



**4M:**  
**My health,**  
**My choice,**  
**My child,**  
**My life**

Developing a national network of Mentor Mothers to support women living with HIV through pregnancy

# Songs of Experience

## Experience-based research

### What is the 4M Project ?

Women living with HIV can encounter significant psychosocial challenges during pregnancy and early motherhood. The 4M project, delivered by Salamander Trust, is an innovative training package that aims to build a network of women living with HIV as 'Mentor Mothers' to support women living with HIV across the UK during this time.

### 4M ToT Workshop, October 2017

During October 2017 we ran a Training of Trainers workshop, funded by ViiV Healthcare, with fourteen of the trained 'mentor mothers' from across the UK. This included a creative writing workshop designed to provide a safe and creative space in which to explore, share and reflect upon their experiences of living with HIV. The following stories were written by participants, based on their own experiences, in response to the question 'What helped you to cope with your HIV diagnosis?'



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I don't remember walking home after I received my HIV diagnosis. But I do remember my mum, how she looked at me and how soft her lap felt as I lay my head there. That love, the acceptance and realisation that I was still her daughter, regardless of this little virus in my blood, gave me the strength to know that, three months pregnant at the age of 23, everything was going to be fine.

My mum had a plan. She told my dad who told the pastor who then prayed for my long life. This further made me believe that I was going to be fine. I was lucky then, and I still am, to have family, friends and a community that loves and supports me. People have tried to stigmatise me but with this foundation I keep standing. I have gone on to have two beautiful children, 15 years and 8 years old. I have mentored countless mothers, won an Inspirational Person of the year award and I am a trustworthy member of my community; all thanks to this love and support.

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Story written by Patricia

So here I am with a positive diagnosis and a pregnancy to carry. Will I pull through? Will I have a normal baby? Will my baby survive? Will my baby be infected? Will my baby have disabilities? These were the many questions racing through my mind. Being in Africa, I didn't have much of a support network, so I had to figure things out for myself. It was as if a monster had just entered my closet. I had no idea how to get it out, but the sun was going down and I needed to get some sleep. 'Oh! What a predicament to be in!' This was all I could think. I couldn't access proper medical attention, I didn't have enough medication to take and the worries kept building up.

I suffered anxiety and panic attacks. I decided to live one day at a time and that's how I pulled through the nine months. I had to decide which voices to listen to and which ones to block out. My baby's daddy wanted me to abort as he disowned the pregnancy. I had to block him off and concentrate on one thing at a time.

When the baby finally came it was ten hours before I could finally see my baby because the anxiety was too much. I kept fainting and passing out. I had to be put to sleep until evening and that's when I met my bundle of joy. I almost denied my baby because he was so handsome. So cute! So lovely! All the words that could describe him. With the anxiety of me being positive and carrying a pregnancy, I didn't believe that I would have such a wonderful baby. That was the beginning, or rather, the turning point of my journey. I am close to eight years on that journey now with my two lovely sons who are both HIV negative.

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Story written by Glam

The diagnosis came as a saving grace in a way; an answer or solution to the bigger problem, which to this day, I still don't know how to talk about. All I do know is that I wanted to die. I've wanted to die for a long time, I just didn't know how to. At 21 years of age a solution presented itself in the form of a HIV diagnosis, which, back in 1995 was pretty much a death sentence. I want to say I felt elated, you know, happy, but it's hardly a description one would use to express this feeling (whatever the feeling is), is it? So I'll say I felt relief. I had given myself two years without treatment. I figured two years would pretty much seal the deal. All I had to do was sit back and wait. I waited. I waited some more. Two years came and passed without so much as a common cold. I was furious. I was vex. I was pissed. But mainly, I was disappointed. What the hell!

So here I was, living, or rather forced to keep on living without my consent. Life's a bitch. And suicide was never an option. You know, Jesus and his Daddy sending me to the eternal fire... not part of the plan. And my mother, my poor mother. She'd lost a daughter only a year earlier. The guilt had consumed me by this stage. I was basically guilt tripped into living. What a mess!

Fast forward. I give in and start to live. I went to college. I worked. I had relationships. Even got married and divorced, you know, like normal people do. I am being so normal at this stage that after my divorce I started a new relationship. I was in love...feeling way normal now...and broody. Gosh, I actually wanted a baby! So, 15 years after diagnosis, on medication and healthy, why not? I went for it! My son is 7 years old now. He's my new guilt trip for living. I have to. Don't get it twisted, I haven't suddenly found a longing for life, I just have to do it for him. The wait continues...

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Story written by K.C

1.

MY BABY —

Still so sad to write

To recall, to rewind, to remind, to re-embody

The shock, the pain, the fear, the heartache

SHE IS SIXTEEN NOW, INDEPENDENT, STRONG, BEAUTIFUL, LOVING, KIND.

I want to concentrate on all she has become, how she has GROWN, how proud I AM.

I live choosing not to look back, focusing on the present, the future, where there is hope.

Those dark days, not forgotten, but not worth dwelling upon.

lessons were learnt, eventually

and life continued, her life, my life.

As I write here in this safe space, I can see my journey clearly.

And I realise,

I am fifty now, independent, strong, beautiful, loving, kind.

How grateful I feel for the opportunity, to learn, to connect, to share,

With my sisters in status and myself.

And I see

How I have grown, how proud I AM.

2.

SUNGLASSES ON THE SCHOOL RUN —

Sunglasses on the school run?  
it's Autumn, so what are you shielding?

NOT the bright light for sure.

You are hiding the dark, the shame, the fears.  
Shading the truth, the bruises, the tears.

Better the devil you know,  
No one else will be with you now.

You have the same status,  
You are HIV positive, so is he.

The father of your children,  
Your husband,  
Your lover,  
Your hater,  
Your beater,  
Your protector,  
Your mind-warper,  
Soul destroyer.

GET THOSE PASSPORTS AND RUN,

RISE UP  
BECOME,  
MORE

TRAIN,  
LEARN,  
MENTOR.

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Stories written by Mel

## Teardrop

So the unthinkable has happened  
Pregnancy confirmed  
My fear that I'd be robbed of Motherhood  
Because of HIV diagnosis  
I have moved beyond  
Where to?  
A man that can't be still  
His life in a guitar  
He is all emotion - says 'I love you'  
But does not know how  
How to be my rock, to inspire confidence  
Let alone provide  
But he plays like a dream... tra la la la la...

This moving within, the changing shape of my belly  
The look in my eyes  
The peace of finding my elephant-ness...  
I know, I remember  
From DNA, From Mother Spirit  
This is my journey

I read all  
I had decisions to make  
They tell me 'You need a Caesarean'  
From my core, I found myself  
Saying NO  
I know how it is for me  
In 1998 —  
Still a time of Risk and fear  
I believe, in fact I know  
I will push this child into the world

"On your head be it" they said  
How else can it be, I thought  
There is no fear for me

There is breath, pain, moments of sleep – so deep - waking to the urge to push  
the cycle repeats over and over again  
culminating  
Birthing is imminent  
That opened my eyes wide  
into the gaze of my sister  
I'm broken open  
I am now the we; Mother & Child  
That makes me whole

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Story written by Janine

What helped me to cope with my HIV diagnosis...

- the health services
- going to lots of Support Groups
- good health

I was referred to the HIV team in my borough. This is where I experienced love, empathy and friendship. I was given advice about immigration and my workplace rights. I was signposted to support groups such as Positively Women. Each time I went to a support groups I made new friends. My breakthrough moment came when Angelina came to our support group to share her own story about having a baby after an HIV diagnosis.

Now I have babies of my own.

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Story written by Neo

## The Positive Side

I was this young vibrant girl with the whole world ahead of her, so happy and hopeful that nothing could get in my way. One day, while on a holiday in England with my boyfriend, we decided to go for a routine check-up, hoping that everything was OK. On the day of the results we were put in separate rooms. He came out first and he was all smiles because his test was negative. I was also eager to get in but the news that I received was not good, I was HIV positive. So, I went out to meet my boyfriend, we went to our car and I just broke down. And cried. I told him if he wanted to leave I would understand and. To be truthful, I thought he would run.

But instead, he comforted me and told me that life would still go on. He encouraged me to see the counsellor and start medication. He supported me throughout my HIV journey and now he is my husband with whom I have three wonderful children. If it wasn't for the support that he and the health team gave me, I don't know how I would have coped. He has shared this journey with me all the way.

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Story written by Edith

(Today)

I am a healthy woman living with HIV for 20 years. I can't believe I made it this far.

It's been a journey of immigration, social services, clinicians, psychologists, CAT scans and endless hospital appointments. I still can't believe I'm here!!! I've gone from taking 40 tablets a day, to only 2 or 3 a day. I am so blessed to have made it this far. From having been told that I was going to die in 6 months, maybe 4. Most people at the clinic had made their conclusions about my date of death. It was even announced in my community and church.

HIV is a journey that can come and destroy lives. I have to fight the so-called AIDS with my mind, spirit and my soul. But most important for me was wanting to be alive and to make my own decision about a death date in the future. I can keep writing my story until the chickens come home. But to summarise my life story, support from Positively Women changed my life.

No one can predict your future. Your past doesn't determine your future. Have hope, and determination. The will to live can give a light at the end of the tunnel.

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Story written by Eileen

It was such an exciting time for us. We were thinking of getting married and starting a family. Finally, my dreams coming true. For some reason best known to himself my then partner decided to go for an HIV test. It turned out to be positive. Me, being the most loving partner and believing in fairytales, supported him and encouraged him that there was nothing to worry about, we will see this through together, as a team. We are, after all, the unshakeable dream team. I also went for a HIV test and found out that I am positive too. It was an all-time low. The shame, the uncertainty of the future. I was not so brave after all.

Little by little, through counselling sessions and faith in God, I regained my confidence. I became pregnant, but our relationship fell apart due to domestic violence.

I was back on the dating scene. How am I going to do this as a single mum? With faith in God, determination and inner strength, I started seeing other people but found it hard to share my HIV status. Then a friend introduced me to a friend of his, a nice Ugandan. A tall handsome man. I was not sure about him at first, but when I shared my status with him and gave him the option to leave, he embraced me and told me that he's not going anywhere. They were the best words I had heard in a very long time. Two years later, he is still by my side and cheering me on; going to hospital appointments, and even to Parliament, with me.

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Story written by Sassy One

I've always thought it would be lovely to have a set of twins, 2 for the price of 1! I remember my HIV diagnosis, two weeks in the hospital with pneumonia, I came out thinking: 'Life's too short.' Living with HIV gave me even more motivation to achieve all my dreams. There is no time to waste, I thought. Get a man, have those twins, travel. I was so excited until I realised, well, how do I find the man? What do I tell him? Do I say I am living with HIV? What will happen? Will I be safe? So many scary questions.

Maybe, I thought, it's not such a good idea to find a man. I realised that I first needed to find other people living with HIV, so I could ask them how they have done it. So my search began. Thankfully I ended up meeting people living with HIV who had all the information and tools to live well. They enlightened me about where and how to get accurate information. I learnt about mental health and was able to get counselling. I was diagnosed with depression and took medication for it. I was waiting for an immigration decision at the time and it was driving me crazy. I was always so angry. I had no recourse to public funds and no right to work so I was really struggling. How can the system take my dignity away like this? How am I expected to keep taking my medication and stay healthy? How is that even possible. This is a human right violation but who cares? I found out about volunteer opportunities with HIV charities and that is what helped me to keep my sanity.

I decided to focus on the volunteering, meeting other people living with HIV and getting regular support. Until I remembered that I used to want to have children. Maybe I should do it now, I thought, since I was with a guy at the time. The GP surgery where I went to find out about the process had no idea what to do with me after my HIV clinic asked me to go there for my artificial insemination. I went to the pharmacy who asked me to go back to the surgery. They surgery had never supported a woman living with HIV before. In the end I asked a colleague and they suggested a turkey baster. The process was so long and frustrating. One attempt took more than 8 months. I actually thought, I'm not sure I can go through with this. I felt sad afterwards. I wish the process was easier for me, because I feel that if it had been, perhaps I could have had my twins by now. I feel hopeful because now that I am well and connected to the HIV community and I have more confidence to take control of the process. I will make the move to have my babies when I'm ready because I now feel comfortable living with my HIV diagnosis and I realise that I am a human being, entitled to full human rights.

At 19 years old I was holding a 3-month-old baby, being told I was HIV positive and had to stop breast feeding immediately. No medication or tests were available. I had to wait 2 years for her to have her first HIV test and 5 years to get a proper confirmation about her HIV status. I was told that we only had 6 months - 2 years to live between us.

I was in the UK when I contracted HIV and received my diagnosis. I was given support. Housing support groups made it possible for me to create an alternative identity and isolate myself and my child from harmful family and friends. What helped me to cope during this journey was my personal values and convictions. I had a child that needed me. She had no one else. It was just the two of us. We are still living healthily, after 24 years.

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Story written by Me2

Just because I have named it...

I so miss the casual chats with my consultant, confidently walking into the clinic, my presence demanding attention, radiating positivity. We would go through my blood results together. He would give me a prescription and then we would chat.

Until one day in February my body refused to get out of bed, my mind was frustrated, how can this be? I am supposed to be running 7 miles before work. OK, maybe a few more minutes and then my body will start to behave...still nothing. In the days that followed there were many visits to the A&E, many tears. And then the ambulance came. I had never been in an ambulance before, I insisted on wearing my high heeled boots. The ambulance had blacked out windows. I didn't know where we were going. A long corridor. I still didn't know where I was. They asked for my belt, phone charger and scarf. They showed me to my room. The bathroom was filthy, so I cleaned it. Then I sat on the small bed, still not knowing where I was. A few minutes later, and then every 15 minutes that followed, they shone a bright light in my room, causing me to stir. I gave up on sleeping.

Morning came. A softly spoken lady sat elegantly and watched me as I shifted uncomfortably in the chair. It was only as I cast my eyes into the garden that I realised I was in a mental hospital. My heart, my mind and soul had gone into shock, after seven years of living with my diagnosis, gotten in sync: I am HIV positive... I am HIV positive...Fast forward seven years. I am here. I stand firm. I am living with HIV, not living in fear of HIV.

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Story written by Stella



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Story collection curated by Nell Osborne.