FFLAG

U=U

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 lesbian, gay, bisexual, trans and non binary 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, trans and non binary members with love and pride.

FFLAG supporters are parents, carers and families of lesbian, gay, bisexual trans and non binary (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, trans and non binary individuals.

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

Patrons

Baron Cashman of Limehouse CBE
Sir Ian McKellen CH CBE
Bobbi Pickard
Prof Ian Rivers
Peter Tatchell

Undetectable = Untransmissible

This drawing by Hannah, Hatta's granddaughter, was the inspiration for the design on the front cover of this booklet.

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 was produced jointly by Hatta and Janice Fakes who shared the vision to create a booklet for other families and friends looking for support and information, as they both did when their own sons were diagnosed with HIV. The Trustees of FFLAG are grateful to them both.

Hatta worked tirelessly for many years with Families Together London **(www.familiestogetherlondon.com)**, a voluntary group that provides a listening ear for parents and other family members of lesbian, gay, bisexual, trans and non binary people. In her later years Hatta used her extensive knowledge to help many others understand the good news that U=U.

Introduction

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 the understanding that when someone living with HIV is on effective treatment not only will they not develop AIDS but they cannot pass on the virus to their partner. U=U stands for Undetectable means Untransmittable.

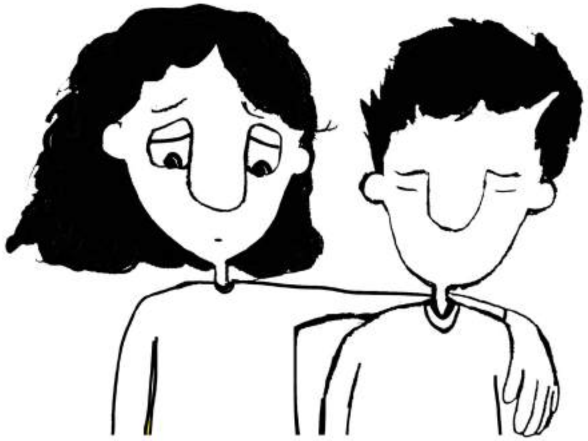
We hope that you find this booklet helpful. Your feedback, which will be treated confidentially, would be really useful and enable FFLAG to keep the booklets current and relevant. Your comments on any aspect of FFLAG's work are always appreciated. Please send comments to info@fflag.org.uk.

"As a consultant looking after people living with HIV, I am able to reassure my patients about effective treatments, stopping transmission and long life expectancies but often their more acute worries are of how their family and friends will take their diagnosis. The FFLAG 'Someone I love has HIV' booklet provides reassurance to families from others that have been through the same experience and is priceless to our patients and their loved ones. That experience is something that we as clinicians are often unable to provide. It has become a valued resource for us to use during the first weeks of a new HIV diagnosis."

Consultant in Sexual Health and HIV, Wiltshire Sexual Health,
Salisbury NHS Foundation Trust

"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?

No. 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."

Undetectable = Untransmissible

Facts and myths about passing HIV to others

MYTH: It's not possible to live a 'normal' life with HIV.

FACT: On effective treatment someone with HIV can lead a long, healthy and full life. An HIV diagnosis doesn't stop you from having children, working, playing sports, travelling or making future plans.

MYTH: You can get HIV by being around people who are HIV-positive.

FACT: 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 and crockery, sharing food or drink (even if the person preparing your food is living with HIV) or providing care as just a few examples.

MYTH: Sex with someone who has HIV is risky.

FACT: 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. This is often referred to as U=U, which stands for Undetectable means Untransmittable.

MYTH: HIV-positive people can't have children

FACT: For women living with HIV, effective HIV treatment and good obstetrics care means it is possible to give birth to babies who are not infected with the virus.

For more information about having a baby when you're living with HIV please see the following link:

www.aidsmap.com/about-hiv/having-baby-when-you-are-living-hiv

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

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, it becomes 'undetectable.' This means that, whilst the virus is still present in their body, it exists in such small amounts as to be undetectable. This doesn't mean that a person is 'cured' – it's important that they continue taking their medication, so that the 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

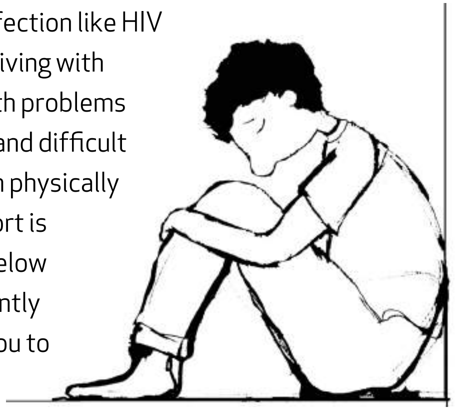
Physical effects that the diagnosis and treatment MAY have on them.

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. Side-effects are less common now than when HIV treatment was introduced, as there are now more drugs available and dosing has improved. 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 HIV clinic to discuss any adjustments to their treatment that may be necessary. 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-hiv-treatment

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

"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."

To read more about the impact of a diagnosis please go to the following link. Here you can read Amanda's story. Amanda is a trans woman living with HIV.

www.ght.org.uk/tdov23

How you can help?

It is vitally important that HIV medication is taken regularly as prescribed. From the outset, encouraging your loved one's adherence to treatment can make a crucial difference at a time when they may be feeling despondent. Gentle enquiries to jog their memory can make an important difference.

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 read the links below about stigma. The aidsmap link explains what stigma and discrimination are, makes some suggestions for how to deal with these problems and gives information about legal rights. The George House Trust link explains the importance of combating stigma if HIV is to be eradicated.

www.aidsmap.com/about-hiv/what-hiv-stigma

www.ght.org.uk/40-years-of-HIV

"With the shock and worry that my son was HIV positive came the stigma, the anxiety about telling people - my own reaction was based on the traumatic 1980's government campaign with a tombstone saying 'don't die of ignorance', and any reference I heard to HIV from others was also influenced by the advert, even in the 2020s.

I felt isolated and tried talking to my GP who was kind but could not answer my questions. For the first time in my life I felt I couldn't talk to those closest to me when I needed to most - my sisters and friends felt out of reach. I knew their understanding was based on the same campaign as mine was, so I was scared if I told them about my son he would be rejected by those who loved him. I was on the sidelines watching my son and feeling totally useless and isolated, believing he was going to die. It took months of anguish before I felt I could bring myself to tell my sisters. However when I did build up the confidence to talk to my family and friends I found they were the same as always, caring and supportive, accepting my son - I had spent all that time feeling irrationally frightened and alone just because of the stigma. My relief was immense.

Before speaking to my family and friends I reached out to FFLAG who put me in contact with Hatta. The relief at finding someone who understood was huge - she shared her vast experience and knowledge of HIV and how far medical treatment had progressed - however we both agreed even though our experiences were decades apart and the medical treatment had improved so much, the stigma was the same and we agreed to do whatever we could to try to stop it - so together we co-wrote this booklet."

Janice Fakes

An Important Message

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.

The end of AIDS

In 2014, the Joint United Nations Programme on HIV/AIDS (UNAIDS) launched the 95-95-95 targets. The aim was to diagnose 95% of all HIV-positive individuals, provide antiretroviral therapy (ART) for 95% of those diagnosed and achieve viral suppression for 95% of those treated by 2030.

The UK health authorities committed themselves to that target and in 2019 set out a vision of zero new HIV infections, zero discrimination and zero AIDS-related deaths by 2030.

The most serious obstacle to achieving this vision is stigma about HIV. Stigma
- hinders education about how to prevent infection
- results in delay in testing to identify if infection has taken place through fear of discrimination, which in turn
- delays the start of treatment, which leads to poorer health outcomes and meanwhile increases the risk of passing on the virus
- causes patients to hide their diagnosis from friends and family, depriving them of the peer and family support that is a key element in ensuring adherence to their treatment regime.

A future free from AIDS is foreseeable. FFLAG hopes this booklet can play a part in achieving that goal.

Further useful links

Aidsmap – Information about Undetectable means Untransmittable (U=U)
www.aidsmap.com/about-hiv/faq/what-does-undetectable-untransmittable-uu-mean

HIV information videos from aidsmap on a range of topics
www.aidsmap.com/videos/type/hiv-information

aidsmap – Healthy living with HIV
www.aidsmap.com/topic/healthy-living

Terrence Higgins Trust - Being Diagnosed with HIV:
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

If you download the digital version of this booklet from our website **(www.fflag.org.uk/booklets-posters-forms)** you will be able to click on any links featured in this guide without having to type them into your browser.

www.fflag.org.uk
email: info@fflag.org.uk

FFLAG
PO Box 495
Little Stoke
Bristol
BS34 9AP

Registered as a charity in England & Wales
Registered Charity 1079918

Published by FFLAG

We have done our best to ensure that the information in this booklet is correct as of November 2023. It is possible that some of the information may become inaccurate over time. The current version can be downloaded from our website.

Second Edition - 11/2023