 or more and having to get to the hospital, it must really difficult. I think my view may be affected because I lost my father three years ago, after a fall. It has made me worried; I get jumpy about stairs and trips. So, I worry about getting older and more frail.

And I’m worried about my home and the fact that it’s not really accessible. If I need an ambulance, or doctors or whatever, I live in a basement flat. I remember once when I was rushed to hospital, and it was a big problem for them getting to me. So maybe my home needs adapting, or I would need to be somewhere else.

“I’m also worried about loneliness, because I don’t have many friends and I know it could be a problem when I’m older.”

At the moment I’m building a friendship network with a group of HIV positive women which is really great. But I don’t just want to sit and talk about HIV, I want to talk about

other things. I want those friendships to be built around other things. There are definitely better things to be talking about than HIV, the beauty of the world, the things we can learn from each other about the places we live and our interests.

“The stigma is still very high in certain cultural or religious groups, they haven’t moved on. I don’t mind talking about it with people who are outside my race, but I won’t talk about it to people from the same culture. Even if they say it is fine, it’s not.”

Black African men classify the women, and they treat them really, really badly. I mean, I’ve had situations whereby a man would have known that a woman had HIV and will beat her up on a daily basis, you know? So, there’s domestic violence within the community, and the women need a lot of support, specialist support. The men, they are just horrible to the women. Obviously, I’m not saying all of them. but some of them. They have partners who beat them, and they have to deal with that on top of what they have.

And there is stigma with doctors and nurses too. I was training to be a nurse because I actually wanted to go into HIV care. But I had a conversation with another student from a similar cultural background to me, and she was concerned about having to deal with people with HIV and thought she was going to catch it. I just thought that if she’s like this, how many nurses feel that way? I was in my second year of training, but with that incident, on top of already struggling with fatigue, I just had to give up, and it was a shame because it was something I really wanted to do.

I’ve tried different careers since the nursing, but I now have a new job, which I want to do well, and to try and be sociable there. I have other things I want to do. I want to travel; I want to go further than Europe. I’d like to spend time in Nigeria, my father’s country, and explore the world. There are many things I want to do, and I am optimistic that I can beat the depression and the reclusiveness and go out and change my life.

If you have any questions or concerns about HIV treatment and possible side effects, you should speak to an HIV doctor, nurse or pharmacist.



STEPHEN IS 57 AND LIVES IN LONDON. HE WAS DIAGNOSED IN 1985.

“We do need support and we do need access to support, and it has to be specific to our conditions and lives. I think we are a group of people who deserve to be looked after.”

I was just 21 when I was diagnosed, and I think that is partly lucky and partly unlucky. Unlucky because it has dominated my whole life essentially, and luckier in a way because at least I’ve had the energy to deal with what it has brought.

My health has been dramatically compromised by heart problems. I had a heart attack when I was 40, which I think was probably to do with the HIV and early medication, and probably stress and tiredness, and the fact that I had smoked, a combination of factors. About three years ago they found another heart problem, blockage of an artery. Then a bit later I developed a blood clot on the heart and a second blocked artery. And on top of all the heart problems I also have neurological issues. I have serious mobility issues to contend with as well. I have to use crutches and leg orthotics to get about.

It’s not always clear who is the lead doctor, who follows who. And it can be easy to departmentalise health and find that nobody is seeing the broader picture. Many GPs are still not really very experienced in HIV. I think they probably have a greater understanding of somebody who’s recently diagnosed but not of somebody who has been living with this in the longer-term. I think we are seeing a different progression of HIV disease from the one that everybody is used to, and I’m not sure the system has kept up. I don’t believe that the be all and end all of your hospital appointment should be, “your CD4 count is fine, and your viral load is fine”. I just think that’s not dealing with the reality of living with long term HIV anymore. That’s like 20 years ago or something. I worry about whether the system can cope. There’s all these analogies about how managing HIV is like managing diabetes, but I mean really I have to ask, how well does the system really manage diabetes and all its complexities?

There is a lot of theory about how the health issues are connected, but not much certainty. More is known now, but the heart issues weren’t really on my radar, nor my doctor’s radar to be honest. The uncertainty and not knowing has been unnerving at times.

I am not in a great position financially. It’s shocking just what a disaster HIV can make of your finances. My working years were defined by HIV. Obviously even finishing studying on my initial degree when I had just been diagnosed was hugely difficult, and then my job choices were affected. I started working with the homeless and saw the challenges they faced and coupled with my situation, I became quite

angry and this made my focus become quite political. It’s difficult because you think, am I just blaming this illness? Is this just because I was wasting my time? All that kind of thing.

I am doing a lot of reflection as I get older. I feel even more strongly now about some of the things we went through, the sheer vengeful nature of certain people in those early days. For a long time, I would try and normalise the HIV as a means of getting by, whereas now I realise, actually it’s been a very odd life experience. As you get older you keep peeling these layers away. I’m learning to look at things differently, I have more understanding now. I’ve not magically turned into this gentle, kind, benevolent old man, but I have learned to try to see things a bit in the round. Maybe I have learned to take it all less personally.

“The ignorance and stigma is hard. You know that you should crusade and re-educate. But when you’ve got a lot of problems yourself you don’t have the energy to fight battles all the time, and you don’t want to be doing that as you get older.”

I would be nervous about being in a care home, there is an issue about both my sexuality and my HIV infection. We do have these issues to think about and I think sadly, a lot of things have changed in terms of support. I mean, there are still bits and pieces of support around. The big organisations, they’ve got funding so they can still do some stuff. But in terms of local support, I know in the city where my family is for instance, and in a lot of places around the country, it’s all gone, it just doesn’t exist in the same way anymore.

For people who are of a certain generation who are long-term diagnosed, you can’t erase them. You’ve still got to deal with them. We do need support and we do need access to support, and it has to be specific to our conditions and lives. I think we are a group of people who deserve to be looked after.

CHARLES IS 52 AND LIVES IN LONDON. HE WAS DIAGNOSED IN 1990.

“There are problems but sometimes I think it is better to just think we have come a long way; things are a lot better than they used to be. The medication has improved so much, it is so much more simple.”

I struggle with my mental health a lot. I would say that I have depression, and some degree of anxiety too. It started around the time I was diagnosed as that was also the time that I lost my wife. I also had a child who passed away in 1992. Those experiences obviously traumatised me and left me with mental health problems that are here to this day. I expect them to continue to affect me.

I have used alcohol at times to try and cope, but I am doing better with that at the moment. I am on antidepressant medication now, and I have talking therapy. These may help a bit, but I think the mental health problems are here to stay. That worries me a little. As I get older, I don't know how that is going to end.

My general health is not really as good as I might wish it to be. I have high blood pressure and also peripheral neuropathy. I am resigned to the neuropathy being permanent, but it restricts me and impacts me. Simple things that I used to do I now find harder, like lifting things, moving around. Sometimes the pain is difficult, even when I'm just lying down.

Generally, I'm feeling less able to do the things I used to do, and that means I have less contact with other people, which is a bad thing. I think human beings need social contact, especially as we get older. Social contact is natural. My social circle is small. I mostly just interact with other people who also have HIV as they understand me. I don't really have relationships with my neighbours, I don't think people are particularly friendly or community oriented, it is very different to back in Uganda where everybody looks out for everybody else in their community.

“I have learned to live with the stigma, and it doesn't make me anxious now in the same way that it would have done in the beginning.”

I think when it is the public, they just don't understand so I can cope with that. The stigma that does bother me is the stigma from healthcare professionals, who should understand HIV. I have had personal experience of that. It can make you nervous, you go for a flu jab, and you are worried they will ask you why you are eligible, in an open space at the GP surgery, you won't be comfortable at all.

There are things I would change about health services. There is a lot of backwards and forwards between the GP and the consultant, and I have had problems with drug interactions when things haven't been checked. I also had

to change my consultant once, the one I had was pushing me toward treatment before I felt ready. I didn't think he was listening to me; it didn't feel like a dialogue between us. As I've lived with this for a long time now, I feel more confident asking questions and challenging the doctors if I need to. But there is a way to do it, you have to do it in the right way, you can't just say what you think, you have to be careful to raise it in the right way. That is something I've learned; I've got the language to do that now.

“I would like to work, but there are a lot of obstacles, and you would need a lot of allowances for your health. You can't take a job and then only be able to do part of it because of your health, you wouldn't last.”

I'm very worried about money in the future, I wish I could have a magic wand that would solve all my problems, but I can't have that.

There are problems but sometimes I think it is better to just think we have come a long way; things are a lot better than they used to be. The medication has improved so much, it is so much more simple. When I think about people living with HIV in other countries, I know that it's really much worse for them. But I think there is a hostile environment here now, everything is designed to make life difficult for people who move here. And that disproportionately affects people who are living with HIV and then that will disproportionately affect older people who are living with HIV.

TIMOTHY IS 56. HE WAS DIAGNOSED IN 2013 AND LIVES IN THE ORKNEY ISLANDS.

“In terms of growing older, I'm happy where I am - and I have a wonderful husband who loves being here. I'm surrounded by nature – there's nothing between my house and the sea”

My diagnosis came when I collapsed after a week of flu, I was down south looking after an ex-partner who was in hospital getting chemo. I was staying with friends in London who dragged me to the doctor. I collapsed in the ambulance and woke up a month later in hospital. I was so ill that I had a near-death experience. There was no person, no tunnel of light and the only voice I heard was my own one. It was a quiet, contemplative time when I wanted to go, and I remember thinking, that there are much worse ways of dying than this, in the middle of a pleasant dream. And then waking up, quite angry that I was still alive. And all the images from the 1990's of people with AIDS, that was me, my body under seven stone, all that stuff. I couldn't eat for three months. Nobody prepared me for being a survivor of intensive care. Everybody who has been in a coma comes out with some combination of symptoms, anxiety, PTSD, muscle weakness, all kinds of problems. My lung problems got a lot worse; I have to use three different inhalers. Obviously, it would have helped if I hadn't smoked, but that lung disease is basically related to my stay in intensive care. All of this still obviously impacts me now. I don't sleep, not without medication. I'm classed as medically frail. I blow over in the wind, and there is a lot of wind here!

Everybody has this view of what it is like to be in a coma that's based on what they see on television, people wake up and they are fine. They don't show you the next week, or the next month. They don't tell you that you remember your hallucinations as real events. They don't show you the person who has woken up and is furious about it. And they always finish with a happy family. My family relationships broke down. It's not easy for people to deal with, someone who has had “a miraculous recovery” and isn't saying the normal things about it. Some people can handle it and some people can't.

This island I live on now has a population of just under 500 with its own GP practice. I can get an appointment the same day, or the next day. When I was first here one of the GPs had worked in South Africa and had a lot of HIV experience. The connection between my GP and my consultant on the Scottish mainland is excellent. I think we have the exact opposite of what many people would expect. I know what the English system is like (I worked there for 20 years) and am very glad that we are not part of it. I'm in an infinitely better position than I would be there. The missing piece is mental healthcare but, after seven years, I have found a support group for people who have survived ICU, ICU Next Steps that meets monthly by Zoom. It has made a colossal difference. My sleeping is better.

I think phrases like “well managed HIV” don't really help with people who have had the severity of illness that I have had. It doesn't deal with everything that sits around the HIV. There is now some funding to look at the ramifications of intensive care, but there is very little evidence right now of what the impact is 10 years on, so it is difficult to know what the future holds, and the same uncertainty is there with HIV. I certainly worry about accelerated ageing and dementia in particular. I have some worries about future financial security. I was lucky to inherit a house from a former partner who became a great friend and who I cared for at the end of his life. I have a small income and some financial resources, but it is an anxiety for the future.

“Things have changed. Younger gay guys, you just think they are so lucky. They are relaxed and happy. They don't have that fear.”

I put off testing for so long. One of the consultants at the Mildmay told me that my generation was the worst for testing because we remembered the horror of the earlier drugs. My late diagnosis made me terribly ill and coloured the rest of my life because of my ICU experience, but had I tested earlier I may not have been able to manage the side effects of the drugs, so who knows. It does annoy me a bit that the message is now, it's no worse than diabetes. You just think, let me tell you about diabetes. That can mess with your head a bit. I've never been in any doubt about the seriousness of this, and what could happen to me if I don't comply with my medication, because I saw it all in hospital.

In terms of growing older, I'm happy where I am - and I have a wonderful husband who loves being here. I'm surrounded by nature – there's nothing between my house and the sea. People look after each other, there's no locks on the doors. We have friendships that are multi-generational. In my view I'm actually living in a much more diverse community than I was when I lived in London. And you are allowed to get old here. You're not tied up in an urban gay culture which is fixated on youth. It is so much more healthy to have those interactions and friendships that cross generational boundaries. Old isn't frowned upon here so there is more community support for older people, and for people when there has been a loss. So, I think it is more comfortable to be here. At last, I can think that it isn't a bad life.

TIM IS 51 AND LIVES IN HERTFORDSHIRE. HE WAS DIAGNOSED IN 2006.

“I’m doing everything I can for my health myself, I’m a regular gym goer, and I just count myself lucky that I am relatively fit, side effect free and am living without the consequences of earlier treatment.”

I was diagnosed quite late. All the signs were there of course, and it was missed. But if I had been a bit more proactive and honest with myself, I could have got a diagnosis and medication quicker. But on the flipside, the medication back then wasn’t half as good as it is now, so my life on it may have been worse than my life as it is. It’s hard to judge what would have been better. When I was fighting for my life in hospital, I would have taken any medication to be honest. So probably I think it would have been better to have been diagnosed earlier, but really there is only one person to blame for that and it’s me.

“Obviously initially it was devastating, as I was so ill in hospital, and I just assumed I was going to die. But once I was out of hospital and feeling better, I actually came to terms with it reasonably quickly, maybe a couple of months later.”

I think I opened my eyes a bit to the fact that I was on some good medication, and there were people out there dealing with other diseases that were worse off than me. I think it is just developing that stamina and that determination to move forward, accept and adapt.

I’ve had medications in the past that have had really very difficult side effects and have really limited my life as a result. I’m now on something where I don’t have any side effects. I think any health problems I have are to do with age really, my eyesight is going, my hearing is going, I’ve got men’s problems starting!

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

It’s odd thinking about getting older. Everyone in my family died really young. Because of that I always assumed I would die young, and I used to be okay with that. Obviously as you do then get older your thoughts change, you realise you still have quite a lot to offer. I get checked every six months or so, so anything sinister is going to get picked up on quickly. And they’ve very willing to over investigate, and to act on your behalf to move things along. So, I actually feel very well looked after. I’ve definitely noticed they ask me more now about whether I’ve had any problems. So, they are on alert now I’m getting older.

I had met my partner six years before I was diagnosed. We are civil partners now, and he’s been with me all the way along. Funnily enough he’s more of a hypochondriac than I am! I’d rather hold off calling the doctor until I know it’s something I really need them for. That may be because of my first career as a nurse. I trained as an HIV specialist nurse before my own diagnosis. I had decided I wanted to do that when I saw the poor care people were getting in hospital. There was one woman, from Africa, who was dreadfully ill, and the doctors and nurses who should have known better, treating her with two pairs of gloves on, stuff like that. It really affected me. It was thirty years ago, but I remember it very clearly. Obviously as a nurse I knew the risks of HIV, and I was still taking those risks myself. It can take a long time to come to terms with that, but I think with age you eventually realise that your brain as a young person is wired differently, and there are reasons for all of it.

I’m doing everything I can for my health myself, I’m a regular gym goer, and I just count myself lucky that I am relatively fit, side effect free and am living without the consequences of earlier treatment. I think I’m starting to look like an older person. I haven’t been offered a seat on public transport yet but I’m sure it’s coming!

There are advantages, definitely. I think with age comes a little bit of wisdom. Things don’t bother me as much now. I think you start to realise that everything is transient and there is no point getting wound up about stuff. I’m much more tolerant now than I used to be. I also know myself better, I know what stimulates me, what makes me happy, so I can use my time better to make my life better.

“I have a good life and consider myself very lucky. Without being dramatic, I know how close I was to dying, so I’m now just extremely grateful for everything life brings.”

JUDY IS A 65-YEAR-OLD TRANSWOMAN, WHO WAS DIAGNOSED IN 2000 AND WHO LIVES IN SALISBURY.

“Really, I see HIV as just a detail in a very full life. It’s not affected my mental health in any way. I realised at the point of diagnosis that it could be managed and that was that. I consider myself a very strong person.”

For me, HIV doesn’t come up. It is perfectly well-controlled, and I am undetectable, with no side-effects from my medication. I am extremely well looked after. I have what I would describe as a collegiate relationship with my team at the clinic. They feel more like friends than anything else, they are very accommodating, and I have a very good relationship with my main doctor.

Really, I see HIV as just a detail in a very full life. It’s not affected my mental health in any way. I realised at the point of diagnosis that it could be managed and that was that. I consider myself a very strong person. If something happens in my life I just crack on, move forward. And that is how it has been. It’s just a pill in the morning and that is that. I don’t even think about it even when I take that pill. I’ve never particularly engaged with the support groups or anything like that, because I haven’t needed them, and I haven’t wanted to divert their attention away from people who do need their support. I would only be taking up resources.

I have had some health problems recently, a couple of years ago I was very ill with thrombosis in my stomach and a situation where I went into sepsis shock. I believe that was all brought on because I have been particularly stressed recently, and don’t think it has anything to do with the HIV. It was very close to going very wrong, but I am still here.

But it would be fair to say that in the last 12 months I have noticed the process of ageing accelerating.

“I am starting to think that perhaps I should be looking after myself a little more, perhaps taking more time off. But then equally I would like to keep my brain active.”

I am certainly not one for retirement. I think retirement is like sitting down in a waiting room and I’m certainly not going to sit in that waiting room waiting for the inevitable to occur. I have noticed that time is going faster and faster. The inevitable is moving closer and closer at rapid speed. You do start to wonder, how long have I got, 10, 20 years?

I have started to wind down a little on some of my voluntary work. I have always done a lot of mental health counselling for people with gender issues, but there’s just too much of that and I’ve been doing it too long. I don’t feel I’ve got the stamina anymore. The brain is willing, but the flesh is getting weaker. So, I am focused on my job as a lawyer, where actually I think I am working harder than I was when I was younger. I now have the challenge of younger people around me, new computer systems to contend with, that kind of thing. I’ve changed in that I’m no longer driven to win in the way I once was and I’m now more driven by supporting others. I recognise that I can’t recreate the high

points of a career that I have already enjoyed. There is a natural curve to your career, a climb, a high point, and then a steady decline. That high point where I was of maximum benefit to society, that is in the past. Other younger people come along who are more willing to adapt to newer ways.

“As to what the future is or even where I’ll be, it is a matter of conjecture. I know I must have a purpose, I’m not about to sit around and watch TV and wait to die. But I think it will involve movement and travel.”

I may end up in Spain perhaps, as long as I am financially able to get back to the UK for treatment. I think I would like to stick with my clinic for as long as possible because they’ve got trust in me, I’ve got trust in them, and I think if I did become ill, they would do their best. There may be passing moments of worry about the future, but that is all they are.

I think with HIV, while many people see it very differently to me, I think, well, you are going to die of something anyway. Why let it be an impediment to the continuous enjoyment of life even in older age?

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.



"I've always been happy to talk about HIV. I need to, as older women with HIV are mostly unseen."

CATH IS 56. SHE WAS DIAGNOSED IN 1985 AND LIVES IN LANCASHIRE.

I was born with a bleeding disorder called Von Willebrand's disease, for which I have required substantial amounts of blood products from early childhood. This is how I came to have contaminated blood. I was only 20 when I was diagnosed and had been positive for three years prior to HIV (then known as HTLVIII) tests being developed. The diagnostic process was very traumatic.

I was told there were 'anomalies' in my blood results; for which my family and I had a difficult six week wait for the result. When I was finally told that I was positive, I was told I had 12 to 18 months to live, to go and sort out my affairs, and to just get on and enjoy the rest of my life.

It was a very difficult time to be diagnosed. My parents were given all this advice about washing and cleaning up after me. I was fortunate, my sister and I have such strong bonds with our parents, and they all looked after me. We were all so devastated and angry too.

When I look back, I was very young. At that point, I was also trying to come to terms with my sexuality, so obviously the diagnosis made that even more difficult. I was also in the middle of my nurse training, so my learning was hugely disrupted. I did manage to complete my nursing eventually, and I first became a RGN (Registered General Nurse) and then a few years later, an RMN (or psychiatric nurse). I eventually had to take early retirement in 1992. Even now, after all these years, I sometimes struggle to think what to say when I'm asked what job I do. People can make so many assumptions and therefore just expect somebody my age to be working. I oftentimes say 'I'm a woman of independent means' as I rather like that!

I do feel my age, but I try to stay young. My wife is quite a bit younger than me, but I think you feel the age gap less as you get older, and we've been together

for 10 years. It's a healthy relationship, whereas lots of my previous relationships were very difficult and I tolerated some very controlling partners. I have had periods of very black depression, and periods where I have flirted with the idea of taking my own life. And there was a degree of chaos in my life for a long time, I was (safely) promiscuous for several years, always able to have the awkward conversation about how a potential sexual partner could stay safe. I built up a great deal of debt at one stage, then put my house in order and paid it all off. I think that I was wild because I was deeply hurt and angry. I think I wanted something to come and kill me, rather than keep waiting; living half a life, which was how I felt.

It was a course of CBT that shifted my brain cognition. I realised that strangely I wasn't dying. The thought that I may live was terrifying, until I faced my fears of what to do with my life. It was incredibly useful in teaching me ideas, techniques and how to have a relationship with myself. So, although I still get anxiety, I don't respond negatively, and I try to be my own best friend.

"I like getting older now! I'm excited for our future. We have plans to travel more, we have a caravan called 'Olive', and we love getting out and about. We may also move further out into the countryside in the future."

I am lucky to have survived for so long. Many others haven't had the luxury. That I am here, and I have the chance to care for my parents now, is so valuable to me. I have a chance to pay them back for some of the love they have always given to me.

The downsides are more fatigue and brain fog. I'm not sure if that is to do with my fibromyalgia, or if it is HIV, or just general ageing. I also have HIV-associated cognitive dysfunction which has caused me to be a bit slower, mentally, but thankfully it's not degenerative. A serious concern for the near future would be, what if I exhaust all the treatments that are available. I know

I'm lucky as I'm very well maintained on my combination therapy. I'm super compliant too, but it doesn't fully quell the worry for me. Research is the hope for eliminating HIV entirely. For new developments to lose funding would condemn many millions more people to the harrowing realities of living/dying with HIV.

But overall, I'm relatively well. Thank goodness it's nothing like the old days. It is a shame that the services we used to have all gone. The lovely retreats and special places like Bethany or London Lighthouse. But we wouldn't be able to go back to those days unless we also go back to desperate isolation and prejudice. And why would we want to go back there? It was truly savage. So, there is a little bit of our community coming to terms with not being that special anymore. And how could we expect all those services when other people aren't getting them for other terrifying illnesses?

Public education has become a source of great disappointment to me. Our society enjoyed brilliant public health awareness in the 1990's and early noughties. But that has all gone and community awareness raising is practically nonexistent now. I've always been happy to talk about HIV. I need to, as older women with HIV are mostly unseen.

To put it into context, I was picking music for my funeral at the age of 20. And here I am, recording my parents' choices for their funerals. I have been very, very lucky. Obviously, I have dealt with a lot of traumas. I can't watch the Infected Blood Inquiry for instance, which is finally trying to deal with the mistakes of past governments, and it really is too painful to see that. But I am here to tell the tale, and I think that what doesn't kill you makes you stronger.

If you need to talk to someone please call the Samaritans for free on 116 123.

1. NHS. Blood transfusion. Available at: <https://www.nhs.uk/conditions/blood-transfusion/> (last accessed May 2022)

LEON IS 57 AND WAS DIAGNOSED IN 2011. HE IS ORIGINALLY FROM EASTERN EUROPE AND NOW LIVES IN THE NORTH WEST.

“I’m not thinking too much about my health in the future. I’m not overthinking or overreacting. It is somewhere in the back of my mind though, in the future, anything can happen.”

The HIV is just part of my life. I don’t focus on it too much. I know that I have to cope with it and there is no cure. I’m taking the medication at the exact minute that I am meant to, every single morning. I keep 100 per cent discipline with that because I know it gives me the chance to live longer and healthier. So every morning at breakfast, I take my medication. I know how important it is.

I think treatment is really convenient. I just have to go to the hospital twice a year, and if everything is going well then it is all good. I usually organise my blood test and my consultation together, in the evening, so I don’t even have to make an excuse to have time off work. I’m happy with my consultant and am comfortable there. I disclosed my status to my GP but we don’t actively discuss it. I would welcome it if he talked to me about the HIV but that is never proactively done. And I don’t then raise it, so it is not something that is talked about.

I’m not thinking too much about my health in the future. I’m not overthinking or overreacting. It is somewhere in the back of my mind though, in the future, anything can happen. I trust the medication and I don’t have any side effects so far, but we don’t have enough experience of people in their 70s, 80s and 90s. Of course, I dream about getting to that age! There are lots of people in their 50s and 60s living with HIV and living pretty well. But I do think it is also on us to contribute to a healthy life. So, I don’t drink much, maybe one glass of wine or two a month. I have a healthy diet, lots of vegetables and good food. At the moment I am experimenting with intermittent fasting. I’m swimming three or four times a week. I do lots of walking. I think I’m in pretty good shape for my age.

“Your interests change as you get older. I am more content now to stay home, have a nice dinner, relax with the TV. Or to go out for a nice walk or hike or a little bit of climbing. I don’t need to be out all the time.”

And then there are some limitations. They come whether you want them to or not. I would maybe think about going on holiday, but now I am older I think twice about long-haul flights and things, whereas 10 years ago I wouldn’t have thought twice about travelling.

I may be getting older and sacrificing a little bit of mobility and wandering less in the world, but I’m so much more confident, 100 per cent more confident than I was 10 years ago. I hope as I age to stay fit and capable, I want to be able to have a walk here and there, I want to be able to cook for myself, or jump on a train or coach and go to places. And to stay digitally connected because I think that

it is important to stay connected. Many older people are isolated because they aren’t digitally connected. I don’t believe there is enough information about getting older with HIV, but even if it is out there it would not reach some people, and we have to find a way to do something about that. I also think there are a lot of people afraid to step out and get help because of the stigma. We need a national campaign that talks about older people with HIV, to give them the confidence.

“I am stronger mentally now I am older. I have had cancer, and actually my experience with HIV helped prepare me for that. I think it will also help prepare me for other health problems I may have in the future.”

I know I can’t change the past, I can’t change the fact that I got infected, but I can have control over my present and my future. I also know that HIV is not the worst thing in the world. I consider things in life differently. I believe I appreciate things much better, everyday little things, nature. HIV has taught me that life is really precious, I don’t take every day for granted, I’m grateful. I live every day looking forward to the next one.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

ANUP IS 72 AND LIVES IN LONDON. HE WAS DIAGNOSED IN 1984.

“Now I’m just very grateful for every day that is extra for me. I think more grateful than people who aren’t in my position. I live with HIV certainly, but the plusses of my situation definitely outweigh the minuses.”

HIV is always there in the background although I don’t really think about it that much. I just get on with things. I have a very good relationship with my consultant, although I have changed in the past because I wasn’t able to get what I wanted from the previous consultant when it came to a medication change. So, I moved, and now I feel I am listened to.

I’m quite satisfied overall with the care the NHS provides. I think there are blockages in the system when it comes to cost, and definitely with time too. I’m not really a regular visitor to the GP, but when you go, you only have 10 minutes. Some GPs I find are extremely interested in my HIV status; others don’t even mention it. Of course, if I am visiting about an ingrowing toenail that is not a problem. If it is something more systemic then that is different and I have found generally that they do ask questions, they are interested. Their lack of time is nobody’s fault, it’s just the system. So overall, I am sympathetic towards them.

I actually get a lot of advice from other like-minded people who are in my situation, who are a similar age group, through the peer support networks. Those networks can be useful in helping to identify if a problem is HIV or medication related, or if it is just old age, or something else. And it can be helpful to help find services, to find a nutritionist, or an osteopath, or a programme at the gym, or something similar. Other people have a lot of information and of course there is mutual support.

Generally, right now, my health is fairly good, although I do suffer from broken sleep patterns. I wake up when it is still dark, and then eventually drop off again and wake up when half the day has gone. I am lethargic. This may just be down to ageing. I do accept the ageing process, I usually fight the changes first, and then when I discover I can’t win, I will accept it. Weight gain, and general slowing down. I’ve now accepted that children walk faster than me and overtake me on the street.

The slowing down is true of mental work too. Everything slows down and I have accepted that. I still do bits of consulting work, the state pension is very slim, and so I do little bits here and there. But I am slower. Something that used to take me 10 minutes now takes me half an hour. It’s not an imperceptible change, you do feel it, gently getting older.

I have been through depressive periods. I’ve lost two partners, and that is very hard, and I have felt I couldn’t share my grief with others as they hadn’t gone through it. I do not want another relationship now, the libido goes, and actually that can be quite freeing.

Now I’m just very grateful for every day that is extra for me. I think more grateful than people who aren’t in my position. I live with HIV certainly, but the plusses of my situation definitely outweigh the minuses. The fact that I am still here is very much due to the miracle of science. And of course, I’m very grateful that I live in this country. I can say that I really love my life.

“I connect very much with the new generation. I am fortunate to have many great nieces and nephews, and I revel in time spent with them. I love communicating with them, playing with them, observing the wonderment they have at nature. They make you open your eyes to things and have gratitude. I consider myself to be a very spiritual person, not religious, but spiritual.”

I feel as though I am in the third phase of my life. I do not have a fear of death. I believe your purpose changes as you get older, and it becomes about acceptance. Acceptance that life is not about being content all the time, it is about learning from your mistakes, and sharing what you have learned, hopefully to help other people.

Being able to meet people and spend time in the company of other people, with all their flaws and imperfections, is a privilege. In itself it is a great reason for living. My advice to anyone in my shoes is to open your eyes in the way young people do, ensure you have good company, and get ready to enjoy the slow lane.

NAMATIRAI IS ORIGINALLY FROM ZIMBABWE AND NOW LIVES IN LONDON. SHE IS 59 AND WAS DIAGNOSED IN 2006.

“I have hopes for the future. I would like to work, ideally. I would like to be able to save money and the money we receive in benefits is not enough to do that, so I think I would like to work.”

Some days I have a lot of pain, in my legs, in my back. And I have high blood pressure. But my HIV is under control. I am just coming through the menopause now, so I have hot flushes. I have recently had a hysterectomy after I had fibroid problems. I was lucky that my HIV consultant specialised in gynaecology, they were very supportive. My GP is really awesome too. They do their best. And I feel they work well with my consultant.

My husband is HIV positive too and I am his full-time carer. He is a lot older than me, he is in his 80's, and he has a lot of comorbidities, and is bedbound now. Although we have support from carers who come in, I still have to do a lot, I do all the housework, all the finances, everything. It does sometimes affect me. And I do worry that with my bad back and pain, I can't push him around in the wheelchair as much, so I can't take him out and get us both fresh air. Pushing the chair also affects my chest. So, as I get older, I worry that will get worse.

We are fortunate that with the benefits we both receive we have enough to manage, although it is really just enough to get by. And we are secure in our house. The housing association have sorted out problems. Our neighbours don't know that we are HIV positive. We are very afraid of being stigmatised. We both have children, and they know, and they are very supportive. Our extended family in Zimbabwe too is very supportive. But you don't know where your neighbours are from, they may be from another country in Africa or in the Caribbean where they don't have the same view. And we don't talk to the neighbours anyway. You wouldn't feel comfortable approaching them even in an emergency. There is no relationship, no community. So, beyond the carers and the clinicians, we don't tell anyone.

“I am honestly very, very worried about getting older. I worry about what will happen when I can't do things for myself anymore. I wonder what will happen to me. I worry about having to go to a care home. I wonder if I would be treated the same as everybody else. I worry that people wouldn't want to wash me and care for me in that way. And if you can't talk or cry out. It's my greatest worry.”

Because the stigma will never finish. People make judgements about how you have been in your life; they think you haven't been responsible for your health. That hurts a lot and is a worry for the future. I wish the Government could make care homes just for people with HIV, and with carers who all have HIV too, because then they would understand.

Did you know the requirements of whether a medication needs to be taken on an empty stomach, with food or irrespective of food requirements will depend on the individual medication.'

My wish is that they could improve medication so that there could be a day when there is no virus in my body. I think having to take medication the way I do has an effect on me psychologically. All the restrictions, with the time I have to take it, having to take it with food. It's okay at home, but if I visit family, they may not be eating at the same time, you have to make sure you take food if you go out. And just knowing it is there in me as well, it does bother me a lot. I will always know it is still there. It is suppressed, but it is still there.

I have hopes for the future. I would like to work, ideally. I would like to be able to save money and the money we receive in benefits is not enough to do that, so I think I would like to work. I am doing as much training as I can through the HIV charities. So that would be my hope.

My life is challenging but it is good. When I was first told, it was just a shock. You just think, well I won't have a long life then. You just think it is a death sentence. Of course, they reassure you that if you start taking medication you can be okay, but you don't really believe that. So here we are, and it feels good. It feels really good. It feels magic.

TREVOR IS 60. HE WAS DIAGNOSED IN 1991 AND LIVES IN SOUTHWEST LONDON.

“I'm enjoying this age, I'm focusing on new hobbies, I've taken up knitting! I know I'm more comfortable in my skin.”

Things have definitely changed. We used to be very privileged, seeing your consultant every couple of months, now you only see them once every six months. In the good old days, I got everything from the clinic, they would have oversight of everything, they'd know about interactions, be on top of everything. Now so much of my care is with the GP practice, and I feel as though I have to educate them to be honest. I don't have a relationship; I don't actually even know the name of my assigned GP. And of course, they don't have time to go deeper into things. I have arthritis, high blood pressure, and high cholesterol, but there may be other problems emerging and I don't necessarily feel I will be supported. I don't feel there are enough proactive interventions in place, it's all reactive. I think a proactive, general MOT every couple of years would be a good idea but actually I would prefer all my care to revert to the HIV clinic ideally.

My mental health is fairly good and stable. I'm not terribly sociable. I have my husband and my close friends, but beyond that, if there is an excuse available to avoid being sociable, I'll use it.

There are possibly mental health connections between now and the early days, trying to keep my status and that of my partner a secret for as long as possible until we had to share it. 1991 was very afraid of stigma.

After he died, I went off the rails, drinking way too much, cocaine, cannabis. I've always been an expert in self-destruction, and I was trying to cope with things by doing that. I also didn't care, as I was thinking I was going to die soon anyway. Eventually of course it dawned on me that on the one hand I was taking treatment to help me stay alive, and on the other hand I was doing coke and stuff that was damaging my body. I knew I had to take some radical action because my addictive personality made it hard to change. So, I felt I had to leave behind my circle of friends at the time and just isolate myself in order to change. I think I have a slightly self-sufficient part of my personality and that is probably why I do okay without too much social stuff now.

It was a gradual realisation for me that I would live. To start with, you realise that the medications aren't making you ill, because you knew older ones did that, then you start to understand that you are sticking around for a bit longer. But it was a good number of years before I understood that it was saving my life. Up until around 2000 I still thought I was going to die, just not yet. I think the advent of U=U was wonderful, that bit of information was hugely liberating, particularly for me with a negative partner, but we still have to make more people believe it.

I will have to work until I drop. I gave up work to care for my partner, and then I had a break for 20 years. I got back into working eventually with the Terrence Higgins Trust Back to Work programme and found my career in the HIV field. I was fortunate with the opportunities that came my way, but because I missed all those years my pension pot isn't massive. Obviously in some ways it's not ideal, but I have to think of those 20 years as my retirement, I've just done it backwards. I know my husband would like me to retire as soon as possible but I don't see how that's possible.

“I don't tend to think too much about old age as I don't think I will get there as my general health isn't good, I still drink too much, and I think I will pay for some of the lifestyle choices I made earlier in life. If I do make it to a bit older, I am hoping my husband will be around and we will care for each other.”

I would worry a bit about financial implications of longer life. I feel comfy with the concept of dying as it is going to happen at some point. It would just be who I leave behind that would be a worry for me.

I'm enjoying this age, I'm focusing on new hobbies, I've taken up knitting! I know I'm more comfortable in my skin. Although in my professional life I spend all my time thinking about HIV, I don't spend much time thinking about it in relation to me anymore, all my thinking about HIV is done with other people in mind.

I know there are downsides to getting older, like the financial worries, but it is better than the alternative. I know I am fortunate as I was diagnosed in that window where I could have missed out on these treatments. It was too late for my partner, and it could have been too late for me.

So, bring it on!

‘Undetectable = Untransmittable’ (U=U) is a campaign explaining how the sexual transmission of HIV can be stopped. When a person is living with HIV and is on effective treatment, it lowers the level of HIV (the viral load) in the blood. When the levels are extremely low (below 200 copies/ml of blood measured) it is referred to as an undetectable viral load. This is also medically known as virally suppressed. At this stage, HIV cannot be passed on sexually.¹

1. Aidsmap. Food requirements and anti-HIV medications. Available at <https://www.aidsmap.com/about-hiv/food-requirements-anti-hiv-medications> (last accessed May 2022)

1. Aidsmap. What does undetectable = untransmittable (U=U) mean? Available at: <https://www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean> (last accessed May 2022)



NICK IS 53. ORIGINALLY FROM BELFAST, HE NOW LIVES IN LONDON. HE WAS DIAGNOSED IN 1993.

“I know my family and friends would come running if I asked them, but I don’t like making a fuss and tend to make a joke out of things or downplay them. It’s what I’ve always done, but now, as I get older, it is all starting to feel a bit more difficult.”

Generally speaking, I’m not that well. I have cardiac issues; I’ve had four heart attacks and I’ve got atrial fibrillation and a heart murmur. I’ve recently been diagnosed with diabetes. I’ve also got arthritis, and pain. I’m going deaf too. Some of it may have happened anyway, I was born three months premature and it’s not uncommon for adults to have some degree of hearing loss if they were premature. But when you add in all the quite toxic HIV medications from the old days, and it just creates a perfect storm.

One of the problems is contraindications and interactions. With my first bout of atrial fibrillation, I was put on a treatment and then got an emergency call in the evening asking me to go into hospital because they’d discovered that one of the treatments interacted with one of the compounds in one of the HIV medications, and I was at risk of a severe internal bleed. It also happened with a cholesterol drug. It’s not uncommon, when I got into hospital, for the doctors to scratch their heads and look and me and say I’m complicated. On the one hand, I try and shrug that off and take it in my stride. On the other hand, it sometimes feels too much. When I was working, in a full-time job it was hard to manage two or three hospital appointments in a week.

I actually recently lost my job, and because I work in the LGBT sector and have done for 25 years, that’s quite niche, so there’s not a huge amount of jobs out there. There are jobs I’ve looked at, but they just don’t pay well enough for me to manage London rent and Council Tax. In some alternative universe where I don’t have HIV, this wouldn’t be my life. I was a registered nurse, a specialist HIV nurse, and a registered counsellor. But HIV derailed my career on two or three occasions due to periods of poor health. In theory I should be in a senior nursing position now or some kind of manager position, but instead I’m stuck at a basic worker level.

“I feel like the swan, from the outside, above the water, it looks as though I’m gliding peacefully along, but actually, underneath the water, my feet are really scrabbling.”

It feels like that at the moment, with my mental health, and with my physical health on top of that. It feels a little bit like I’m sinking to be honest. And being in my 50’s just makes it all harder. I was better able to deal with my first heart attack when I was in my 40’s. But when you get older, all the physical stuff just feels like more of a challenge. I’m feeling a bit tired of it all.

Also, I’m single, so I’m facing it all on my own. I’m unlikely to get a partner now. Dating is all very club oriented and going out to pubs and clubs is a challenge with hearing loss. And the apps, it’s all very sexualized, and my libido has gone now. So that doesn’t seem likely, which leaves me facing everything on my own. That’s okay when I am well, but it would be nice to have somebody there when I am ill. I know my family and friends would come running if I asked them, but I don’t like making a fuss and tend to make a joke out of things or downplay them. It’s what I’ve always done, but now, as I get older, it is all starting to feel a bit more difficult.

I think psychological services should be better. There are times when you are in crisis, and you have to wait in a queue, and you’ll be told your application might be seen in six months’ time which isn’t a lot of good when you are in crisis. There are some specific services available of course but they are only short-term as well. Just long enough to open a can of worms.

If you have any questions or concerns about HIV treatment and possible side effects, please speak to an HIV doctor, nurse or pharmacist.

For the future, I’m weighing up whether to return home to Belfast, to be closer to my extended family. I think if my next heart attack leaves me in a position of needing care, I’m better off there. I do know my HIV care won’t be as good there, but the benefit of being near family, and the cost of living, probably outweigh that. It would be a permanent move at this age, so it is a decision I am thinking carefully about. But if I’m going to do it I need to do it soon while I am still physically able to manage a move. These big questions come up as you get older.

I think there is too much emphasis now on HIV being just about taking one tablet a day, that it has basically gone away. It’s still very much there. That focus draws attention away from those of us that are longer-term positive and may not be coping as well as it looks from the outside. One tablet a day and have a happy long life, that’s overly utopian and simply not true for some of us.



THE IMPACT OF COVID-19

The *Fifty Over 50* interviews were conducted in the summer and autumn of 2021, not long after the end of the second period of national lockdown in response to the coronavirus pandemic. Therefore, it made sense to ask contributors about the impact of this on their lives.

A number of the group indicated that the pandemic and lockdown measures had not particularly impacted them in any way, in some cases indicating this was because of an already limited social life. Some people recorded enjoying the time or benefiting from the opportunity to work from home or engage with peer services for the first time via Zoom.

Other contributors told us how lockdown has had a negative effect and contributed to a sense of loneliness, for example:

“JUST STAYING AT HOME FOR SUCH LONG HOURS WAS DIFFICULT, IT WAS HARD NOT BEING ABLE TO GO TO SUPPORT GROUPS AND VOLUNTEER REGULARLY AS PEER SUPPORT. MY BLOOD SUGAR HAS BEEN A RECENT PROBLEM AND I BELIEVE IT’S DUE TO COMFORT EATING DURING THE LOCKDOWN. DURING THE COVID PANDEMIC (LOCKDOWN) LIFE WAS DIFFICULT, WITH PERIODS OF WATCHING TV FOR HOURS AND ZOOM” MEETINGS”

Estelle, 53

A number of contributors who are long-term survivors highlighted that the pandemic had impacted them in a different way, provoking reflections on their past experiences, for example:

“IT TRIGGERED A LOT OF MEMORIES OF THE EARLY YEARS OF HIV, AND THAT WAS UNEXPECTED. I HAD TO DEAL WITH A LOT OF EMOTIONS THAT CAME UP. THERE SEEMED TO BE TOO MANY PARALLELS IN THE EARLY STAGES OF IT.”

Emma, 52

“THE PANDEMIC IS SOMETHING THAT THE WHOLE WORLD WILL REMEMBER FOR THE REST OF OUR LIFE, IT HAS LITERALLY BROUGHT THE WORLD TO A STANDSTILL. DURING THE HEIGHT OF THE PANDEMIC, WE WERE ABLE TO LOOK DEEPLY WITHIN OURSELVES. IT GAVE THE WORLD A CHANCE TO MAYBE LOOK AT HOW PEOPLE ARE TREATED, SUCH AS RACE, SEXUALITY AND INEQUALITY THAT MOST MINORITIES FACE DAILY, WOMEN’S ISSUES AND HOW IT EFFECTS OUR DAILY LIFE’S. I CERTAINLY WILL NOT TAKE ANYTHING FOR GRANTED NOW. WHO KNOWS TOMORROW BRINGS?”

Mercy, 55

“MORE PEOPLE HAVE DIED IN JUST OVER A YEAR WITH COVID COMPARED TO THE 40 YEARS SINCE HIV APPEARED IN THE UK. AND YET LOOK AT THE WAY PEOPLE STILL TREAT US. LOOK AT THE WAY SO MANY PEOPLE DON’T GIVE A STUFF ABOUT COVID, THEY GO OUT, THEY DON’T MASK, THEY COUGH. THEY MAY HAVE IT AND THEY DON’T CARE. BUT LOOK AT THE WAY THAT THEY STILL STIGMATISE PEOPLE LIVING WITH HIV, THE FEAR THAT PEOPLE TODAY LIVING WITH HIV HAVE, THAT MAKES THEM FEEL THEY’RE NOT ALLOWED TO GO OUT. IT DOESN’T MAKE ME ANGRY SO MUCH AS ANNOYED AND DISAPPOINTED.”

Alan, 66



“But now that I am on the road to recovery. I know that I don’t want to kill myself, now I want to actually stick around for quite a long time. So, then you have to think about the future. That’s partly why I do the campaigning, to try and make things better for the future for me and for everyone else.”

Simon, 57



APPENDIX

Appendix 1

Contributors to the *Fifty Over 50* project were asked about the following topics.

Physical and mental health

- HIV health
- Experience of co-morbidities
- Experience of complications
- Side-effects of current treatment
- Side effects of previous treatments
- Ageing process
- Mental health issues
- Access to mental health services
- Engagement with HIV health services
- Engagement with primary care health services
- Coordination between health services

Quality of life

- Happiness and wellbeing
- Loneliness and social isolation
- Accessing of peer support networks
- Important relationships
- Sex and dating
- Family relationships
- Friendship networks
- Living circumstances
- Financial security
- Work and practical circumstances
- Stigma and self-stigma
- Experiences of prejudice
- Attitudes to disclosure

Looking back and looking forward

- Circumstances of diagnosis
- Changes in services
- Changes in public awareness
- Advent of U=U
- Changes in perception of HIV status
- Impact of past trauma
- Reflections on HIV journey
- Expectations of older age
- Consideration of future medical needs
- Consideration of future care needs
- Consideration of future social needs
- Hopes for the future

The impact of the coronavirus pandemic

- Practical impacts
- Emotional impacts

Female and BAME contributors were additionally asked about specific, additional challenges they face, and representation within the HIV community.

Contributors who have worked in HIV advocacy were also asked for their reflections and observations about growing older with HIV gained from that work rather than their own personal experience.



Appendix 2

Glossary

Please find below a list of acronyms you may have come across within the e-book and their definitions:

HIV – Human immunodeficiency virus

PrEP – Pre exposure prophylaxis

PEP – Post exposure prophylaxis

ART – Antiretroviral therapy

HepC – Hepatitis C

U=U – Undetectable = Untransmittable

HRT – Hormone replacement therapy

CBT – Cognitive behavioural therapy

ICU – Intensive care unit

ITP – Immune thrombocytopenic purpura

PCP – Pneumocystis pneumonia

DEXA – Dual energy X-ray absorptiometry

GP – General practitioner

PTSD – Post traumatic stress disorder

LGBT – Lesbian, gay, bisexual and transgender

ACKNOWLEDGEMENTS

We would like to thank each individual contributor who participated in the *Fifty Over 50* project for sharing their interviews. Every interview has helped us to gain deeper insights into the needs of people who are growing older with HIV. We hope that they will feel proud to have been part of a project in which the insights they provide will bring us one step closer to achieving the best possible care for every person living with HIV in the UK.

This project was made possible by the collaboration of the individual representatives of the patient advocacy and professional groups who are part of the Whole Person Care Partnership. They have been fundamental in shaping the project from start to finish, including determining the recommendations of what happens next. This is one of the biggest collaborative projects the HIV community has yet seen and it's exciting to see so many passionate people becoming part of this piece of HIV history.

About the Whole Person Care Partnership

The Whole Person Care Partnership is a collaboration between MSD UK and HIV advocacy, education, and scientific organisations, including Africa Advocacy Foundation, National Aids Trust (NAT), NAMaidsmap, Terrence Higgins Trust (THT), Positively UK, NAZ, the UK Community Advisory Board (UK-CAB), Sophia Forum, British Association of Sexual Health and HIV (BASHH) and British HIV Association (BHIVA). The partnership was formed in 2017 and its membership has grown since that time, it aims to communicate and support the needs of people living with HIV in the UK.

Media Enquiries

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