

HIV Stigma

A resource for people living with HIV
when attending healthcare services



“

*When you experience
stigma it knocks your
confidence...*

***you feel like you
did when you were
first diagnosed.***

”

Introduction

Many people living with HIV are still experiencing HIV-related stigma and discrimination when attending healthcare services.

This is unacceptable.

Within NHS Greater Glasgow & Clyde (NHSGGC) we are working hard to tackle this issue. As part of this, the Brownlee HIV Patient Forum decided that this booklet was necessary for patients.

It has been developed by Brownlee Centre patients living with HIV for other patients using their words and ideas:

“To give fellow patients the confidence to speak out and the knowledge to question HIV stigma and discrimination in healthcare.”

For more information visit www.brownleehiv.org

What is Stigma?

Stigma is usually based on fear, ignorance and prejudice. Patients describe it as “*the look*” a “*gut feeling*” or they “*recognise the anxiety*” in the other person.

“

You just get **The Look**.

There's like, an immediate judgement. As if you've done something wrong.

”

“

There is a lot of inaccurate information about how HIV is transmitted.

*This creates irrational behaviour. **We need to educate people.***

”

Misconceptions and a lack of knowledge about HIV contribute to stigma. Sometimes, when faced with these we need to remind ourselves and others that they are incorrect and challenge them.

What is discrimination?

While stigma is found in a person's attitude or beliefs, discrimination is about their behaviour.

Discrimination means unjustly treating one person differently from another based on their characteristics.

HIV-related stigma and discrimination is when your HIV status has been disclosed and a member of staff then treats you differently. Disclosure can occur in person or through medical notes when and where relevant.

Below are some examples from HIV+ patients:

- Your appointment is delayed or you are moved to the end of the list.*
- The person puts on two pairs of gloves to treat you.*
- Openly discussing status in front of other staff or even patients.*
- Treatment was poor. Their fear made them aggressive towards you.*

How to challenge stigma?

When asked, patients said if you notice someone's behaviour changing towards you, or they seem frightened then the best course of action is to be assertive.

This might seem daunting, but be calm, speak clearly and try to find out what the problem is. Within this booklet there are some examples of how a conversation might go in certain scenarios to help you challenge stigma.

However, if you still feel that you have been unfairly treated then you have the right to take further action and this is detailed later in the booklet.

“

Stigma is wrong.

I don't put up with it anymore.

I'll tell them how it is, but

I've been diagnosed a long

time and I'm more confident.

I do worry about those

maybe not as confident.

”

Scenario 1

The following scenario looks at an interaction where HIV status has been disclosed and a healthcare worker (green cross) is taking blood from an HIV+ person (red ribbon).



Okay. I just. I just need to take some blood now.



I'm a bit concerned, they seem worried.

Is my HIV status worrying you?



Well yes... if I'm being honest, then yes a little bit.



Do you mind if I ask why?

Continued over

Scenario 1 *continued*



You're the first person I've taken blood from that I know has HIV. I don't know much about it.



*Sometimes people are afraid of 'catching' it, but HIV is actually pretty hard to transmit. **Standard precautions** (see box opposite) when taking blood are more than enough to protect you. There isn't anything different you need to do.*

Standard Precautions are intended for use by all staff, in all care settings, at all times, for all patients whether infection is known to be present or not. These include the use of gloves and aprons when in contact with blood and body fluids. Staff can refer to NHSGGC Prevention and Control of Infection Policy for more details.

Left feeling uncomfortable?

If you have any concerns about how you were treated then you can take further action, please see pages 18-21.

Scenario 2

The following scenario looks at an interaction where an HIV+ person (red ribbon) is attending service and they feel they should disclose their status to the healthcare worker (green cross).



Hi there. Come in and have a seat. How are you today?

Oh no... Do I need to tell them about my HIV?!



I'm very nervous. I nearly never came... but I know it's important.



I can see you are nervous. Is there anything in particular you are concerned about?



I'm not nervous about the procedure or the treatment. It's just that I feel I should tell you that... I have HIV?

Continued over

Scenario 2 *continued*



*I appreciate that you feel you should tell me. Thank you. However, it's unnecessary as I am not going to treat you differently to anyone else (see **Fact box** below)*

Fact box

- *Up to 25% of people living with HIV don't know they have it*
- *Healthcare staff don't need to treat you differently due to HIV*
- *You do not need to disclose your HIV status*
- *Your HIV status should remain confidential unless consent to disclose is given*

Left feeling uncomfortable?

If you have any concerns about how you were treated then you can take further action, please see pages 18-21.

Your rights

Everyone is entitled to fair and respectful treatment.

The Patient Rights (Scotland) Act 2011 which informed The Charter of Patient Rights and Responsibilities. This summarises what you can expect when you use NHS services and receive care in Scotland.

“

HIV is a protected characteristic under the 2010 Equality Act –
it is illegal to treat someone less favourably because of it.

”

The key rights for people living with HIV are:

Access

You cannot be denied treatment due to HIV.

Respect

You should be treated with dignity.

Safety

Your care should be effective.

Confidentiality

Your personal health information should be secure.

If you feel that any of these are being compromised due to stigma then ask to see someone else, or you can exercise your right to Feedback or Complain.

Feedback & Complaints

NHSGGC encourages feedback to improve service delivery.

If you wish to feedback your experience or make a complaint, all departments have information available on how to do that.

To make a complaint

Phone: 0141 201 4500

Email: complaints@ggc.scot.nhs.uk

Visit: www.nhsggc.org.uk

We know that some patients feel making a complaint it is “*too complicated*” or “*is more trouble than it is worth*”. In spite of this, please consider submitting feedback or at least speak to member of staff at the Brownlee Centre.

“

*It is important to complain...
**you could be preventing it
happening to someone else.***

”

Continued over

Feedback & Complaints *continued*

Patients have said “*positive feedback could be used to highlight good practice*”, but if you have a negative experience it has also been said “*it is important to complain... you could be preventing it happening to someone else*”.

Above all patients have stated it doesn't matter whether you are new or long-term diagnosed, first and foremost you have human rights and should be treated with dignity and respect irrespective of HIV.

“

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Additional copies available from:
Peer Support & Patient Engagement Manager
0141 211 0060