

HIV HAPPY

(Second Edition)

PAUL THORN

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DEDICATION

On July 17th 2014 my friend Glenn Thomas was killed when Malaysia Flight MH17 was shot down over Eastern Ukraine. He was among 298 passengers and crew who died. Glenn was traveling via Kuala Lumpur to Melbourne to attend the International AIDS Society 2014 Conference. This Second Edition of *HIV Happy* remains dedicated to his memory, as was the First. You can read my tribute to Glenn, published in the September 2014 edition of *GT (Gay Times)* magazine in Appendix A of this book.

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Most importantly, I want to thank readers of the First Edition of *HIV Happy* who took the time to write to me from all corners of this funny old world. You are truly inspirational.

PART I

1: INTRODUCING *HIV HAPPY* (AGAIN)

Welcome to this Second Edition of *HIV Happy*! It's been a very interesting time since the First Edition was published in July 2015. The book met with, on the whole, a very positive response; indeed, beyond my expectations. There were some great reviews, and the personal emails from readers all over the world made the hard work worthwhile. I'm truly glad that so many of you have found the book useful in your everyday lives.

As I said in the First Edition, "From the outset I want to convey to the reader my belief that it's possible for someone to co-exist with HIV, when on treatment, and to be happy in their own skin and satisfied with life. Secondly, I acknowledge that not everyone who reads this book will

be HIV-positive and gay. I can only write from my own experience, which is that of a gay man. While you may not identify with this, I would encourage you to read this book with an open mind, to take what you want from it and to leave the rest.”

Before I go on to address my motivation to publish a Second Edition of *HIV Happy* and for those who haven't actually read the First Edition, I should briefly explain how the book originally came to be written.

I've been HIV-positive for nearly 30 years. I was diagnosed in the “dark old days” before there was effective treatment to manage the condition. I've written for a long time about HIV and I've seen, and personally experienced, the evolution of living with the virus over a period of nearly three decades. In those early days I was very sick myself. Sadly, many of my friends, acquaintances and others I never knew didn't make it to these more positive days of treatment to manage the course of the virus.

Prior to the publication of the First Edition of *HIV Happy*, I'd written a column (in various forms) for nearly a decade about living with HIV for *GT (Gay Times)* magazine. The *HIV: Recipes for Life* column was published during 2014 and it was my intention then to try and present a new and different perspective of life with HIV, one which I felt had

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been neglected. The First Edition of *HIV Happy* was the next natural evolution of the column. I should at this juncture give a nod towards a health promotion campaign in both the UK and US that encouraged people to get tested for HIV under the slogan: “Take the test and take control”. This also played a part in my original inspiration. On the basis of this comment alone I couldn’t help but wonder at the time what was next for many in terms of “taking control”. As I’ve said repeatedly during the course of my writing career, there’s a lot more to being HIV-positive than just taking medication.

So, what’s different about this edition of the book from the previous one? I’ve learnt many lessons since the book first came out, some of them very hard, and although sometimes painful, they were ultimately worthwhile. This Second Edition expands on some of the original ideas presented, based on this new learning. I’ve also had the chance to reflect on feedback from readers who liked the book and, likewise, its critics. In this new introduction I shall attempt to address some of the latter.

Firstly, to provide clarity: a former English teacher used to joke that, “Clichés should be avoided like the plague”. As a writer, I don’t like using clichés, but in this instance I shall: Don’t judge a book by its cover. It’s evident

to me that I have to explain in more detail what being ‘HIV Happy’ actually means in the context of the book and what it doesn’t. One of the main criticisms made by a handful of people (who know of me personally) is that I don’t myself appear to be very happy! This leads me to guess pretty accurately when someone hasn’t actually read the book, or probably got beyond the front cover. Allow me to explain: there are two strands to the overall concept - *HIV Happy* is unashamedly about self-sufficiency. There will always be those who require the services provided by HIV organizations, but for those who base their identity purely on being HIV-positive, who wear HIV like a badge, who haven’t or will not adapt to the new future offered by effective treatment to manage the condition and who choose dependency, let me say that I believe this is doing a disservice to those who we have already lost to AIDS. We owe it to them to embrace the possibilities of a better future and get on with our lives.

That doesn’t mean walking around laughing your head off all of the time. The primary concept of being ‘HIV Happy’ means a willingness to CHOOSE to co-exist with the virus without letting it define you as a person, holding you back from life and your dreams and making you thoroughly miserable. It’s as simple as that.

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The secondary concept is that of happiness itself. Surprise! We human beings are not in a continual state of happiness – go figure! As life unfolds in front of us and throws up challenges, our mood state adjusts accordingly. It's OK to be unhappy sometimes, and it doesn't mean failure. Maybe it isn't comfortable or usually where we'd like to be, but it's a reflection of where we are in that given moment of time. Happiness is a GOAL which all human beings strive to achieve, and we can make appropriate CHOICES to facilitate a happier life if we WANT to. The primary purpose of this book is to help cultivate the emotional wellbeing of people living with HIV and help them to address self-stigma.

Secondly, I make no apologies to anyone for being a fallible human being or for trying to better myself and lead a happier life. As I said in the Introduction to the First Edition; "...my default state is not one of happiness, but it's something that I CHOOSE to work at". I'm by no means perfect and I've never professed to be. I'd love to be able to follow ALL of the principles that I've presented in this book ALL of the time. After the First Edition of *HIV Happy* was published my life certainly didn't get easier! Quite the opposite; I fell in love with someone completely inappropriate for me. I abandoned important commitments

I'd made. I also ran away to another country hoping for a fresh start, only to fall into the murky world of addiction. Shit happens! I too get lost in the trials and tribulations of life. Yet, when things got really tough I still turned to the methodology that I originally set out in this book to sort my life out. It enabled me to gain a different perspective and to make more sense of the world around me, to try and make better choices today and for tomorrow. And tried and tested, as usual it worked.

This book is about **living your life as an individual with HIV**. Certainly there's power in "community". If it were not for many brave people with the virus coming together as the "HIV community" decades ago we'd never have seen the great strides that were made towards the successful management of HIV we have today. However, I want to express my thoughts and add a few words of caution about the double-edged sword that is the "HIV community". Do we all get automatic membership to it on diagnosis with HIV, whether we like it or not? Does everyone with the virus need or want to be part of it? Potentially, can belonging to this 'collective' ultimately disempower us as individuals?

There's no 'one-size-fits-all' approach to living with HIV. Many of us have nothing more in common with each

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other than a positive HIV test result. The life path some of us want to take may be different from the standard ‘road-map’ offered by HIV services or what’s generally expected by the “HIV community” as a collective. I believe that there is room for all approaches to life with HIV, including the road less travelled for those of a mind to take it. No one should stand in the way of their efforts – instead, why not respect them?

I know that this book isn’t going to be for everyone, and that there will always be those who complain of being “left behind”. However, in my opinion, this is one of the dangers of considering ourselves, being HIV-positive, to be part of a larger ‘collective’ and a community that works like some sort of huge, social organism like a wobbling jelly fish. If everyone has to move together, or considers themselves having to be in the ‘same place’ because of the risk of possibly leaving some behind, then they are not allowing themselves as individuals to move forward and reach their full potential. We must never allow ourselves to be held back by the collective conscience of those who haven’t kept up with developments in HIV treatment and their deep-rooted, negative perceptions of themselves as HIV-positive individuals. That’s, however, their CHOICE, and should also be respected, but there should always be room to

consider new thinking and approaches to dealing with challenges, and the same is true of the fast-changing landscape and the reality of living with HIV today. Since the book was originally published in 2015, increasing attention has been paid to self-stigma and the emotional wellbeing of people living with HIV. It sometimes takes time to become accustomed to new ideas and start accepting them.

Having addressed some of the critical feedback to the First Edition I want to now look forward to the new content in the Second Edition. Originally I described “Five Pillars of HIV Happy”; a framework within which those living with HIV can navigate their way through life in the most simple, clearest, positive and productive way. Today, I perceive this as a slightly different model. It too is very simple, and this book will explain in detail how it works. There’s also a new chapter about HIV and ageing. Throughout the entire book I have reviewed and expanded on some of the original ideas presented.

Finally, I end this introduction to this Second Edition of *HIV Happy* as I concluded the First, with these words to the reader... “I encourage anyone who reads this book to do so with an open mind. You may not and probably will not agree with everything I’ve written here – it's only what

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has worked for me - but at the very least I hope it presents you with something thought-provoking, perhaps an opportunity, a catalyst for change, and maybe even a major transformation in the way you co-exist with the virus. Take control of it, and don't let it control you.

The cliché is that “Life is what you make it”. If it is, then I would like to add a caveat... that it's your choice whether or not you make it a good one.” (OK, I do use clichés sometimes – no one is perfect. ☺)

Paul Thorn, 2017

2: A VICTIM BY CHOICE

I was infected with HIV in 1988 when I was only 17 years old. I am 47 at the time of writing. I'm not sure who transmitted the virus to me and it's not really important. All I knew at the time I was infected is that I didn't care enough about myself to be concerned whether or not I contracted the virus. This is a very sad admission to make, but true. Writing this now, I'm struck by how things have changed for me. Today, I care about myself. Yes, I want to live and experience all that life has to offer me.

In the late 1980s, being diagnosed with HIV was perceived to be pretty much a death sentence. And for many it was. This a book about honesty, so here goes: I was an odd one - HIV liberated me. In a strange way, it enabled

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me to excuse myself from life and provided a reason (in my own mind) for my sad, screw-up of an existence. Now I could truly be a victim! The blood test proved it.

You may think of the “playing the victim” role as weak posturing, on first appraisal, but it's far from it; a lot can be gained in the short term. This apparently weak position is actually a subtle form of manipulation; it's about getting our own way, and there are some HIV-positive people who have perfected it to a near art-form! However, in the end playing the victim ultimately disempowers us, and if we do it often enough we start to believe our own propaganda. Our perception of reality changes and we truly do become the victim. The same can be said collectively of any tribe that comes together with this attitude, which looks outwards at those it perceives to be persecuting it as if it were a herd of gazelles being circled by a pride of lions.

Back to an individual perspective; in the early years after my initial HIV diagnosis I used having the virus as a means of being allowed to do, or sometimes not to do, things. I refused to meet my responsibilities to others and myself. I wouldn't work, I didn't care about managing my money and, well, I cringe when I think of some of my other behaviors. It was as if being HIV-positive was an ‘ace card’ that I could play to excuse myself from a variety of

situations. The craziest thing is that I got away with it most of the time. Whenever I played this ace card, particularly against people who weren't HIV-positive, they either felt genuinely sorry for me or they were too cautious about being non-politically correct to say or do anything. It gave me the advantage.

I can understand the newly-diagnosed initially going down the ace-card path; it's a natural reaction for many on finding out that they're HIV-positive. It can give us a breathing space to come to terms with our new circumstances. Yet there does come a point when it's time to throw away our armbands and swim for it. Not everyone with HIV does this; they have come to believe that living a happy life with HIV is unobtainable. They relinquish responsibility and, therefore, control.

In all fairness, I need to point out here that for some newly-diagnosed – and indeed some of those who have been diagnosed HIV-positive for a while – their perception of what it is to have the virus may be an old one. For many on treatment HIV is a manageable condition, yet if someone holds a dated view of HIV, one that harks back to the dark days of the pre-anti-retroviral era when a large number of people were ill and dying, then it's very understandable that this will affect their thinking about

what it means to be HIV-positive today and what the future may hold. It would be easy to take on the role of the victim. It should, however, become apparent over time to anyone on treatment that their old perception is not a valid one. There is a future for people who are diagnosed HIV-positive and on treatment. To refuse to accept this is a cop-out... and a choice.

At this juncture, I need to make something very clear.

The reality is this: being HIV-positive does not exempt anyone from living, from working or from paying the bills. It would be all too easy to just say, “I can’t do that – I’m HIV-positive”. I’ve done it before and found myself in a position where nothing seemed possible. It was not a good place to be at all.

If I can get one idea in this book across to the reader above all others, it is this one: being HIV-positive doesn’t mean you are a victim. A victim is something some people choose to be or not.

It’s easy to understand why victimhood has become the most sought-after political status in the United Kingdom today – it brings with it many advantages. The ace-card tactic is not used only by those who are HIV-positive; the

same goes for many groups who might describe themselves as minorities. On many occasions this approach to life and playing the victim has given me the edge over my non-gay, HIV-negative fellow human beings. This tactic has not been fair of me and I regret using it so much in my earlier years with HIV. It was just the easier road to go down. Equality, diversity, mutual tolerance and acceptance of others are noble causes to fight for, but once gained they're easily abused by those seeking an advantage.

Challenge someone playing the ace card? No way! It seems to me that we've become a nation of people treading on eggshells because of political correctness and for fear of upsetting anyone. Playing the victim has become a perverse way of demanding capitulation from others. Anti-discrimination legislation was never meant to be twisted in this way; it was supposed to promote equality, but things have now gone so far that current political correctness isn't conducive to creating the free, fair society it was meant to. In a funny way, it's gone full circle and those who hold an ace card have a very good hand indeed.

Where did playing my hand lead me? One of my biggest regrets is that I spent my 20s, what should have been perhaps the best years of my life, preparing myself mentally for death. Here I am in my late-40s and I look

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back on that young man, wondering how I got through it. At the same time I feel sad that what should have been my best years were wasted through being fearful of what the next day held.

The first indication that something was wrong with my immune system was when I went to see a dentist for a routine appointment and she discovered white patches in my throat. It was oral candida, or oral thrush, which is a very common opportunistic infection in the early stages of undiagnosed HIV infection. She told me that I should see a doctor and perhaps have an HIV test. I ignored her and tried to erase the possibility from my mind. When I finally did pluck up the courage to have an HIV test it took me another 18 months to go back for the result itself.

I chose to finally go and get the result of my HIV test after meeting someone who was very ill, dying because of an AIDS-related illness. I went to see him in the hospital and was so impressed by his courage that it made me want to know my own HIV test result. If he could have such a positive attitude in the face of defeat by the virus, then perhaps I could also?

I went back to the clinic, and the receptionist found my file immediately on a shelf at the back of the room. I found this curious at the time because it had been so long

since I had been there, and I thought that perhaps it would have been filed somewhere deep in the bowels of the hospital. This should have been an indication of what was to come.

Eventually, the doctor called me into his room and asked me why I had come to the clinic. I told him it was for the results of my HIV test and he gave me the result that I had been so frightened of. What he said to me next stays with me now: “You are so young”. He asked me what I was going to do next. I told him I was going to have a large drink. That is exactly what my scared 19-year-old self did; I had a large brandy, and a few more, and I don’t remember much of what happened after that.

At the time I was diagnosed I was a student nurse and about halfway through my general nurse training. I went to Occupational Health to tell them the news, and with that I lit the fuse that was to end my nursing career before it had even started. To cut the story short, it ended with me living in a bedsit with a mattress on the floor and not much else.

I think back to that young man and now feel compassion for my youthful self. I remember the fearful nights when I hadn’t been able to pay my bills and sat in the dark with no heating. I remember the Christmases alone, thinking of my family being all together while I lay on my

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mattress, the bed my father had told me I had made and that I must lie in. I remember trying to live off of bread that was so stale it could only be toasted and the breakfast cereal that I ate from the box because the milk had turned sour. The only peace I seemed to get was when I took sleeping tablets, hoping that I wouldn't wake up. I remember thinking about how nice it would be to be dead and sleep forever. These things I can't and don't want to forget, because it reminds me that today I am a survivor and how far I have come.

After the initial shock of diagnosis, fear itself was my biggest enemy. I was grateful for every drink I drank, every cigarette I smoked and every dreadful person who would have sex with me, just so I could have the feeling of being cared for and held afterwards, even if it were for an hour or two or, if I was lucky, the whole night. It kept me alive. Sometimes my 'bed guest' would leave a little money on the bedside table or go out and buy some food for me. I existed in a hellish, drunken limbo and I could see no future.

I made some very foolish, unhealthy and wrong choices in my early years of living with HIV. I took many risks that most sane people wouldn't have. I would sometimes think, "What the hell, I'll take a risk... I'm going to die anyway!" My risk-taking led to using more than my

fair share of drugs. There were many times when I really didn't care if I woke up or not, though my biggest problem taking all these drugs was that I couldn't get to sleep in the first place.

I took drugs and drank alcohol to reinforce what little confidence was there. The upshot was that I seemed able to do things when I did drugs and drank and seemed unable to do anything when I didn't. In later years I was to learn that this wasn't the way forward and that I had to find my own inner strength without the aid of a chemical cocktail, but at the time they served a purpose and without them I don't know if I could have gotten through those early years.

Why am I telling you all of this? Primarily to illustrate that I haven't come from a happy place. And my childhood before I became HIV-positive wasn't a happy one, either. I see little constructive point in going into any of the gory details here. So I won't. The point is that for nearly two decades I thought – wrongly – that I was a victim of circumstance, bad luck, of misfortune and of other people's actions. None of it seemed to me to be my fault.

The truth: my life was (and is today) a result of my own choices and decisions and, more importantly, how they translated into my actions. The reality: my

choices and actions fashioned my past life, and likewise I can make a whole lot of new choices and take appropriate action to change my life today, tomorrow and beyond.

So, how do we create the right environment for change and, more importantly, the right mind-set to be able to accept new opportunities for change as they present themselves? The method offered in this book for living with HIV is a very simple one that I've developed over the years and applied to myself whenever I've wanted to find direction, to take control and change things for the better. You might be asking yourself, does this work? I can assure you that for me it has.

Fast-forward from the mattress on the bedsit floor to today: I'm an award-nominated writer and I've written several books. I've travelled the world to places that I never dreamt I'd go, working as a freelance advocacy and communication consultant. I live in a nice home by the sea and I have my health back. I've effectively re-invented myself and my life. (I'm also doing well, one-day-at-a-time in terms of my recovery from addiction.) Today, I'm more like the person who, as a child, I used to imagine I would eventually become. When I look back on that frightened

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young man and what he did to himself after he found out he was HIV-positive, it feels like I'm looking back on the life of someone else, not my own history. I'm not a victim anymore. Healthy and free from fear of the virus, I'm looking forward to a brighter future. Why? Because I made a conscious CHOICE to do so.

3: THE CHOICE TO CHANGE

Maybe there is no need to change anything in your life. Maybe you're happy with it just the way it is. I don't think anyone who is HIV-positive would read this book out of curiosity alone; they'd read it because they desired change in their life, desired something happier and more fulfilling. Perhaps I'm wrong – if you think so, to you I say there's always room for improvement. You might already have a good idea of where you want to be and what needs to change in your life for you to get there – and having a direction for yourself is a very good start. Indeed, you're halfway there already. But what if we really have no plan for ourselves or attaining the future we want seems an impossible dream? A lot of people who are HIV-positive

feel stuck in a rut, especially if they've had the virus for a long time. For everyone, at the very least there's always something that could be a bit better. We human beings can get trapped in the monotony of routine and just accept it. For some reason, there comes a point where we seem to settle for what we have instead of trying to go the extra mile to get what we really need and want. That's the saddest thing, when someone gets that second chance and future offered by anti-retroviral treatment and they don't grasp it with both hands and attempt to make a difference in their lives. It's as if they've become too tired to try.

To ignite change and take control we need to make a conscious decision to do just that, to make a choice and then put in the effort to make that change. It's no good only thinking about it – and it isn't all just about putting in the footwork. It's a combination of the two. Once we make the choice to change we must nurture it and take responsibility for it. The best place to start, if you haven't already, is to take responsibility for where you are in your life right now. It will provide you with a baseline.

Time for some tough love: I am HIV-positive and have been for a long time, so I can get away with saying what others may be too afraid to say. It's all about responsibility; there is no point in apportioning blame to a

particular person for your own HIV-positive status – that’s a fruitless exercise, and little can ever come of it. I acknowledge that people can become infected with HIV in a variety of ways. There are no innocent or guilty ‘victims’, no-one deserves to have the virus, but if you put yourself, like I did, in a situation where you were infected with HIV, then own it. However difficult this is, you need to accept it to be able to move forwards. The ‘blame game’ only holds you back. Some do this quickly, others take time, and some never can forgive the other person, or themselves, for becoming HIV-positive.

Another truth: what's happened has happened and your HIV-positive status can't be undone or changed. What CAN be changed is what happens in the future – if you take responsibility for it.

Everyone, at some time or other wants change in their life - the texture of it would get boring if we never changed what we did for a living or the place where we work, where we live and how we live. Change could be about the things we spend our money on, the exercise we do (or really ought to do!). It could even be about the friends we have and the people we associate with, or, if we’re in a relationship,

possibly the person with whom we're in that relationship. Changing your life for something better can be achieved if you take responsibility for the control of it and put the effort in – but it can sometimes take time and longer than we are prepared to wait. It can be very easy to just stay with what's familiar and settle for second best, especially if the change that we want is a long-term goal and seems, on first appearances, to be out of our reach.

How do we create change? By making a conscious choice to change and then putting the effort in to instigate change. We need personally to take responsibility for this change and for the choice itself. We also need to take responsibility for where we are in our lives now before we can progress forward.

As I explained in the previous chapter, for years I took no responsibility for what happened in my life. Was it purely just the random bad luck I've had in my life that put me in the situations in which I found myself? No! They were my own choices, my own actions and my own decisions. I must take a good deal of the responsibility for what my life, my health, my relationships, my home, my work and my finances were in the past and what and where they are

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today. Just as the choices I made modelled and fashioned my life in the past, so I can also change things NOW, the choices I make for today, tomorrow and the future. I can choose for my life to continue how it is, or I can make a choice to TRY and change it – at the very least, for it to go in the general direction in which I'd like it to be going, and to always be OPEN to new possibilities and any opportunities that may present themselves. If I'm closed to change, then those possibilities and opportunities will, in all likelihood, pass me by.

Some of you reading this may be frightened. But it's fear, real or imagined, that can prevent you from making a choice to change something. You may prefer to stay with the familiarity of the past poor choices you've made. Better the devil you know, right? Definitely not! Everything in life changes, nothing stays the same. Anyone's life, irrespective of their HIV status, is a sequence of losses and gains that have brought them to the present point. As well as fear of the consequences of the choices we make, there is also the fear of commitment to a choice once it has been made. It's fear of the risk involved in any given choice, rather than the actual choice itself, that may prevent us from making that choice and seeing it through. We can choose out of fear not to make a choice, but in doing so we ARE making a choice,

a choice for inaction, a preference for what's familiar, however uncomfortable and unhappy our lives may be, because of what we already know. Fear stops us from taking control.

We are a product of all the choices we've made throughout our lives. That includes the way we behave and think, including allowing fear to dictate choice for inaction. Taking responsibility for the past, and for where we find ourselves today, takes humility. To look closely at your life and to admit to yourself that you're entirely or partly responsible for where you are can be ego-deflating if the place in which you find yourself isn't a good one. Yet this is the first step in any sort of change. Reality check, please! Yes, it's a reality check, a turning point that provides us with a baseline against which to measure future progress, a launch-pad where we can say to ourselves, "I AM capable of change," and then make the CHOICE to try to do things differently from here on. We CHOOSE to find direction for ourselves. We CHOOSE to TAKE CONTROL, to OWN our future and take RESPONSIBILITY for it.

4: EVERY GRAY HAIR IS A GIFT

Time is the great equalizer. Everyone is subject to it, whoever they are, however powerful, wealthy, beautiful and talented they are – and whether or not they are HIV-positive. Time is also the one thing that can't be forced or recreated in a laboratory. All of us on treatment and doing well could live near or even normal life spans. It's a new frontier for people living with HIV, and frankly we have to wing it! However, two things are for certain:

- 1) Ageing is a natural process for all of us, and we all, irrespective of our HIV status, have no choice but to go with it.
- 2) We're all going to die in the end.

There isn't a lot we can do about the latter, but we can do something about how we choose to deal with ageing itself.

Throughout Part I of this book, I've stressed the importance of choice. On first inspection, as a concept it looks easy, but the reality may be quite different. Let's examine some of the common issues and thinking that people living with HIV may face and the impact of these on their lives as they grow older with HIV.

Firstly, it's useful to look at the long-term diagnosed, from the point of view of those who found out they were HIV-positive before anti-retroviral therapy (ART) became available in the late 1990s, and from the point of view of those diagnosed after. It's highly probable that the perspectives of these two groups are going to be quite different.

Diagnosed before the late 1990s and Anti-Retroviral Therapy (ART)

The majority of people diagnosed before the late 1990s have had a much more challenging time than those diagnosed afterwards. (I acknowledge that this is a controversial statement to make that will be disputed by some.) This group are often termed as "long-term

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survivors” who watched helplessly as partners, countless friends and acquaintances succumbed to the virus. Meanwhile, they were forced to contemplate their own mortality, sometimes at a very tender age. Never far from their minds the thought: whose turn is it next to die?

Indeed, many of these long-term survivors are today traumatized from their experience of HIV and have sustained deep emotional damage – some still live in a perpetual state of grief. Perhaps some of these people were strangely comforted by the possibility that ageing wasn’t an issue they would have to deal with. (I know that I personally drew small comfort from it.)

We prepared ourselves for what then seemed inevitable... then they told us that they had found medication that could manage the course of the virus. Hey, we could even live to a ripe old age! You’d think we would all be doing a celebratory jig, but the reality was quite different. Many were plunged into mental and emotional chaos. Some even chose not to take the medication that could have saved their lives. Being told that we were very possibly going to live, and coming to terms with that, was almost as much of a shock as being told we were likely to die.

Some had participated in drug trials that had caused

permanent damage to their bodies. Many still live today with the ravages of experimental treatment and the consequences. Maybe because of past opportunistic infections they have permanent disabilities, have lost their sight, and/ or have aged long before their time. Life isn't going to be easy for these people. For them, reading a book like this is going to seem glib. There are others who fared better and managed to scrape through the "dark old days" somehow. Yet all of us who experienced the horror that was AIDS before treatment are going to be permanently affected in some way, even if only on an emotional level. Undoubtedly, there's going to be some 'baggage'; potentially, there may be guilt that "we survived when so many others were snuffed out in their prime", there may be confusion and fear over a future that we thought we would never have to grow older and contend with. Those who think like this will potentially need on-going support throughout their lives.

Diagnosed HIV-positive after the late 1990s and Anti-Retroviral Therapy (ART)

I'm sticking my head above the parapet again: for those diagnosed since effective treatment to manage the virus became available in the mid-to-late 1990s, has being HIV-

positive carried the same kind of trauma as before? Maybe, maybe not, but the reality is that being diagnosed HIV-positive today still jolts lives onto seemingly unknown trajectories of fear for what the future may hold. The big difference is that people diagnosed HIV-positive today can be offered treatment to arrest the course of the virus. The situation today is clearly very different from two decades ago. Today, the very newly-diagnosed walk a path that has already been paved for them.

HIV and Ageing

Both the pre- and post-ART groups of people living with HIV are going to face the usual challenges people face when ageing, irrespective of HIV status. For example, the normal illnesses associated with later life, and other factors such as feeling lonely and isolated, our ability to care for ourselves, living independently etc. They may also encounter other health implications brought about by treatment. Put simply, ART means that people with HIV who take the treatment can and will remain healthier than if they are untreated into old age. That's not to say that we completely know the long-term effects on the body of ART over time. There's evidence to suggest that some on treatment will be also challenged at an earlier age by health

problems commonly associated with ageing – for example, heart disease, issues with bones and joints etc. We continue to learn about the long-term effects of treatment as time progresses.

Like it or not, irrespective of how long you've been diagnosed with the HIV, you need to consider how you're going to meet your needs as you get older, just like everyone else. In the UK, the State welfare system treats those living with the virus no differently from those who live without the virus. People living with HIV are expected to jump through the same hoops as everyone else to get sickness and disability benefits. There's no convincing argument why people living with HIV should be treated any differently when they do well on treatment. If we want a world without HIV stigma, why should they? When it comes to State benefits, it's a much more level playing field than it has ever been. There's no room for any sense of entitlement just for being HIV-positive. What many of us will have to look forward to (for those who are not over retirement age already) is, like everyone else, a State pension. The first question is, what are we going to do until that time? Clearly everyone living with HIV and doing well on treatment needs to have a life plan. The next big question is how do we do this?

PART II

5: THE WHEEL OF HIV HAPPY

Life isn't completely random – at least, I've come to believe that it isn't. Without direction and a plan for the future you're going to need a big dollop of luck for everything to fall into place and work out the way you want it to. Less than a couple of decades ago it may have seemed a pointless exercise for someone who is HIV-positive to plan too far into the future, because (and, indeed, sadly true for many without effective treatment to manage HIV) there just didn't seem to be a future on offer. Today, it's a completely different story; most HIV-positive people who have opted to be on treatment are grasping the future with both hands and making plans for it.

You may have heard the question during a job

interview, “Where do you want to be in five years’ time?” For a lot of us HIV-positive people, the answer to that question may once simply have been, “Still alive, I hope!” Personally, I find deciding where I want to be five years ahead is a little too far off to think about. I like seeing quick results from the effort I put into things. I’m a ‘quick-fix’ kind of guy! I may be a bit vague on the “five years from now” question, but I have a clearer idea of the near-future – today, this week, this month, the next three months, and a year ahead.

I’m a big fan of making lists. In fact, I have several notebooks in my bag right now. It’s a source of mirth for some of my friends to see me pull one out, mid-conversation, and start to make a few notes. The notebooks and other ‘scribblings’ I carry around provide a sort of roadmap for the near- and not-so-distant future. It is the way that I feel that I have some control over the direction in which I’m going.

I have a simple method for assessing where I am at now and how I find the direction in which I want to go. I want to share that with you later, but before we go into any depth on method, the reader needs to look at some fundamentals and concepts.

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In the First Edition of *HIV Happy* I described “the five pillars” of ‘HIV Happy’. These were stand-alone categories that could apply to anyone, irrespective of where they are in terms of their journey with HIV, or indeed their HIV status itself. However, my thinking since the original version of the book came out has developed further. Allow me to share this with you: I now see what were “the five pillars” as a ‘wheel’, or what I call, “The Wheel of ‘HIV Happy’”. I describe it as wheel as it’s the easiest way to understand how the concept works. At the center of the wheel, the axis, is the most important concept, without which everything else can become very unmanageable. The center of the wheel is the core concept of what I call ‘Health and Self’.

Health and Self

The ‘Health and Self’ category covers a wide spectrum of things. The beauty of this core category is that it encapsulates many topics that are relevant to ourselves. Not only does it cover physical, mental and emotional health, but it also covers potential addiction problems (in my case, my personal recovery from addiction is a core element), self-esteem and self-worth issues, adherence to treatment and the like.

Everything else relies on the integrity of this core, or axis. The other categories, or ‘spokes’ of ‘the wheel’, that anyone should be able to break their life down into for examination and to work on are:-

“Relationships”

“Home”

“Fun”

“Work”

“Finances”

I list each of the above categories in order of importance to me – by this, I mean in terms of the areas of my life which need most attention. When I first started working with this method it was difficult to put things into any priority order because *everything* seemed to be a pressing issue and needed work. Things were a bit of a mess! It felt quite overwhelming! I suggest that you don’t get too hung up on trying to get things in the exact order – but there is one exception. It makes sense to me to say that the most important aspect of anyone’s life has to be health and the way we feel about ourselves. It should always be the priority, irrespective of which other areas of our lives need attention. Addressing self-stigma and negativity is also

central. If our perception of who we are and what it means to be HIV-positive, consciously or unconsciously, doesn't come from a good place then this can hinder our efforts to improve other areas of our lives.

I find that most aspects of my life fall loosely into the other categories that revolve around the core element of 'Health and Self'. I'm going to describe briefly what each category, for me, is about, then go into more detail on working with each of them in the next chapters. Later, we'll be working with what you've learnt and putting the method into practice.

Relationships

For myself and many others, the next priority to 'Health and Self' are the Relationships that we have with others. Again, this is a broader category than it first appears, because it includes *every* relationship we have, good or bad, positive or negative, from our relationship with ourselves to those with partners (if you have one), friends, to those who could be termed as acquaintances and to those who have a negative impact on our self-esteem and wellbeing and need to be kept at arm's length.

Home

Everyone needs to have a home. Wherever we live, it's probable that we can improve our environment and surroundings. What needs to be done in your home? Housework? Decorating? But there are issues at home that could be more complex – for example, living with an unbearable room-mate or having problems with others with whom we share our home. These matters may be more tricky than keeping up with the housework or painting a wall, but they are still ‘Home’ issues, so this is a broader category than it first appears.

Fun

All too often we prioritize things in our lives that we consider to be most important, to the exclusion of enjoying ourselves. I’m guilty of this, to the point where I completely omitted this important part of life from the First Edition of this book! It’s time to rectify this and talk about having fun.

If your focus is merely surviving, then having fun probably isn’t going to feature very highly. Today, with treatment, we are not only surviving, we also have the prospect of living potentially long and healthy lives.

Many years ago, the term “living with HIV” was coined. People with the virus didn’t want to be described as

“suffering” or defined as being an “HIV or AIDS victim”, mainly because of the disempowering connotations of the terms. Now, for those fortunate enough to maintain adherence to medication and who continue to do well on it, we truly can “live” and have fun... if we CHOOSE to.

Of all of the categories I’m describing here, this is sadly the one that I have least experience of. This is probably (next to ‘Finances’) the one I need to work hardest at. On reflection, when I started thinking about the sort of fun I had, it consisted of going to the pub and drinking (got me into big trouble), anonymous sexual liaisons (even bigger trouble), watching my favorite films (again and again), shopping, eating food that isn’t good for me and sleeping. Looking back on this list, I sound like a bit of a slob! Maybe I am? That’s OK, too! However, I’m increasingly aware that there’s more to life than the activities I’ve listed – for the most part, they’d stopped being fun for me, and in some cases had threatened my health and wellbeing.

Work

The ‘Work’ category is not exclusive to paid employment. Whilst I’m an advocate of those living with HIV and doing well on treatment looking actively for and being engaged in

work, I've already acknowledged that not everyone is going to be well enough to be in full or part-time employment. Also, some may already be of retirement age and there's an increasing number of people ageing with HIV. However, this particular category, like the others, is also very broad. It can include any voluntary work, education or study, setting up a small business or actively looking for or making plans to get back to work eventually.

If you can't work in the ways mentioned here, then work towards improving your health and getting physically and mentally fit enough to give some energy to doing so. This category applies to everyone, irrespective of whether they are in some kind of work or not. We can all work towards a goal.

Finances

Groan! The 'Finances' category is the one I've struggled most with. I've never been very good with money; I am stupidly generous and sometimes accidentally give away what I need. I seem to have a problem understanding the value of money and the role it plays in my life, forever paying bills and coping with debt! This category covers which bills need to be paid first, debt repayments, savings (if I have anything left) etc. At the very least, even if I don't manage to pay my

bills in any given month, I do have a realistic idea of where I am financially. Although at times this has been difficult to acknowledge – and something I would prefer to ignore – it is in the spirit of responsibility and being in control. I do this not for my creditors, but for me.

Summary

I have provided a brief definition of each aspect of “The Wheel of ‘HIV Happy’”. No two people are the same, so each of these categories is going to mean different things to different people. I mentioned in Chapter 1 that I can only write from my own experience, but I’ve been around the block a few times in terms of HIV and met a lot of other people with the virus along the way. There’s always something new to learn, especially from others with different experiences of living with HIV. Again, there’s no “one-size-fits-all” solution. To help the reader to identify how the categories apply to them, I propose we now look at each of them in more depth, to provoke some thought and consideration that will be useful when it comes to using the method described later in the book. More than that, I want to challenge some old thinking common to many people living with HIV, and perhaps assist the reader to see the world from a new perspective.

6: HEALTH AND SELF

This is the most important element of “The Wheel of ‘HIV Happy’”. It’s the central point around which everything else revolves. Everyone wants to be in good health. If we are HIV-positive then we need to work a bit harder at it, and there are certain things we must do to remain healthy in the physical, mental and emotional senses.

A confession: when I started writing this book I didn't want it to turn into a manual on diet and exercise. I hate those books – they are the worst! They just state the damn obvious, and trying to apply their advice to your life feels ‘so uphill’ that it's easy just to give up. I'm not going to promise anyone a six-pack in as many weeks! If your body is a temple, if your diet is fantastic and your idea of fun is

going to the gym, then I salute you.

I am the first one to hold my hands up: I'm not what would be termed as fit. I'm a pot-bellied 40-something. I like an English fried breakfast (bacon, sausages, fried egg, the works) occasionally on a weekend morning. I smoke – too much – and if I even think of exercise, then I have to sit down for 10 minutes! I rarely run for anything, unless I'm going to miss a train. Get the picture?

If I were to advise you on your diet and exercise then I would be a complete hypocrite. What I do want to offer is a book that's written for everyone, not just people who are or who have a desire to be super-healthy. Just everyday people, like you and me.

There is, however, one thing that's core to the health of EVERYONE who is HIV-positive. There comes a time when it's necessary that someone with the virus is going to need to go onto treatment, and your doctor will usually advise when the time is right to start taking the meds. If you don't take your tablets at all, or only chaotically, then, I'm sorry, but you may have a really rough ride of it, and not in a good direction. There's no need for this to happen... if you take your meds. It's very important that someone on treatment for HIV infection takes all the meds when they're supposed to be taken. Period. It's the only thing that needs

to be done one 100%. Anything else is ‘work in progress’.

Not everyone finds this easy, myself included. I'm only human, and on occasion I forget to take my tablets. I try not to beat myself up when it happens, I just try to do better next time. Surprisingly, adherence for me can be harder work when I feel healthy. Part of the problem is that I feel REALLY well. Gone are the days when I felt so tired I couldn't get out of bed. I lead a very full life and have a good amount of energy for the things I need and want to do. When I felt ill, I had no problem at all remembering to take my meds; my fatigue was the reminder. Yet, not feeling lousy means the factor motivating me to take them is no longer there. It's when I feel really well that I need to ensure I'm vigilant and stay on track with my medication regimen.

I've tried a number of memory-joggers – novelty beeping pillboxes, putting signs up on kitchen cupboards – but the best method I've found so far is to put them by the kettle. When I make a hot drink in the morning, there they are. That's the plan, but that also doesn't always work, either, so I have a backup: a supply of meds in my desk drawer at work, just in case I forget in the morning and then remember later. Of course I know how important it is to take the medication that keeps my viral load undetectable. I also know that if my tablet-taking is irregular

there's a risk of developing resistance, and then the drugs won't be as effective. It's taking them that keeps me uninfected and healthy. I'm not stupid, just a bit disorganized and forgetful sometimes. I can easily feel guilty. There are people in the world who desperately need this kind of treatment and can't get it, but I can just go to the doctor and get given three months' supply. I could really beat myself up about this issue – and no doubt some of you reading this are tut-tutting and 'C'mon, bro'-ing – but that's really not the issue. What's important is how to get back in control of adherence to your regimen when things go wack.

Firstly, I reassure myself that all I can do is my best. If I know I've done my best to remember, then I can't be too down on myself. Secondly, I embark on really getting to grips with re-establishing my routine. I've found it most easy to take my meds when I've been going out with someone else who's also HIV-positive. Maybe it's because of a shared experience with someone close to me and being able to relate to it that helps. When I'm not involved with someone, then I must turn to my friends. I always choose someone I trust and who isn't going to tell me off, but just gently remind me. There's no shame in doing this. No one should die because of their pride.

Side effects of HIV treatment are an issue for some people. Most of us, however, find that any side effects settle down after about the first month or six weeks of taking the meds. It's a question of perseverance while your body adjusts to treatment. If you experience side effects from treatment, then it's very important you discuss this with your treating physician because there could be other combinations of treatment available to you that are more tolerable. There are often additional medications that can be taken to counter side effects, or other strategies for dealing with them. For me, the only side effect I'm blighted with is diarrhea. It is not nice to have to run to the can, and there have been times when I've had accidents that have upset me greatly. If this is a side effect that you also experience, then in addition to any medication to counter this problem (and/or strategies), ensure you carry spare underwear in your bag and anything else you may need to clean up. Horrible, I know, but if you can't get to a toilet in time and you're out and about this can be a life-saver. What I am saying is, be prepared if you need to be.

I spoke earlier about how in my early days I didn't care enough about myself to be concerned about the risk of contracting HIV. Poor self-esteem is certainly a factor in HIV transmission, but this is not always the case, and there

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are many people who have very good self-esteem who become infected. It is not a prerequisite, by any means. Either way, discovering that you are HIV-positive is at least initially going to have an impact on how you view yourself (self-stigma), while others know it can also affect the way they will view you, possibly in a negative way. As if we don't have enough to deal with without having to navigate the prejudices of the ignorant and misinformed!

Sometimes, concerns about how others, including close friends and family, would treat us if they discovered that we're HIV-positive has prevented many people from having an HIV test in the first place. Sadly, when some of these people do finally discover that they are HIV-positive, they're already ill. When this used to happen in the pre-ART days they often died. Today, even when someone presents very ill with HIV there is a lot that can be done to turn the situation around. Treatment today is so good that it provides individuals with the chance to take control (if they choose to). They used to say of HIV that "Ignorance = Death". The same is true today, but for different reasons. Ignorance about safer sex is what was meant in the past; today, ignorance of one's own HIV status could potentially equal death.

Stigma has the potential to kill. If we already have poor

self-esteem, then not only can it be a factor in our becoming HIV-positive in the first place, but it may also affect our decision whether or not to be tested and, if necessary, seek treatment. Our level of self-esteem is going to have an impact on how we view ourselves and influence our day-to-day lives. If we don't think we're worth making the effort for, then how in heck are we ever going to make the choice to change our lives for something better? What if, on some deep level, we don't think we deserve happiness? This kind of thinking, alongside poor self-esteem, is one of the biggest factors that holds HIV-positive people back from getting on. I know – I've been there.

There is still stigma around HIV. We can be our own worst enemies when we internalize it and consciously or sub-consciously turn the guns on ourselves. We sometimes punish ourselves with such thinking, or believe that we at least deserve to be punished. This skewed thinking has to be sorted out before there can be any progression into a brighter new future. Poor self-esteem and self-stigmatizing voices in the back of our heads that tell us we're not worth it are the most undermining aspect of trying to move forward. Speaking from experience, if you really can't find it in yourself to believe you are worth the kind of life you

want... then fake it to make it! Tell yourself something often enough, like choosing to believe you're a victim, say, and it will become the tangible reality.

The premise is simple: if you want to build your self-esteem then do 'self-estimable' things! For example, be kind to yourself (very important), take your HIV medication (even more important), try and eat well, treat yourself to something nice at least once a day, do seemingly insignificant but productive things at home, such as cleaning out a drawer or have a clear-out of clothes you don't wear anymore. Most importantly, allow yourself time to daydream. It isn't something wrong or pointless, as our tutors would tell us in the classroom – quite the opposite, because it serves a function. It is the time when on a deeper level we can find clarity about what we really want out of life.

Even if you don't think you are capable of making sweeping changes to your life, then see it as making tiny refinements and adjustments to what you already have. These refinements build up over time to become a bigger kind of change. Try and 'refine' something once a day. Big change starts with the seemingly small things we can do on a daily basis.

If you start to question why you're doing such seemingly small things, then I say to you that none of us knows what's around the corner. See the small refinements you're making as being about preparing the ground to ensure that when an opportunity for making a big change does come along everything is set for it to take root. It's a bit like tending to and weeding a garden; nothing good can grow on stony ground.

A high proportion of people who are HIV-positive not only have poor self-esteem, but also sometimes have additional emotional and mental health problems. I said that I would be as honest as I could be in this book: at the time of writing I have been, for sometime, in recovery for addiction to alcohol, and I want to assure readers who are in the same boat and who may have other emotional or mental-health problems, that being happy and in control and co-existing with the virus is still possible – if we are willing to address such problems with vigor.

Those of us with mental health issues have the additional burden of coping with the stigma that exists around this. It isn't always easy; I can't help thinking of a handful of people who also are living with HIV yet who have been very cruel when I have clearly not been emotionally well. It illustrates that even those in the exact

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same situation have the potential to damage us if so inclined. Our peers, or others who are also HIV-positive, are sometimes our harshest critics, and we're not immune to being prejudiced ourselves and capable of stigmatizing others. We're potentially subject to the same kind of thinking as everyone else.

If you have mental-health and/ or addiction issues then ensure you're hooked into the appropriate services. I say this only because my adherence to HIV treatment has suffered when my mental health has declined. For me, the two are connected. See what I said at the beginning of this book? Happiness is not my default state, and now you know why I have to work at it! Being 'HIV Happy' is not a luxury, it's a necessity. I've learnt that I can quickly spiral downwards if I'm not feeling good about myself or if I'm feeling depressed. My physical, mental and emotional health are intrinsically linked, and all require effort to maintain.

Now you have come to the end of this chapter about 'Health and Self', I hope that it makes sense why I've linked adherence to treatment with self-esteem. It is at the center of everything, it's also a very broad category, and no two people are the same. Everyone's level of health and self-esteem is going to be different and to fluctuate. I wanted to show readers who might think that their case is 'too

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complex' for the method presented later in this book that this is not case. I contend with life with HIV and my recovery from addiction on a daily basis. I experience stigma and ignorance, even from others who themselves are HIV-positive, and yet I can still work with this method to be 'HIV Happy'. And I'm sure that whatever your situation, you can too – if you have the WILLINGNESS to try.

7: RELATIONSHIPS

As I have discussed in the previous chapter, poor self-esteem issues are common for many HIV-positive people. I've also mentioned that, in part, my level of self-esteem was one of the reasons that over two decades ago I became HIV-positive in the first place. I try and look back on my younger self with kindness, and today I have a much better self-image and fiercely protect it. I have a small core group of friends who genuinely care about me. In any walk of life there are going to be unpleasant people. Some people can be cruel, just for the hell of it. Having the friendship of a few good quality people who genuinely care about you is essential if you are HIV-positive.

Most people I know I'd term politely as acquaintances,

but the number of people you know is not a marker of success or of how popular you are. There are people I've come across who it's important to keep at arm's length for the sake of my self-esteem. Toxic people have an adverse effect on me emotionally and, if sustained, it can eventually have impact on my physical health. Over the years, I've met some fantastic people and others who were not so great. I guess that's just the melting pot of people that life is.

In Fall 2012 I had pneumonia and ended up having to take three months off work. I didn't feel like socializing, but it wasn't a completely unproductive time. It provided me with some breathing space to take stock of my life and to realize what I really wanted for my future. Such episodes of ill health can sometimes be a blessing if the time is used well. It was during one of those episodes when making the choice to change seemed so much easier.

One of the things I did was to take an 'audit' of my friends and the other people around me. On a practical level, I found it useful to make a list with three columns. The headings were "Friends", "Acquaintances" and "Arm's Length". Those who I definitely considered good friends went in the first column, those who were pleasant enough acquaintances went in the next, and so on. The list I ended up with was very telling and useful; I realized that I had

fewer genuine friends than I originally thought, more acquaintances than I could fit on the list, and a small number of completely toxic people in the third column from whom I needed to protect myself. The outcome of the exercise was that I developed a better picture of the people around me, those who cared about me, who I could be grateful for knowing, and those who I needed to spend more quality time with; those I could be amiable towards, but not such an open book as to disclose too much information about myself – not only in terms of HIV, but also other aspects of my life – and those who I should have no communication with at all for the sake of protecting my self-esteem.

I have learnt that the few good friends I have are the cement that holds the building blocks of my self-esteem together and are an important element of surviving with the virus. My advice? Stick with a handful of those who you consider winners and the people that make you feel good about yourself.

You only need a few good quality people around you for a little of the diamond dust to rub off and for the relationship to be mutually fulfilling and worthwhile for everyone.

Relating to Ourselves

If we're not comfortable in our own skins and with who we are, if we don't appreciate the health we have, or if we neglect ourselves, then can we expect to have positive and healthy relationships with others? To be clear, I don't believe that if you don't love yourself no-one else can love you. I've had three really beautiful relationships with people who I met when I was at my lowest emotional ebb. All of them carried me for a while and showed me love until I could stand up a bit better on my own and start to care about myself. I remain very grateful to them all. What I'm saying is that having the right relationship with ourselves (however much we may love someone else or they love us) has to be core to our ultimate wellbeing.

It took a long time and many mistakes before I realized that my relationship with myself was dysfunctional. I wanted everyone to like me, and put more of my energies into trying to get the approval of people who I really should have kept at a distance than I did concentrating on those who I knew truly cared about me. It's bizarre to me now that I invested so much time and energy into trying to get them to like me when actually they were not very likable themselves. Why had I not concentrated my energies on myself? Eventually the light-bulb moment happened!

Relating to Others

Some people will already understand the principles I am about to present. However, if you're like me, you may not have seen your relationships with others in the way I'm about to describe.

Imagine a pyramid with five steps to the top. Everyone we know – or don't know, as the case may be – fits on one of these steps. The most important elementary principle of the pyramid is where we place certain individuals on its structure, mentally and emotionally, and how we categorize them. The individuals on whom we place the higher expectations are probably not aware of them. Our expectations are really a form of projection of our own point of view, whether it's based on reality or what we think reality should be. We can become 'needy' when individuals don't behave the way we want them to, but neediness has an underbelly that is rarely seen. That underbelly is manipulation and trying to get people to meet our expectations, which is a projection of the way we think things should be. It's similar to the manipulating tactics of the person with HIV who plays the 'victim' role, ready to pull the ace card out to demand capitulation, absolve themselves of responsibility, or to excuse their behavior (as discussed in Chapter 1). Placing the responsibility for our

emotional wellbeing so firmly in the hands of others is dangerous and can only lead to unhappiness and dysfunctional relationships.

You!

The most important relationship we can have is with ourselves. You occupy the top step of the pyramid! It sounds obvious, but when we abandon ourselves by focusing solely on others, we're placing them on the top step of that pyramid. If you were told as a kid how selfish you were, you may find it difficult to imagine yourself at the top of the pyramid. Being a late learner, I believed that I had to comply with others' demands in order to be loved. I was emotionally neglected and overly chastised, and my parents' failure to look after and nurture me left me emotionally underdeveloped by the time I was finally forced to leave home a week after my 17th birthday. By then, I had a deeply ingrained belief that I was only loveable if I pleased people and complied with their wishes. So, naturally, I grew up learning to put everyone else's comfort and happiness above my own.

I spent my 20s feeling incomplete without my family, who by now had begun to disown me. Distance was showing me a different world, but even so, I spent my time

trying to get them to love me and accept me and to please them, but no dice. As the hole inside me got bigger, so did the feeling of incompleteness. I sought a nurturing influence from other men, who were often older than me. They, I thought, gave me what I had needed but had not received from my parents. All it did, however, was lead me into often other dysfunctional relationships with equally damaged people. Repeatedly, I found myself emotionally dependent on others' actions and emotional states. Time and again I wondered why relationships hadn't worked and how I kept getting myself into the same situation. Healthy relationships never happened, but, I thought, I would never be complete without the love and approval of others, a trait I had been conditioned to learn.

Sometimes, to rebalance things we have to be purposely selfish – in the most positive way. Having the self-worth to put our own wellbeing first may be difficult, but not doing so is down to old programming, and we have to choose to change. Try it – you may be surprised!

Partner

The second step below the top step of the pyramid is taken up by your partner (if you have one), and for many of us the person in this position is also the one who may cause

equally the most pain and the most joy. In the past I continually allowed inappropriate people to occupy this very important place, but – and here's the kicker – it doesn't have to be filled. You wouldn't topple from the pinnacle of the pyramid if you were to remove the 'partner' brick completely. For me, however, it used to feel imperative to my very survival to have somebody – anybody – there. I always felt that if this position was filled, then I would feel complete. Wrong!

You need to fill this space with someone who wants to be there – and who **DESERVES** to be.

Again, let me dip into personal experience. For many years, I would try to open the doors to my heart and let in anyone who showed any interest in me. But I didn't actually believe that anyone who was emotionally or mentally well, or who had what I really wanted in a partner, would want to be with me. I was constantly looking for someone to fill this position, and there was a sense of urgency about it. If there wasn't someone in this important position, then I thought I would die alone. Consumed by panic and lubricated with alcohol and drugs, I was that guy unable to stand still in a bar, running up and down by the end of the evening, looking for anyone who would have me. Love me, love me, I can't love myself! I hoped that any transient nocturnal

union would blossom into the relationship I felt I lacked. I would wake up next to people in unfamiliar surroundings, wondering, “Who is this person? What’s your name? Where am I? What did we do last night?”

Sometimes short relationships did develop from such desperate beginnings. They would start well and I would feel temporarily complete. The hole inside would get smaller at first, as it filled with a feeling of false satisfaction and warmth, but gradually, as I put all my energies and effort into trying to please the other person and hoping to God that they didn’t stop liking me, the hole would start to get bigger again. I felt a cold void threatening to swallow me up. Consequently, I often put up with bad behavior from my partner. I was terrified of losing the relationship because it seemed infinitely preferable to being on my own. At other times, if someone was too nice to me I would wonder what the hell was wrong with them. I would make a pre-emptive strike and finish the relationship first, before they saw the light and had the chance the finish it. Whether I finished a relationship or my partner did, it led to the same thing; a feeling of being alone and incomplete.

Either way, I now know that when I’m lonely, it’s because I’m missing ME. I also know that when I concentrate my energies on someone else, then I’m not

looking after myself. The men in my past life were not relationships, they were hostages. I just wanted the pain to stop and my feelings of incompleteness to end. It's insanity to just try and fit any old person into this role. The inappropriateness of their appointment to the position becomes a self-fulfilling prophecy. We spiral down again into relationship breakdown/ return of the feelings of incompleteness/ obsession/ looking for 'another hostage' cycle. There is such a feeling of urgency, such loneliness, that once again we grab the first interested (or non-interested) party who comes along. And so on, ad infinitum. We are never fulfilled. We remain incomplete. If there is no one special in your life right now for the 'partner/ second brick' position, just consider it 'situation vacant'. If someone comes along who is suitable for this position, then, great! But accept that it might not happen for a while or even ever.

It's important that you get your relationship right with yourself first, because when we get this right we naturally become more attractive to other people. We also become more able to identify those who are appropriate for us. You don't have to settle for second best.

Family and Friends

Unfortunately, a lot of families of people who are HIV-positive are not supportive. I know of many who have been disowned. But rejection is something that all HIV-positive people have got to get used to. When this happens to me, I remember that it's fear and ignorance that drives their reaction; it's a choice being made by someone else and, short of educating them, it's something that we ourselves need to deal with on a personal level. This can take time – it's effectively a grieving process. It's at times like this that we need to reach out for help, maybe in the form of counseling. Most of us come out of the other side eventually. In time, I came to accept the choice my parents had made and it is something that I can now live with. But not everyone's close family reacts negatively; I know of some families who have been very supportive to those they love who are HIV-positive. If this is not part of your story, then I want to assure you that it's possible to be happy without your family. When we learn to accept the choices of others, we find freedom. Our happiness shouldn't be dependent on their choices and actions; happiness is something we allow ourselves to experience because we believe we are worth it.

They say that if you can count your friends on the fingers of one hand, then you're lucky. I've had good friends in the past, but they've come and gone. Throughout my 20s there were only a few friends with whom I hadn't had sex, and I wasn't interested in making new friends. Friends were either people who hadn't made it yet into the 'partner' role, or who had already 'been there' and, for some reason, decided to stick around. They were people who I felt hadn't hurt me enough to warrant becoming an enemy. It has only been from my mid-30s that I've been able to form non-sexual relationships with other people.

I have had some very good friends. Sometimes we were separated by circumstances, such as someone moving abroad. Sometimes our lives had become so different that it caused a natural separation. Sometimes I lost friends because my expectations of them were too high, or they stopped being a friend and became more of an acquaintance. Some of us can have lots of acquaintances and few friends. People come and go in the fluidity of life, and sometimes we meet briefly and for a short time may have much in common, but then things change. How many times do we exchange cell phone numbers and addresses when we've met someone on vacation whom we have connected with, only never to see them or speak to them

again? Our good intentions, which may have been real at the time, often fade once we've gotten back home. Reality strikes and life goes on. My firm friendships used to be something that I considered to be a secure zone – so strong, they would always be there. I, however, often failed to put in the energies required to maintain those friendships, which alone was enough to cause a drift or even rift.

Today, I have a few core people in my life whom I consider to be real friends. I feel I can really be honest with them and can expose my vulnerability and weaknesses. I try to maintain regular contact with them, and just as I have entrusted them with confidences, so they have entrusted the same to me.

A major part of a friendship is trust, and it isn't usually given freely – it's earned over time. One of the defining markers of friendship is maintaining someone's confidence. It's what friendships are usually built on. Don't abuse it, because there's a binding power that comes from sharing and keeping trust.

Acquaintances

As I started relationships with some individuals and then over time stopped putting in the necessary 'friendship'

energy – just as I wouldn't invest energy in myself – quite a few friends become acquaintances. Some disappeared into the ether, dissolving into the 'everyone else' category. It's possible that if expectations are high between friends, when they can't all be met the friendship can turn bad. Confidences we have entrusted to our friends may become common knowledge. Then, our former friends move into the 'arm's length' category.

Arm's Length

Once we start to look at our relationships, we become more attuned to what behavior is suitable, depending on the categories into which we put people. Personally, I've found putting people into the 'arm's length' category is most liberating. We don't have to like everyone to be liked ourselves. Often, once I had done this I became more aware of how I had behaved around these people. There was a time when whenever I met certain people I would greet them warmly, maybe even give them a hug and a kiss, yet deep down inside I squirmed, especially if I knew that the person I was hugging or kissing didn't like me – or worse, that I was doing this when actually I didn't like them. It just wouldn't sit comfortably in my gut. By doing this with them, I was being dishonest with them, and, more

importantly, deluding myself. Such dishonesty to myself makes me feel uncomfortable on a very deep level. This isn't good for me or my self-esteem.

Often, clear and strong boundaries need to be set up against people who we need to hold at arm's length, but it should always be done with dignity and politeness. It shouldn't be overtly defensive or offensive. I prefer, if I'm keeping people at a bit of a distance, not to see or socialize with them at all. Frankly, I have nothing to say to such people. If we do have the misfortune to meet them we may have to say "no". Far too often, we say "yes" when we don't want to, so as not to displease people. If another's behavior is unacceptable to us, we must let them know it's unacceptable and that they've crossed a boundary line. Having boundaries is an act of self-worth, and saying "no" to someone is setting a boundary. But, like other principles discussed so far, learning how to set boundaries takes a lot of practice.

When I started to learn how to say "no" and refused to accept behavior that directly affected me, it was very strange. It certainly sorted the good guys from the bad in terms of who my friends were. The positive effect of practicing this principle has improved the quality of friendships that I now have and made them more enjoyable.

Setting boundaries is about protecting ourselves and our self-worth; we do it for ourselves because we're worth doing it for, however uncomfortable that may be at first.

It is, however, important not to bad-mouth or tattle-tale about people. When we do that, we're inviting them into our 'reality'. And we shouldn't allow them or their past transgressions to exist rent-free in our heads. We shouldn't hate them, we should detach from such thinking if we can, remembering that it's better to "live and let live". There's room for all sorts in this funny old world we inhabit.

Everyone Else

For good reason, this category of relationship dynamics sits on the bottom step of the pyramid. The lowest part forms the largest group. We will only ever know the smallest, passing details about these people and we will never come across most of them more than once – on the street, at the movie theater, in the queue for the bus – so how can we also have better relationships with people whom we've never met?

Once again, it all comes down to us. Though we never speak to or acknowledge others we don't know, we can and often do make judgments about them. We may base our judgments on the way they look, the color of their skin, if

they identify themselves (by the clothes that they wear or by their hairstyle) with any particular group or affiliation. Whether they look happy or angry, we figure out just by looking at someone if that person is likely to be a threat to us. In a world driven by market forces we may also judge a person by the fashion labels they're wearing and what we perceive to be the cost of their clothing. In the same way, there are many aspects of ourselves that we communicate to others without ever saying anything.

I say, "live and let live", but how many of us practice this in our day-to-day lives? Making assumptions about others based purely on their appearance means that our perception of them is often wrong.

We're only human and our perceptions of others and the world around us is merely a projection of our own reality. Our perceptions are based on our past 'programming' and often received from a very early age. We nearly always consciously (or subconsciously) adopt the perceptions and moral philosophies of our parents, and they surely can be and are often wrong. They too are only human, so it's possible that our perceptions, which relate directly to our reality, are wrong also.

I'm not going to suggest here what is right and wrong, but I would ask you to think more seriously about the

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saying “live and let live”. Instead of holding onto your judgments and perceptions of others, I encourage you to let them go. The only person you need be concerned about is you. And you deserve all of your energies.

When we choose not to make judgments about others we, in turn, feel less judged by them. When we don't spend our time worrying, or constantly make judgments about others we are more focused on ourselves. We can't change anyone else; the only person we can choose to change is us. We need to accept others for what they are, whatever that may be. After all, our approval of them isn't relevant.

8: HOME

All of us need somewhere we can live, feel safe and secure, and it should be a place where we enjoy spending time. In years gone by, in the UK being HIV-positive would have been enough (if you didn't have somewhere to live already) for your local authority to provide you with a place to live. Today, everything has changed, a testament to the advances made in the way we can manage the course of the virus. If you live in the UK, I hope that you already have somewhere to live, because HIV-positivity alone now will likely not cut it when it comes to asking for help to find somewhere to live. You face the same hurdles to jump as everyone else – you aren't a special case anymore.

Maybe you rent a room or apartment, or are buying or

own your home? Whatever your living circumstances, the order in your home is a reflection of, and directly affects, your physical, mental and emotional state.

Out of all the categories on 'The Wheel', 'Home' is the one where we can create a tangible impact very quickly. In terms of taking control, it may be as simple as having a good clean-up, or maybe you have grander plans for where you live? Whatever you need to do, the benefits of getting on with it should not be underestimated. Even making the smallest refinements to improve your living conditions is good for the soul. More than that, maintaining things at home is a 'self-estimable' thing to do. Again, do it for you and no one else.

My home used to be a mess! I felt so overwhelmed whenever I attempted any chores, to the point where I just felt like crying whenever I tried. I hated where I lived, I didn't want to spend time there and I felt ashamed of it when anyone came to visit. It wasn't a good, restful place to be in and it wasn't good for me in any respect, physically, mentally or emotionally.

Once I'd finally got a grip of myself and made the choice to take control and change things in my life, I realized that I couldn't continue in the way I had been going if I was to survive HIV in the longer term. Taking

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control at home became the first visible improvement that I achieved. It also cost virtually nothing – I'm certainly not suggesting Extreme Makeover here – and the benefits on an emotional level were well worth the effort that I put in. Progress was piecemeal and day-by-day. There was no way I could tackle the issue all at once, but collectively these small refinements created a bigger change.

Firstly, I had a major clear-out. I'd hoarded so much stuff over the early years of being HIV-positive, terrified to let anything go (particularly documents, brochures, magazines etc. which I was unlikely ever to read). It was very cathartic and liberating to throw away what was no longer needed and start to take control. It felt physically like drawing the line between old and new ways of life. Choose to be ruthless! I would ask myself; when was the last time I used or needed the item I was considering getting rid of? If I wasn't sure, I'd ask myself, "What's the worst that could happen?" In the whole scheme of things, did it really matter? So, invest in a shredder, get rid of any papers that you don't need to keep, especially old bank and credit card statements, for example, that are more than six years old. File the papers away that you are keeping – I have a file for every fiscal year – because you may need such documents, and as much as throwing a recent bill away may feel good,

the debt will remain. Do the same with clothes that don't fit and other items which have become obsolete. Once you have gotten to the point when you have pared down what you're going to keep, get cleaning and make the other refinements that you can realistically do on a daily basis to improve your home.

Does all of this sounds obvious? That's because it is, but for me the degree of control that I regained in creating this new order at home makes it worth mentioning. By putting the effort in, I started quickly to feel less like a ship without a rudder.

The rule is, less is more. Home needs to be somewhere that's ordered in this often seemingly chaotic world. We're bombarded by marketing that strongly suggests life should be about accumulating as much as you can. Don't be fooled! The most enlightened people often live with very few possessions. Know the difference between what you actually WANT and the things that you NEED. Once your primary needs are met, of course a little of what you want is a nice thing, but it's not the end of the world if you don't have ALL that you want. That's an ambition for another day. (I will cover the subject of Needs vs. Wants in the chapter called 'Finance' in more detail.)

The point that I'm making now is that many people

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surviving with HIV can find the world overwhelming from time to time, and home should at least be the one place that isn't. Having a sanctuary where you can sleep soundly and wake up feeling content with your surroundings is the best medicine anyone can have. Relevant? If an orderly home is the difference between taking and not taking your HIV meds, then it most surely is!

9: FUN

What's the point of it all if we don't allow ourselves to have some fun? We're human beings, not human doings. If I have any regrets about the First Edition of this book, it's that I didn't look at the concept of having fun and doing things which are enjoyable in more detail. As I stated back then, "Being happy is not my default state. I have to work at it". It's also the same when it comes to having fun. There is much to be enjoyed in life and it's easy to deny ourselves this, especially when we might believe, on a deeper level, that we don't really deserve it. All too often we prioritize things in our lives that we consider to be most important to the exclusion of enjoying ourselves.

If your focus is merely surviving, then having fun

probably isn't going to feature too highly as a priority. As I've mentioned, with treatment today we're not only surviving, but we also have the prospect of living potentially long and healthy lives. It could be a long haul – no in-flight movies? No playlists? – if we're not having fun along the way! For those who already feel their lives are over, who cannot see beyond or identify with more than being HIV-positive, this can just be too much to contemplate. The ability to make a choice for change can be a lot harder if the point from which you're starting out seems hopeless. It's understandable why the use of substances and addiction are commonplace among those living with the virus.

I appreciate that not everyone who is HIV-positive is going to have problems with addiction, but as I've stated, I can only talk from my own experience. Addiction problems are well document among people living with HIV – for some, it's the cause of their infection with HIV in the first place. As I've revealed, I've had my own battle with addiction to alcohol. I'm in recovery now and as a result the things I do for fun are very different from what I did before. I had thought 'fun' was drinking too much, drug use and anonymous sex. When getting over the effects of a night (or several) of excess, I often felt very alone, unable or not wanting to socialize. I spent my time with the curtains

closed, watching the same DVDs over and over. Forming healthy and strong friendships was difficult. Mainly because the people whom I had ‘friendships’ with were engaging in the same kind of behavior. Eventually something had to give. I needed to make the choice to change things, and that includes what I do for fun today.

Here are some pointers to get you thinking...

- You don’t need to be rich! Having fun doesn’t mean you have to spend lots of money. They say, “The best things in life are free!” This is true. Meeting with friends for a coffee and being in the moment can provide respite from the trials and tribulations of daily life.
- Making time for fun is very important. It’s all-too-easy to get so busy that there just doesn’t seem to be time for it. Even if you can just find 30 minutes to stop what you’re doing for some downtime, it will be half an hour of your day well spent.
- Fun doesn’t need to be planned, though. Very often, the things that are most fun are spontaneous. I try to say “yes” to things a lot more these days and to be open to invitations I might ordinarily say

“no” to. Be open to invitations and new experiences. Sometimes the way forward is to see things in the nature of an experiment. You won’t know the outcome unless you try. I recently went to my first music festival (I’m 47, so it’s never too late to start!) and I found that to my surprise I enjoyed it. What I took from this is that sometimes I have to break the mold, to do the opposite to what my default is. At the time of writing I’ve just agreed to be someone’s ballroom dancing partner in a charity fundraising competition. I can’t actually dance! I shall be going on an intensive course and performing at a gala dinner at The Grand Hotel in Brighton, East Sussex. Not sure why I said yes to this, but I think it could be the source of some hilarity!

- There’s also the capacity for fun when life doesn’t go to plan. Things don’t have to be perfect for you to have fun, and waiting for ‘the right time’ is projection into a future that hasn’t happened – and it takes us away from the moment. Having said that, I’m prone to taking myself and life in general way too seriously. If I were to take time to look in from the outside, from someone else’s perspective,

what would I see? Would it be funny? In all probability, yes!

- Being genuinely grateful for the fun that comes your way and acknowledging it when it happens means that it won't pass you by.
- The most important aspect to having fun is to allow yourself to have it! Again, it's a choice.

10: WORK

Where does your money come from? In the UK, being HIV-positive no longer means you can rely on the Welfare system to provide a well-feathered cushion to sit on until the end of your days. And rightly so. I'm a firm believer that if you are able to work you should do so. If those on treatment are doing well, being HIV-positive no longer absolves them from contributing to society. If my thinking on this matter seems harsh, especially to those who are long-time diagnosed with HIV or who haven't worked for a long time, don't forget that an increasing number of people with HIV are reaching retirement age (who would have thought that would happen?!). It's also true that some people in this age group are becoming infected in later life

when they have already stopped working.

For those who already have a job, great! Being in work is good for your health because it provides a sense of purpose and keeps you mentally and physically active, strengthens your self-esteem and sense of personal wellbeing. It needs to be viewed as an important part of the package of staying well and healthy with HIV.

If you are HIV-positive, on treatment and doing well but not in work, then this chapter is aimed at you. Firstly, I know personally how difficult it can be to get back into employment if you haven't been in the workplace for a while, particularly if that means starting your career from scratch again. I also know that, potentially, what you get paid for working may be less than what you receive right now in welfare (that can be the case in the UK today). This can be a much harder pill to swallow than your tablets, but I promise that getting back into work can completely transform your life for the better in so many ways.

If you've been HIV-positive for some years, not in work and relying on welfare it may not be easy to get back into employment. There are going to be some large holes in your resumé and although it's illegal for an employer to discriminate against a prospective employee because of their HIV status, you can't help but think it happens. These are

challenges that can be overcome. Don't be put off!

You may need to get yourself into the mind-set where you're fully prepared to start again if need be. It's quite possible that on treatment you could live beyond retirement age. Nobody in their later years wants to eat Princes' Beef 'n' Mushroom Pie and canned potatoes every day of the week and sit there worrying about how to pay the next monthly instalment on the car. This is your opportunity! What do you want for the rest of your life? What kind of work would you like to do and think you can make a go of?

Again, we find ourselves at the place where we can, if we want to, make a choice for change. This is as much about drawing a line underneath what went before and what could be in the future. And just the action of deciding, "I want to go back to work" is the first major step. It will allow you to be open to the new opportunities out there that before you might not have been in the 'right place' to consider. Perhaps you'll need to retrain or go to community college to study, or maybe you need to do some voluntary work to get some experience? Could working for yourself be an option? Create a resumé: there are lots of different ways to write one and it doesn't have to be chronological. If big gaps are a problem, make it a competency-based resumé. Look online to find different ways you can present

it. Once it's done, make a few trial applications for jobs that you like the look of and think you could do. Like I said, what's the worst that can happen? Chalk up the rejections to experience and learn from the mistakes you make.

The important thing is that by putting in the effort you are, at the very least, making yourself available and OPEN to whatever new opportunities may come along. If the door to a new future is partially ajar, it's more likely to swing OPEN than if you have made the choice to keep it firmly shut. Willingness is the key.

The fact is that, with treatment, many people with the virus are fit enough to work, if not full-time then part-time. I know a lot of people who choose instead to play the old 'ace card', but the general opinion is that if you can work, you should. Studies have shown that people who remain in work do better than those who give up working on finding out they are HIV-positive. Today is a far cry from when HIV organizations could only help people wrap things up in the final years of their lives; it's quite the opposite. Some of them now offer back-to-work schemes, training and careers advice. Working is certainly a good thing for you, if you're well enough to do so.

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Like many others, in the early years after being diagnosed I gave up work. It didn't seem like a viable option and so many other HIV-positive people I knew were doing the same. It was almost as if it was the 'done' thing. Unsurprisingly, it wasn't long before I got bored and decided to do something about it.

At first, I became a volunteer with an HIV organization. It offered me the flexibility to work when I wanted to. Then, I started to write about HIV, studied journalism part-time and accumulated a portfolio of written work, including several books which have been published. Essentially, I cobbled together a career using my HIV status like a qualification. I turned it into an asset. Even something that seems as negative as having HIV can be turned into something positive.

The meds are there so that we can lead as near-normal a life as possible, if not completely normal. I acknowledge that some may have other health problems and/or mental-health issues which could prevent them from being in employment. If this is the case, then I say that work as a concept is still a consideration. It could mean voluntary work, working towards a qualification or some sort of goal, even if that goal is walking the long road to improved health. For many of us on treatment there's a good chance

that we could live a near-normal lifespan and we need to prepare for that eventuality. If employment isn't genuinely a possibility because of the circumstances that you find yourself in right now, then it should be a goal to work towards in the future.

It's going to become increasingly difficult for those with HIV and on treatment to expect the government to fund their way through life. It's often the long-term diagnosed who find it most challenging to make this adjustment, but to them I say at least choose to be open to the possibility of going back to work in the future. Sometimes we need to take small steps to get to the place we need to go. Take control of this area of your life and be amazed at the results.

11: FINANCES

There's no doubt in my mind that whether you're newly diagnosed or have had the virus for many years, you can use it as a catalyst for change in your life. There are those who say it's the best thing (with hindsight) that ever happened to them. There are also those who get annoyed at others' gratitude for being HIV-positive. I suppose it might sound a bit glib to them, or like something on *Oprah* or *Ellen*, but I definitely fall into the first category. Being HIV-positive can allow you to transform your life in many remarkable ways if you choose to.

Previously, I've written about making the choice for change, health and self-esteem, relationships, having fun, home and work. The reason that I've placed 'Finance' as

the last category of being ‘HIV Happy’ is not because it is the least important; it's because there are a few other concepts that I also want to present in this chapter that will be relevant to finance yet are intertwined with what I've already discussed in the previous chapters. It will all make more sense and come together before you move onto the method. Stay with me!

So, back to ‘Finance’. At some point, how much money you have available comes into play. How much does making the choice for change really cost? The answer to this question is that it doesn't have to cost you anything if you choose for it not to. It's an inside job, about how you feel about yourself and perceive the world around you. I'm not saying that money isn't important, and from personal experience having more money than you need will not change the way you feel about yourself and life in the medium to longer term.

I received a substantial amount of money for a medical negligence case in the late 1990s. I wasn't expected to live very long when I received the compensation, so I used the cash to try and enjoy what time I thought was left. Knowing what I know now, I'd certainly have done things differently! I had some ‘quick-fix’ fun along the way, but ultimately having money didn't make me happy. I could

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more or less have what I wanted – but I just didn't know what I did want! It was, if anything, frustrating and burst the bubble of my thinking that plenty of money would and could change the way I felt. It was an important and valuable lesson to learn, albeit a disappointing one, to discover that having plenty of money wasn't the answer.

There's a big difference between what we NEED and what we WANT. Mostly, the needs of an HIV-positive person are the same as someone who's HIV-negative, but the main difference is that someone who's HIV-positive is going to need access to great healthcare and treatment to manage the condition. Otherwise, there isn't much else in it. Our wants are going to be as many and varied as there are people in the world. More often than not, the things we think we want aren't needed by us at all. We just think they would be nice to have, or maybe, at the other end of the scale, that we've "gotta have them right now!"

It's taken me a long time to discover what makes me happy. And, as I've mentioned, it isn't money or material things; they are merely nice to have. So long as my needs are met and a few of my simple wants, then I find that for the most part that's enough for me to be content with my lot in life: a good work-and-life balance, the money to pay my rent and not to have to worry about the next electricity

bill, to be able to go out and have a drink and socialize with friends, to have a meal out a couple of times a month, to be able to buy some nice clothes occasionally, the odd weekend away and one or two holidays a year. This is what I want for my future, and I don't think that it's a tall order. They're all achievable goals to have.

Sometimes when my desire to have something is very strong, I can become unsure if I actually need it or just want it. I'm reminded of a quote from the 1980s film *Wall Street*. For younger readers who haven't seen the film, it defined a decade of greed and excess. The line I'm thinking of is said by a young stockbroker, Bud Fox (played by Charlie Sheen), to the greedy tycoon Gordon Gekko (Michael Douglas). I don't remember it verbatim, but it goes something like this; "Just how many yachts can you water-ski behind at once, Gordon?" A good question – barring the obvious speed problem! There's only so much anyone actually needs, and once we've realized that we own nothing, that we're merely custodians of the things that we have for the time being, letting go becomes easier. Truly understanding and knowing the difference between what we need and what we want is liberating – it helps us focus on what's really important. Our needs must always be the priority.

I've mentioned before how writing lists helps me get

perspective. A notebook is an essential bit of kit. I have a page with two columns titled, “Needs” and “Wants”. It helps me to discover if the “must-have” purchase is something that I could live without, even when my feelings tell me I can’t. The majority of the time I come to the understanding that maybe I don’t really need what I want so badly after all. This doesn’t mean that I come to a state of acceptance that I shouldn’t have anything. Quite the contrary; what this exercise does is put into perspective my strong desire to have something. I start to see the thing I want differently, and realize that I can’t have it right now. It becomes a goal, ambition or dream for the future rather than a “must-have now”, and allows me to continue to ensure that my needs – the things that are really important for living and which keep me healthy – are not compromised by an impulsive purchase or commitment.

Yes, a little bit of what you want does you good, but when you can afford it. If you can’t have what you want today, make it a goal for the future. Some people living with HIV feel an underlying sense of urgency that time is against them. It’s not. All anyone has is today. If everything we wanted and desired were to come to us in one go, right now, then what would there be for us to aim for tomorrow?

Having the money we need is a necessity. The rent and

household bills must be paid. We need to eat, we need clothes on our backs and it's very important to have some fun along the way, otherwise what's the point of it all?

I used to have a 'devil-may-care' attitude about money so that when I decided to take control there was quite a financial mess that needed to be cleared up. This has been an on-going process that still continues today. Admittedly, I can feel resentful sometimes about my hard-earned cash seemingly evaporating from my account on the day it's paid, but the truth is that with treatment to manage my condition I may be on this earth quite a bit longer than I had once thought. I need to prepare for it.

I had to bite on the bullet and list what I owed to my creditors and also what income I had coming in. I made realistic re-payment proposals to my creditors, and for the most part I manage to make those payments on the day that money comes into my checking account. It hasn't been easy, but over time my debt has decreased considerably. I can cover the cost of the things I need and I have a little disposable income each month which allows me to do and buy some of the things I want. As each individual debt is finally paid up, I'm clearing the wreckage of the past that I (yeah, me!) created piecemeal. By making a choice to address the problem I've taken control of it. I have said

several times before that being HIV-positive doesn't absolve anyone from at the very least trying to meet their responsibilities. If we're going to attain the kind of life we want for ourselves, then we must take responsibility for it. No one else is going to do it for us.

Now, I have only one real aim: to improve the quality of my life. I've said before about making a "refinement" to at least one thing once a day and how these refinements build up overtime to create a better standard of living. This is a daily rule that I stick to, without fail, whether the refinement is small, such as clearing out a kitchen drawer, big, like redecorating a whole room, paying a bill I resent paying or buying myself something that I really want (if I can afford it). It's these things collectively that improve the quality of my life, or what I like to call "QOL".

In the past, life has been very difficult. A couple of times I was barely clinging onto it before the new treatments became available. There was the wreckage of years of drinking and drug-taking in my younger years and a mountain of debt that had paid for the privilege. There were the hangovers and the comedowns that were so bad I couldn't go to work, and seemingly one infection after another to battle, sometimes several at once. Then there was waking up with people who, through a pair of beer-

tinted glasses, had looked alright the night before and in the morning looked quite different. I'd roll over in bed (hoping my bed guest wasn't a 'morning' person), yet again on the edge of tears, wondering what I'd done with them the night before. I'm reluctant to call it a lifestyle because it was more of a painful existence. I had no "QOL".

What I've just described will be familiar to a lot of people living with HIV. Substance abuse, depression, poor self-esteem, work and financial difficulties are all well-documented problems. That was perhaps more the case before effective treatment to manage HIV came along, but still for many it's a reality of life with HIV today.

I confess that I can very easily slip back into old habits, and indeed sometimes do. This is when I have to start employing some of the tools in this book to pull myself out of it – for example, writing a list of things to be grateful for, and putting the effort into refining, or improving one thing every day, however small. In the last sentence is the key to better "QOL"; it's all about the action you put in to try and make things better. And it doesn't have to cost the earth.

QOL, for me, is not having to do the washing up (I hate it!) so I bought a dishwasher. I hate household chores, too, so I have a cleaner who comes once every two weeks

to blitz my flat. It's money well spent. I throw away socks and briefs when they become worn or a hole appears and replace them, because I deserve it. I insist on having clean linen on my bed because I sleep so much better. I spend time cuddled up with my cat on the sofa and watch silly films that I've seen hundreds of times, but so what? I like them! I don't engage with people who tattle-tale, because if they're doing that about others they will probably do it about me too. I don't have a personal Facebook profile for this reason. What other people think of me is none of my business. I don't answer my cell phone if I don't want to speak to the person calling right there and then. I don't have sex with people if it isn't the kind of sex I want. I allow myself to enjoy things, even if they aren't fashionable. I sing very bad karaoke and don't care what other's think. I'm doing it for me, no one else... and if I'm struggling to think of even one thing on a given day to improve my QOL, to do something good for me because I'm worth it, then I do the one thing that will – take my HIV meds.

I mentioned about writing a list of things that you're grateful for. Is your glass half full or half empty? What I mean is, are you a half-full or half-empty sort of person? The difference is merely the way we perceive ourselves and the world around us. The power of gratitude never ceases

to amaze me, and feeling gratitude can completely change your life for the better.

Back to the list: writing down things that you are grateful for, often just small, daily things, can cause a positive shift in the way you think and feel in a very short period of time. I've written a gratitude list regularly for nearly 20 years and in my darkest moments this simple exercise has really saved me. Mainly from myself. It's so easy to get trapped into a way of thinking that's negative when living with HIV, to feel unsatisfied with life, almost like a kind of grief. It's a personal hatchet job that isn't an easy mental and emotional state to live with because it taints everything, blinkering us to all that's good in our lives and to the opportunities out there.

I used to think that having more of everything would make me happy. Once I had attained whatever I'd set my heart on there was always a feeling of disappointment because any satisfaction or positive feeling gained was always short-lived. I'd then start looking for the next 'quick fix' and focus my efforts on getting it as soon as humanly possible. Having this sense of urgency about almost everything is not a good way to live. I was always chasing something, so much so that it took me away from 'the now' and my ability to live in it and enjoy the current moment.

Someone very wise once asked me where my feet were. I didn't understand what I was being asked for a long time, but I realized eventually what they meant: where was I in THAT particular moment of time? Put very simply, what has passed is history and the future hasn't happened yet. Don't concern yourself too much with it. All any of us has is NOW. Getting one's head around this concept can be challenging if we're sandwiched between shame of the past and fear of the future. (Some readers will benefit from engaging in Mindfulness groups and classes. I strongly recommend you try it out!)

Gratitude for what we have today costs nothing. It's really not difficult to get, either. I'm not talking about the fleeting feeling of something being nice, but really feeling gratitude deep down in your gut. Crack this, and the rewards are beyond most people's imagination. (Personally, I can imagine quite a lot!)

Here's what to do: you can write a gratitude list on anything – a serviette, if you like! I keep a dedicated notebook for mine. I used to be in a very negative place and unhappy, and at first I found it difficult to think of anything to be grateful for, so I had to keep it very simple. I wrote down the obvious: I'm alive, I have my senses, I have all my limbs, I have somewhere to live etc. Over a short period of

time the list got longer and the practice of writing it stopped feeling like a chore, mainly because what I actually got from writing it was so positive. I can easily write down over 50 things in my life I can be grateful for now, and the feeling I'm left with when I come to the last items on the list is a heightened sense of satisfaction for everything I have. When we are grateful for what we already have and really feel it by acknowledging it's there, the world around us becomes a different place.

Writing a gratitude list can set you up for the day ahead and influence the way you behave, think and feel. And the most exciting thing about practicing this tool on a regular basis is that it makes you open to receive even more to be grateful for. If we can't be grateful for what we already have, then why in hell should we notice when anything else that's new and good comes to us?

12: BECOMING HIV HAPP(IER)

Introduction to the Method

Many of the issues that have thus far been discussed in this book are relevant, poignant and common to people living with the virus. Life isn't always easy, and the added burden of being HIV-positive can make it more difficult if we allow it to. It's easy to fall into the trap of feeling (and living life) like a victim, of being negative about the future and having a sense of urgency that forces us to imagine a future for ourselves that hasn't and might not ever happen. It takes us away from 'the right now' and today. We can live with regret for the mistakes we've made or those that we blame on others, a throwback to a past that we can't undo. It helps sometimes to get a fresh perspective when we notice that

our thinking has become negative.

This chapter presents some tools that are designed to help shift negative thinking and to cultivate a more positive state of mind. They're useful for establishing where we are right now; to help us to recognize and acknowledge the good things that we already have in our lives, and to assist us in finding some direction and taking control of a happier and more optimistic future. They can be used either on a daily, weekly, monthly or even yearly basis. However, I suggest that looking too far into the future isn't always a productive exercise. Life has a way of forcing us to change our best-made plans sometimes. It's about finding what works for you in terms of frequency. As well as adding to my 'gratitude' list every day, at least twice a week I tend to take an audit and review where I'm at. I also have an on-going list of goals of different sizes, some small, some bigger. I try to make one small refinement a day in an effort to meet these goals. Collectively, when the fruits of these three steps come together, my QOL improves tangibly and I feel happier and more content with my life.

I should say that it doesn't matter if you don't achieve what you were aiming for. It's the intent itself that's important; it allows us to be open to new opportunities and prepared for the good things that life has to offer. There is

no outright failure – there can always be progress towards our goals.

Viewpoints

There are three very different mind-sets/ ways of looking at things that we need to employ in this method: from the perspective of an adult/ parent, that of a third person looking in, and that of a child.

When reviewing our life (Step One) we need to look at things from an ‘adult’ or ‘parental’ perspective. We need to be extremely honest, but always kind to ourselves. The process of reviewing our lives is not to be used as a stick to beat ourselves up with, even if that’s our past experience of treatment by other adults, or indeed possibly our own parents.

In Step Two, which is about developing a sense of gratitude about what you have, the best way I find to look at this is from the perspective of a third person, someone looking from the outside in. What good things in your life could they identify?

When it comes to Step Three and the ‘making choices/ setting goals’ aspect of the method, we need almost to approach it in the same way as a child would, dreaming of what they would want for their future, with

innocence and wonderment. A word of caution: it's very important that these 'adult/ parental' and 'child' viewpoints or mind-sets never get to meet! By that I mean that when reviewing your life, the hurt, sadness and disappointment held by the 'child' part of us must not play a role. Likewise, when making choices of how we want to change and setting goals, the more critical viewpoint of the 'adult/parent' must not come into it whatsoever.

When these two mind-sets are in play at the same time there's a possibility of emotional pain and a feeling of hopelessness. This is negative thinking and will not create the internal conditions for change that you're aiming to achieve. With a bit of practice you will find it gets easier to switch between mind-sets, but when you first start to practice the method you might prefer to leave a day in between each step so you can ease yourself into the right frame of mind.

Method

For the following three practical steps all you'll need is a pad of paper, a pen and a quiet space for contemplation. I find that an A5 pad works best for me and is easy to carry around.

Step One: Reviewing Your Life (Adult Viewpoint)

To be sure of where things are at ‘in the now’, in this current moment of time we need to review our life. Most people can divide their lives into the six categories described earlier in Chapter 5, ‘The Wheel of HIV Happy’, so write each of these headings on a sheet of paper. Each of them needs to be considered separately. I stress again that you need to be very honest with yourself, in an ‘adult/parental’ mind-set. Try not to let emotions govern what you are writing. Here are some things that you’ll need to consider for each section heading.

Health and Self: Your health is the most important thing that you can have. Without it, life can be very difficult. Write an honest appraisal of where things are at. Do you have any health issues besides HIV? Are you overweight? Do you eat healthily enough? Do you need to stop smoking or drinking, or do you have other substance-misuse issues? Do you need glasses? Do your teeth need the attention of an orthodontist? Which good aspects of your health are you happy with?

How do you perceive yourself and how do you think others perceive you? Also, review other important (seemingly trivial) aspects of yourself – for example, the

clothes that you wear. Take a look in your closet. Do you like what's in there? Do the clothes in it define you? Is it how you want to be defined? Are you unhappy with your 'do' (or lack of hair!)? Do you like or dislike the way you look? What can you realistically do something about?

Relationships: By relationships, I mean all the people in our lives. Start with the most important relationship... WITH YOURSELF! Then think about people in order. Perhaps the next person might be a significant other, or a family member. Then best friends, and finally acquaintances. I also found it useful to write down those people in my life who are 'Arm's Length', the ones I really don't like to be around but who, in some way or other, are there. They may be people who hold us back or those who have a particularly negative impact on our lives. Next to each name of the person write down what's good, or not good, about the relationship.

Home: Most of us are fortunate enough to have somewhere to live, but is it the kind of home and area that you want to live in? Is your property rented, but you had always hoped that you would have been able to buy somewhere? Is there enough room for you (and your cat/

HIV HAPPY

dog/ family)? Are you happy with how it's decorated? Is it tidy or untidy? Do you not have enough to be comfortable or do you have too many things. Do you hoard? What do you like about your home, if anything?

Fun: What do you enjoy doing? Perhaps you're having too much of the wrong kind of fun! Do you need to address the amount of alcohol you drink or other substances? Write down honestly what you like to do for fun. Is it *really* fun? If it is, then great. If it's not, then this is important and needs to be addressed.

Work: For some of us, work is part of our lives. You may be fortunate enough to have a job, but it may not be the kind of job that you want to be doing. Do you earn enough? Do you think you're worth more? Also, write down your achievements, things that are work-related and you're proud of. (This review exercise isn't only about things that you're unhappy about.) Think of it as if you were checking what food you have in the cupboard. The good stuff also needs to go down on paper.

Finances: They're a fact of life, whether we like it or not. Finances need to be managed and they're more than likely

also linked to our job/ career, unless we're lucky enough to be a trust-funder! So, reviewing your personal finances is very important. It is likely they're going to be central to the decision about what kind of change can be immediate and which other goals are going to have to wait a while until we have resolved financially what is in hand.

Make a list of what you definitely know you have in terms of income. Don't include income that you're unsure is definite. Next, write a thorough list of what you owe. By thorough, I mean absolutely everything! Leave nothing out. This for many this is the most frightening part of the review exercise, but remember that you're approaching this with the 'adult/ parental' mind-set, so don't let the fear of the 'child' come into play. You may need to work hard to remain emotionally calm dealing with the 'Finance' category of this exercise. It terrifies me! The most important thing is that by the end of the process you have a really clear idea of where you are in terms of your finances. **DO NOT GUESS** figures; if need be, dig out statements, nasty letters, bills etc. **AND WRITE IT ALL DOWN!** Perhaps you only have limited or no financial problems? Write this down also. Isn't it something to be grateful for?

What Next?

If you're new to the method, I recommend not moving onto the next stage until a day or two after completing the Step One review. Sit with the feelings that have been generated by completing this part of your life review. It may not be comfortable, but you may be surprised about the revelations that can come up. If they're relevant, add them also to the review.

Step Two: Getting some Gratitude (Third Person)

This time I don't want you to be so 'adult/ parental' in your approach. I want you to try and look at your life through the eyes of someone who isn't you, a third person. Write a list of all of the things that you can be grateful for and use the section headings I mentioned before, if that helps. Even if you don't FEEL grateful, write down things that you COULD be grateful for. Start each item you could be grateful for with the prefix "I have...", or "I am..."

Eg.,

I have my health

I have a job

I am going on vacation soon

Get right down into even the simplest things that you COULD be grateful for (even though you may not FEEL it right now).

Eg.,

I have my eyesight

I am able to walk

I have a roof over my head

At first, you may find it difficult to think of things that you could be grateful for, but I remind you that this is an exercise, which means sometimes just going through the motions. Try setting yourself a target, for example, of 10 or 20 things you COULD be grateful for, and increasing it by five every time you write a list.

It's important for this exercise that you do not just add to an old list – you need to write it every time from scratch. By externalizing on paper the things you think you COULD be grateful for, you eventually start to FEEL them. This really is a type of brain training, so I recommend that you do this on a regular basis for the best effect. I personally go through periods of time, sometimes weeks at a time, where I'm writing a gratitude list every day. And I can say now that I enjoy writing them, because if you keeps doing this,

even if it feels very mechanical at first, in time you'll start to FEEL gratitude for the good things you have in your life. It's a nice feeling – addictive, even, in a good way – and is a great way of getting perspective and a selfie of your life. Keep doing the Step Two gratitude exercise until you start to FEEL gratitude. It doesn't need to be an overwhelming feeling, but the 'green shoots' of feeling thankful. It happens quicker for some people than others. Persevere! Once it starts to happen, you'll be ready for Step Three. The fun part!

Step Three: Setting Goals (Child)

This is where the fun begins. You need to approach this exercise from the mind-set of a 'child', with wonderment. Dream a little! Most importantly, don't let the critical, 'adult/ parental' part of you have a say. It will try, so push it out whenever it says, "That isn't possible, get a grip, who are you trying to kid?" etc. The two mind-sets must never meet when going through these exercises. If they do, there's a risk you will quit before you've gotten started.

Using the same headings as were used for the Step One exercise when you did the review, write what you would like your life to look like, how you want to feel about yourself and how you would like others to perceive you.

Below are some examples of the kind of thing you may choose to change, but ultimately it's YOUR LIFE, so it's for you to write down what you want and not for me to tell you. Use my comments as a guide only. This exercise is about identifying what YOU want and setting YOUR OWN goals.

Health and Self: We would all like to be in excellent health. What could you do to improve it? Eating healthily, going to the gym, losing some weight, working on a more defined body shape? Do you want healthy gums and pearly-white, straight teeth? Do you want to give up smoking, drinking, or possibly other substances? Would you prefer to have laser eye surgery and not wear glasses anymore? Would you like to train for a marathon? Is there some prescribed medication that you need to be more regular at taking? How is your adherence to HIV medication? Write down what your ideal health would be. If you're happy with the way things are presently, write that down also.

The focus on self is about inner change, not external change. You may find when you look back on the review of your life you carried out in Step One that a lot of it was about what you have and haven't got materially. Often these things are of concern, because deep down we worry

about how other people perceive us as an individual based on what we have got, what we haven't, what we do for a living, or where we live. Effectively, we think of ourselves as a kind of brand, but the reality is that changing our life goes way beyond the brand of who we are. It is about change on a very deep level – in other words, it's an 'inside job'.

Relationships: This is a term I use to cover a broad spectrum. I mean ALL people we have interaction with, but most importantly the relationship that you have with YOURSELF! IT IS ALL ABOUT YOU! Anyone who tells you any different is talking garbage. In each of our independent lives we are the one constant and we need to be there for ourselves. This is not a selfish action, but a necessary survival response to the world around us. The priority goal has to be that we end up feeling comfortable in the 'meat suit' that we live in and comfortable in our own skins – apologies to vegetarians and vegans among you! If as kids we became used to being told we were attention-seeking and only thought of ourselves, then we can sometimes carry this crooked thinking into later life. If this is the case, then it's something that you can start to change right now, if you CHOOSE to! For the purpose of

changing this perspective you'll need to become what others may think of as selfish and self-centered. Once you have gotten your relationship right with yourself, you will be in a better position to give more of yourself to others. Again, do this for you and for no one else.

Do you have a partner, and are you happy with them? If you aren't, for whatever reason, then you need to seriously think about what you are going to do about it. Does your partner have a place in your 'child' mind-set of what you would like your life to be? (Again, be aware of the 'adult/ parental' voice that may challenge your 'child' mind-set.) If things are good with your partner and you're happy, then great! Write it down.

Most people only have two or three really good friends, people they can call at 3am when in trouble and need help. If you have more than two or three, then count yourself very fortunate indeed! If you need to make a couple of really good friends, then what kind of people would you like to be friends with? Who do you see yourself associating with?

What about the people who you associate with today? Do they really have a place in your life? If not, then also think about letting them go. Sometimes things need to be knocked down before they can be rebuilt. Change often

isn't a comfortable process: a useful analogy is that a new house can't be built on a plot of land if the old one has yet to be demolished.

Home: If you're happy with your home, then great! If not, what would you like to change about it? How would you like your home to be? Would you like it cleaner and tidier, or does it need to be redecorated? Perhaps you want to move to a completely new area or zip code and start again? If you're a hoarder or just have too much stuff, do you need to have a de-clutter? Don't underestimate the power of down-sizing or getting rid of clutter and re-organizing things – it's one of the best ways of at least giving yourself the feeling you're starting over. Having a clear-out for the most part doesn't cost anything either – hey, you could have a yard sale! The key is to be ruthless. But if your home is just right for you, then write that down too. Another check on your 'gratitude' checklist.

Fun: What's your ideal fun day? How close does it come to the reality? Remember, you're looking at this from the 'child' viewpoint. Let your imagination go ape! If there's a large difference between what you would like to do for fun and the way things really are, how can this be addressed?

Does fun solely center around alcohol and drug-use? Is this really having fun? Do drink and drugs cost you more than money? Does the ‘child’ aspect of you really enjoy this? Do you honestly need to make a choice for change here?

Work: Would you prefer to be doing something completely different from what you’re doing now? What is it that you would like to do? What’s your dream job? Again, be careful not to let the ‘adult/ parental’ mind-set in. It will be saying, “Don’t be crazy”. Ignore it! What does your ‘child’ want? When I was a kid, my grandmom would say, whenever I spoke of a career I might like, however unfeasible, “Why not? Someone’s got to do it, so why not you?”

Do you just want a job where you can earn more money? Perhaps you aren’t employed at the moment and just need a job... any job! In an ideal world, what is it that you’d really like to do? Perhaps a job isn’t what you want at all, or things are perfect as they are? Write it down.

Finances: Personally, I don’t like money very much, but unfortunately in the world we live in it’s essential for survival and to realize our dreams and ambitions. If your finances are a mess, then the task is to make them right. This often takes time and is the main thing that can hold

back some of the more ambitious plans for changing our lives for the better. During the Step One exercise, you should have gotten a good idea of the current state of your finances. This is central to what you can realistically achieve in the short term to reach your goals. The most important thing is to acknowledge the problem. If you haven't done so already, speak with your creditors and get some kind of realistic re-payment plan in place. In the first instance, your goal needs to be financial stabilization at an amount you can realistically afford. Seek advice from a consumer debt organization if necessary; look into whether it's worth going down the debt-management-plan path. If poor finances are not an issue for you, then way to go! You'll have more freedom to move towards your goals for better QOL.

For those of us who do have financial issues, there's still a lot we can do at little or no cost. If financial issues are pinning you down, a good antidote is not to dwell so much on what you haven't got, but what you have got. This, for me, is where the true power of writing regular gratitude lists is apparent.

And Finally...

From the beginning, this short book has attempted to challenge some of the common perceptions held by people

who are HIV-positive that harm and stop them from getting on with life. Some of you will disagree with (possibly be mad at) what I have written, but likewise others will instantly identify, recognizing themselves in these pages. Either way, if this book has churned something up inside you, if it has provoked some soul-searching and self-examination then maybe the point is made. What has been presented is not a magic formula for happiness; its intention has been to cause a shift in thinking and to encourage people with HIV to let go of negative ideas about themselves. Maintaining positive thinking is an on-going process, and I hope that using the tools presented in this chapter regularly will assist you to achieve this.

If we are to live harmoniously and co-exist with HIV then we need to take on some new ideas and discard some of the old ones that we hold about ourselves, some of which may be born from the stigma that we HIV-positive people face on a daily basis and which all too often come from an internal place.

Life can seem complicated, so to summarize simply the fundamental concepts presented in this book:

- 1) We are not victims. If we made mistakes, we must take some responsibility and have the willingness to accept

them. It's a waste of our energy to replay 'old movies', wishing we had done things differently if what's done is done and can't be changed. What should really concern us is today and the future. Life isn't so much about what has happened in the past, or even finding out or understanding who we were, it's about knowing who we are now and working towards who we would like to become.

2) We have choices. We can choose to stay with what is familiar and not move on, to stay trapped by others and our own old and negative perceptions of what it is to be HIV-positive. Yet, there is an alternative. Change is possible if we have the courage to choose it. There is a world of possibility and opportunity out there if we are willing to be open to it.

3) Happiness comes from being grateful for what we have already in our lives and acknowledging it. We so often take what we already have for granted. It's very possible that the things that could make us happy are already in our lives, when we recognize that they are there. Again, I say that it isn't about reaching up for something, but simply reaching out.

4) All you need to do today is make at least one refinement, however small, to create the change you desire. If you do that then you are a winner. It's the seeds that we plant today that become the harvest of our individual futures and tomorrows.

5) The most loving thing that you can do for yourself is to take your HIV meds and adhere to the regimen. Love yourself every day!

6) All of us who are not only living with HIV but SURVIVING with it have a duty to those who didn't make it before us to grasp the future and the second chance of life that treatment affords us. Your future is in your own hands now.

What will you choose to do?

APPENDIX A

Tribute to Glenn Thomas, killed on flight MH17

When I heard that Malaysia flight MH17, flying from Amsterdam to Kuala Lumpur, had probably been shot down by a missile over the east of Ukraine, like many I was very shocked and saddened at the senseless loss of life. It wasn't until the next day that I discovered my friend Glenn Thomas had been on board and was among the 298 killed. He had been traveling to Melbourne for the International AIDS Society (IAS) Meeting 2014. Glenn had a positive impact on so many people's lives, including mine. I have asked the editor to pull my usual *HIV: Recipes for Life* column in this month's issue of *GT* so I can pay tribute to my friend, tell you a little about who he was and how he

touched my life.

Glenn was from Blackpool and proud of it. He was 49 years old when he died. A journalist, he worked for the BBC and then for many years thereafter as a Media Officer for the World Health Organization based in Geneva. He probably never thought, nor wanted, that he would one day be such a prominent part of the story himself. Glenn always made it his mission that those without a voice were the focus of attention and the ones being heard. He understood the power that the voices of people directly affected by diseases such as HIV, TB, and malaria could have and also how they could be used for positive change. He had an amazing ability to pull ‘rabbits out of hats’ and come up with fresh new ideas to ensure that the most marginalized were heard. He was often able to make those ideas happen and if he couldn’t himself, he was so well-connected he always knew someone else who could.

I first met him at a conference in Paris in the autumn of 2004. Only a few months after first meeting Glenn, I found myself working for a humanitarian organization and living in Geneva also. I’m very grateful for the hand of friendship he offered because I found Geneva such a difficult city to live in; I don’t speak very good French and I felt very lonely. Glenn went out of his way to make me feel

welcome. He introduced me to the gay bars and his friends. Even though I had only lived in the city for a little over six months by the time I returned to the UK, I was privileged that our paths were to cross many times thereafter, usually at health conferences and other official meetings. Wherever we were in the world we would meet for a drink or three and many good times were had. We would chat until the early hours. Glenn was very inquisitive, he always had questions to ask and showed a genuine interest in how I was doing both professionally and personally.

Clever, witty, funny, charming, generous, thoughtful Glenn: I am so grateful that I knew the warm and gentle person that you were. I thank you for the hand of friendship you so freely offered and the kindness you often showed me, especially if I was feeling a bit down about things. You had the ability to make me laugh when things seemed hopeless, especially at myself. I thank you also for the effort you put into me on a professional level. You are one of the people who taught me that good advocacy isn't just about being noisy and expressing anger, that it's about engaging with those who have the power to change things on the deepest level possible. To appeal to their humanity and get into their hearts beyond their politics and to convince them that positive change is possible. You helped

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to build my confidence as an advocate, once telling me; “Paul, you often speak a lot of shit, but sometimes there are diamonds in there”. I shall try for more diamonds in the future, Glenn.

Glenn Thomas was looking forward to his 50th birthday party with his twin sister, Tracey, in September. He leaves behind his partner, Claudio. He will be greatly missed by his many, many friends and those he worked with, past and present.

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ABOUT THE AUTHOR

Paul Thorn has been writing about HIV for over two decades. In 2014 he was a finalist for Stonewall's Journalist of the Year. He also writes self-help books on a variety of other subjects. He lives with his partner in Hove, East Sussex.

Find out more about Paul Thorn and his work on his website www.e-m-press.com

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