

**FFLAG** 



WHEN SOMEONE  
YOU LOVE IS  
DIAGNOSED WITH HIV

# What is FFLAG?

**FFLAG is a national voluntary organisation and registered charity**

**FFLAG** is dedicated to supporting parents, families and their gay, lesbian, bisexual and trans loved ones.

**FFLAG** offers support through its website, email answering service and local parents support groups in their efforts to help parents and families understand, accept and support their lesbian, gay, bisexual and trans members with love and pride.

**FFLAG** members are parents, carers and families of lesbian, gay, bisexual and trans (LGBT) people. LGBT people and families still face homophobia, biphobia and transphobia in our society, which brings in its wake prejudice, bullying and alienation.

**FFLAG** supports the full human and civil rights of lesbian, gay, bisexual and trans individuals.

**FFLAG** speaks out and acts to defend and enhance those human and civil rights.

## Patrons

Baron Cashman of Limehouse

Angela Mason CBE

Sir Ian McKellen CH CBE

Baroness Massey of Darwin

Prof Ian Rivers

Deidre Sanders

Peter Tatchell

# U=U

Undetectable = Untransmissible



This booklet is dedicated to the memory of Hatta Hodson, who was the first to recognise the importance of sharing the experience and knowledge gained by parents of HIV positive children with other parents and families, dispelling the myths and fears. This booklet could not have been produced without Hatta's enormous contribution and that of the dedicated mum who took Hatta's vision through to completion. The Trustees of FFLAG are grateful to them both.

Hatta worked tirelessly for many years with Families Together London ([www.familiesstogetherlondon.com](http://www.familiesstogetherlondon.com)), a voluntary group that provides a listening ear for parents and other family members of lesbian, gay, bisexual and transgender (LGBT) people. In recent years Hatta used her extensive knowledge to help many others understand the good news that U=U.

# Preface

This booklet has been written to help you understand what an HIV positive diagnosis means, including the treatment recommended to all people who are living with HIV and the possible side effects they may experience.

This booklet is not a medical document - our hope is that it provides answers to some of the questions and concerns you may have when you are first told about your loved one's diagnosis. For those who are looking for more specific medical details, we have included some helpful links to fact sheets and organisations that we hope will provide the information you are looking for.

The U=U drawing was made by Hatta's granddaughter, Hannah, to celebrate understanding that when someone living with HIV is on effective treatment that lowers the level of HIV to the point it is undetectable, not only will they not develop AIDS but they cannot transmit the virus to their partner.

# "I've been diagnosed

# "with HIV""

*"When my son told me he was HIV positive I felt devastated and believed he was going to die."*

You may feel a whole range of emotions when you hear the news that someone you love has been diagnosed with HIV, including shock and fear, worry and helplessness, possibly even anger. However, you may find surprisingly quickly that at the same time you also need facts as you are trying to come to terms with these feelings about the news you were totally unprepared for.

*"When I learnt that my son's long-term boyfriend was HIV positive, I felt my world fall apart. I was so afraid for my son. I didn't want to talk about it to any of my family or friends because I thought that if I did, I would never stop crying."*

*I had to educate myself and stop being haunted by all the negative images and misinformation that I remembered from the 1980s."*

# What is HIV – is it the same as AIDS?

HIV stands for Human Immunodeficiency Virus. HIV attacks the immune system, and gradually causes damage. This can mean that, without treatment and care, a person with HIV is at risk of developing serious infections and cancers that a healthy immune system would fight off.

AIDS stands for Acquired Immune Deficiency Syndrome. AIDS is used to describe a combination of potentially life-threatening infections and cancers, which can develop when someone's immune system has been damaged by HIV. If someone is on effective HIV treatment, they will not develop AIDS.

*“Many years ago when my son came out to me my first thought was that I was frightened that he would ‘catch AIDS’ and my reaction to him was to say “please don’t get AIDS”. Many years later when he told me he had been diagnosed as HIV positive and we talked about it, he reminded me of what I had said all those years ago. I felt stunned, upset and ashamed at what I had said - my fear had come from the awful AIDS campaign of the 1980s and its stigma and showed clearly the need for an up to date positive campaign about being diagnosed HIV positive today.”*

# Facts and myths about passing HIV to others

HIV is a delicate virus and does not survive for long outside of the body. For this reason, there is no risk of acquiring HIV during normal domestic interactions, such as hugging, sharing cutlery, sharing food or drink (even if the person preparing your food is living with HIV) or providing care as just a few examples.

When someone is on effective HIV treatment, it reduces the levels of virus in the body until it becomes undetectable. When someone is undetectable on treatment, they cannot pass the virus on through sex, even if they do not use condoms.

There can be a lot of misunderstanding about how HIV can be transmitted. For authoritative information about HIV transmission we recommend looking at the following links:

[www.aidsmap.com](http://www.aidsmap.com)

[www.aidsmap.com/about-hiv/impossible-routes-hiv-transmission](http://www.aidsmap.com/about-hiv/impossible-routes-hiv-transmission)

*“I felt guilty when I was told that someone I love was diagnosed as HIV positive because I was frightened that there may be a risk that it could be passed to my child, who loves them dearly. Now having been educated on the medical treatment of HIV my fears have been laid to rest and I am so happy that my child continues to have the same very happy relationship with our relative who is HIV positive.”*

# Treatment for HIV

Every person is of course different. However, when initially diagnosed it may take some time for the correct medication to be established - during this period there are likely to be frequent medical appointments and blood tests which check the amount of HIV (viral load) in the blood. As the viral load decreases, the person's immune system (CD4 cells) will become stronger. Once the amount of HIV in the body is reduced below a certain level, a person becomes 'undetectable'. This means that whilst the virus is still present in their body, it is in very small amounts. This doesn't mean that a person is 'cured' - it's important that they continue taking their medication, so that the HIV virus remains suppressed. If a person stops taking their medication for any reason, their viral load will increase.

Please see the link below for further information about the treatment for HIV:

[www.aidsmap.com/about-hiv/starting-hiv-treatment](http://www.aidsmap.com/about-hiv/starting-hiv-treatment)

## Physical effects that the diagnosis and treatment MAY have on them.

As with any medical condition - everyone is different so it is important to be aware that everyone's reaction to treatment will be unique to them.

When a person starts their treatment, they may have periods of being unwell whilst their doctor adjusts their medication. Seeing these side effects happening to the person you care about can be upsetting and alarming. For most people living with HIV, any side effects of treatment are minor or short-lived. If side effects persist, people with HIV should seek advice from their healthcare provider about alternative treatments. There is very helpful information available that hopefully will help you understand what they are going through and so relieve some of your concerns.

[www.aidsmap.com/about-hiv/side-effects](http://www.aidsmap.com/about-hiv/side-effects)

## The psychological impact on the person when they are diagnosed

Being diagnosed and living with a serious viral infection like HIV can have a significant emotional impact. People living with HIV, as a group, have higher rates of mental health problems than the general population. It can be upsetting and difficult watching someone you care about suffering both physically and mentally following their diagnosis, but support is available for them should they need it. The link below is to a booklet which helps people who have recently been diagnosed, however you may find it helps you to understand what they are going through so you can offer them support.

[www.aidsmap.com/about-hiv/hiv-mental-health-emotional-wellbeing](http://www.aidsmap.com/about-hiv/hiv-mental-health-emotional-wellbeing)

*"Watching the suffering and struggle my son went through when he started his HIV treatment was heartbreaking and harrowing, I had no idea that for some people the side effects for the first few months of treatment could be so difficult, physically and mentally - and apart from telling him I loved him and offering my help, I could do nothing to ease his pain."*

# Stigma

People living with HIV often feel anxious about telling others that they have HIV due to the fear of stigma or discrimination. Stigma is often attached to things people are afraid of. Ever since the first cases of AIDS in the early 1980s, people with HIV have been stigmatised.

Please see below the link to the aidsmap booklet that explains what stigma and discrimination are, makes some suggestions for how to deal with these problems and gives information about legal rights.

**[www.aidsmap.com/about-hiv/what-stigma](http://www.aidsmap.com/about-hiv/what-stigma)**

*"After being told my son was HIV positive, I felt frightened and very alone. Due to the stigma that exists around HIV I did not feel able to talk to my family and friends about his diagnosis and speaking to my local GP did not help, they were kind, but were unable to answer my questions about what he was going through."*

*A year after my son's diagnosis - having reached out to FFLAG I was put into contact with a remarkable and inspiring lady who by sharing her own vast experience and knowledge of HIV has informed and educated me - I now have better understanding of the virus and how far the medical treatment for it has come.*

*I feel the legacy of this wonderful lady's work must be that as much is done as is possible to remove the stigma linked to HIV and ensure the progress that has been made in the treatment of this virus is shared as widely as possible.*

# Final thoughts

It's not unusual (and it's ok) to feel a mix of emotions when you find out your loved one has been diagnosed with HIV. FFLAG hopes this booklet helps but it is important to seek help and advice for yourself if you feel you are struggling a bit. Do please be kind to yourself and recognise that you are likely to need some time and space to work through your feelings.

## Further useful links

Terrence Higgins Trust - Being Diagnosed with HIV:

**[www.tht.org.uk/hiv-and-sexual-health/being-diagnosed-hiv](http://www.tht.org.uk/hiv-and-sexual-health/being-diagnosed-hiv)**

Terrence Higgins Trust - Family and Friends:

**[www.tht.org.uk/hiv-and-sexual-health/being-diagnosed-hiv/telling-people/friends-and-family](http://www.tht.org.uk/hiv-and-sexual-health/being-diagnosed-hiv/telling-people/friends-and-family)**



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