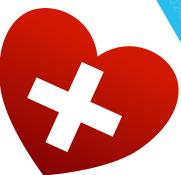
Lawson Unit Patient Panel Newsletter

Introduction

"This edition of the Lawson Unit Newsletter is particularly special as it's the first time it has been coproduced by Lawson Unit patients!! Collectively, we felt this was an important step as our patients need to be at the heart of everything we do.



I would like to extend a massive THANK YOU to our Lawson Unit Patient Panel group for their contribution to this Newsletter, in particular, David Fray and Nigel McCutcheon for designing, proof reading, sense-checking and making it look so fantastic."

Colly Fitzpatrick - Clinical Nurse Specialist

What is the Patient Panel?

The Patient Panel is a group of patients of the Lawson Unit, who volunteer their time to attend panel meetings, where we share our experiences of using the clinic. This important feedback helps improve the experience of using the clinic for patients and also for staff.

We can learn so much about ourselves, and our own journey with HIV, if we learn from the experiences and strategies of our fellow patients. The current Panel agrees that we would like representation from as many diverse people affected by HIV as possible.

Patient Panel Meetings are held on Wednesday evenings approximately every three months. Light refreshments are provided, so you don't miss your dinner.

So, if you are are living with HIV, and can spare a few evenings a year, then why not share your unique perspective and become a Patient Panel member?

Please <u>contact Clinical Nurse Specialist</u> <u>Colly Fitzpatrick</u> at the Lawson Unit for exact dates, times and further details.

Thanks to the local Brighton drag queens!!

In October, Brighton drag queens ran a fundraising event to raise money for some artwork at The Lawson Unit.

THANK YOU SO MUCH!! Thanks also to <u>Legends</u> (@LegendsBrighton) for hosting the event, and to <u>Brighton</u> <u>Box Gallery</u> (@box_brighton) for the amazing images.

Lawson Unit 'community space'

Now that we have settled into our new home, we are delighted to have space to welcome back our community partners into the Lawson Unit. These include: <u>Lunch Positive</u>, <u>THT</u>, <u>Change Grow Live</u>, (CGL), Psychology and Psychiatry services & Peer Mentors from <u>The Sussex</u> <u>Beacon</u>.

Pictured below is the community space and the smaller image shows Welfare Rights Advisor, Michael from <u>Terrence Higgins Trust Brighton</u>, on the Wednesday when we visited

Lunch Positive

Lunch Positive is a local HIV charity now entering its 15th year of community based support for people living with HIV in Brighton & Hove and across Sussex.

Led, and provided by people living with HIV, we run a range of welcoming and inclusive services.



In Brighton we bring people together to provide social support, peer-support, advice & information at our weekly Tuesday drop-In and Friday lunch club, and our quarterly evening Supper club.

We run an HIV befriending & buddying scheme, and also provide a range of wellbeing activities.

We connect people with specialist support and workers from other organisations and our own Support Worker is available to provide help and advice.

We have a food bank and provide food parcels.

Our amazing volunteers are part of a programme that is always open to involve more people living with HIV in a range of roles that help deliver services and provide peer-support.

"It's more than just lunch, it's a whole community. It's provided me with support and involvement that I've not found anywhere else" (Service User)

Please look at our website <u>www.lunchpositive.org</u> if you'd like to know more, or come along. You can also contact **Jim** our Support Worker on **07312 862768**

jim.stanford@lunchpositive.org

im can explain how things work and help with your first visits. We know that the first steps becoming involved in a new group can sometimes feel a bit daunting, and we are always here to be at your side whilst you first come along.



Looking after your mental health

People with HIV often struggle more with mental health issues compared to others. We don't fully understand why, but research indicates it might be because of a combination of factors, such as ongoing immune system problems from HIV, feeling judged or treated unfairly, and facing challenges related to money or social status.

It is important to talk to a healthcare professional if you are worried about your mental health because several sources of support are available, and you can choose what suits you best.

For a full list of services available, please visit

www.brightonsexualhealth.com/hiv-mental-health

Your GP

If you are having thoughts, feelings and emotions that are affecting your daily life for the worse, you might be struggling with your mental health. Your GP provides overall care of your physical and mental health. They can help you get the support you need.

Where to get urgent help / crisis support

If you are experiencing a mental health emergency or thinking about ending your life, **reaching out can help you realise you are not alone and that you do have options**.



If your life is at risk right now, or you may have seriously harmed yourself

- Call 999 for an ambulance or go straight to A&E
- Call 111 and choose option '2' for urgent mental health support

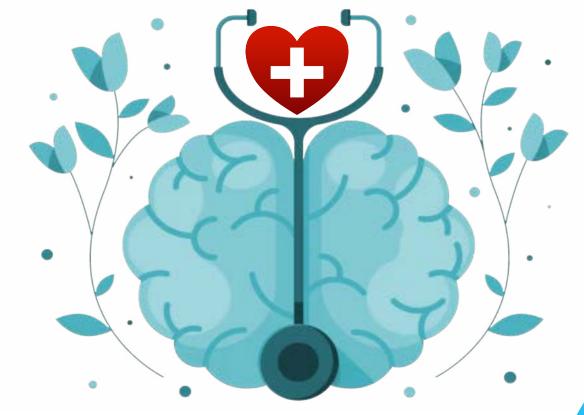
The 'Mental Health Rapid Response' service

This service supports adults who are experiencing an **immediate** crisis with their mental health, who are at risk of harming themselves or others.



Open 24/7 for Brighton & Hove residents

You can also contact the Samaritans on **116 123** to talk about your mental health or suicidal thoughts.



What is Mindfulness?

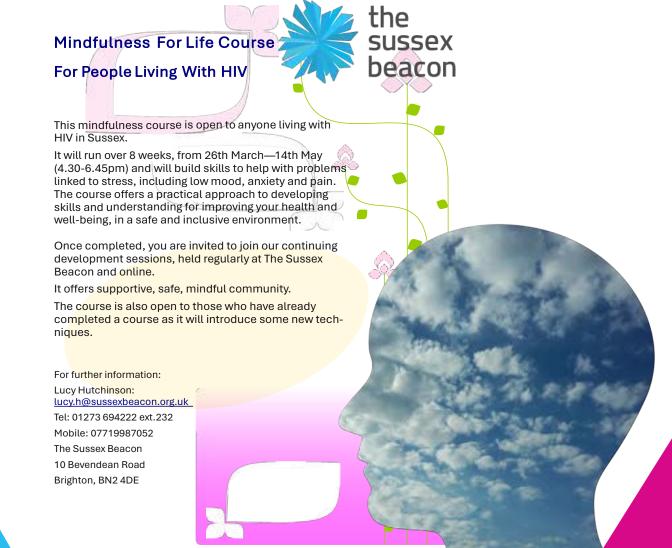
Mindfulness is being conscious and aware, without being reactive to the mind, thoughts, and actions. It is a useful tool with which we can manage our mental health. The future and past can influence how we behave in the present, but this is not always good for us. For example; self medicating to avoid mental or physical pain may be a habit, and harmful. By becoming more aware of our mind we can choose to react differently.

The Sussex Beacon Mindfulness Course

The Sussex Beacon is running another mindfulness course. The mindful meditation course was originally developed by doctors to help patients manage long term conditions such as depression, pain and anxiety, where medication has not given much benefit.

The benefit of doing the course with the Beacon, is that there are monthly follow up sessions to help maintain practice and discuss aspects of metal health care. Also, with this course being at the Beacon, we know that it is a safe positive space for people living with HIV.

See the poster below for more details.



HIV opt-out testing initiative

In 2022, the UK government announced £20 million to hugely expand its highly successful opt-out HIV testing programme to emergency departments in an additional 33 areas with high HIV prevalence. This investment in HIV testing is crucial as part of Government's commitment to ending new HIV cases by 2030 and to help diagnose the estimated 4,400 people in England who are unaware they are HIV positive.

The HIV opt-out testing programme was initially launched in London, Brighton, Manchester and Blackpool from April 2022, and now includes 46 hospitals throughout the UK. With this landmark investment, opt-out HIV testing in A&Es will account for more than half of all tests in England.

Opt-out testing means that routine bloods taken at these hospital locations will include an HIV test, unless the individual specifically requests otherwise.

In Brighton, there have been 10 new HIV diagnoses made via the A&E opt-out testing initiative over the last 12 months. It is inevitable that there may be an initial increase of new HIV diagnoses as we expand testing. However, this major ramping up of testing is absolutely crucial to find the 4,400 people still living with undiagnosed HIV - and help us end new transmissions by 2030.

Why are we telling you this?

Well, there is no cure for HIV yet, but if we test everybody, then we can get their HIV controlled, to the extent that we could be one of the first countries to have no new cases by the year 2030.





In modern life we are being encouraged to use services online, such as banking, utility bills and ordering prescriptions from our GP's.

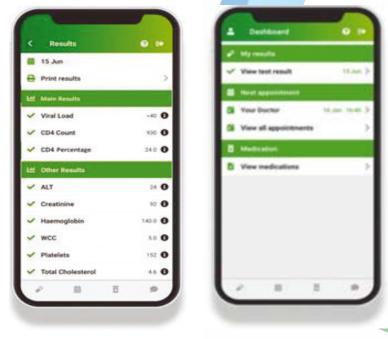
The quality of our experience of using online services may be mixed, however digital tools can make life easier for us and safer too.

On these pages we list two digital tools that patient panel members have found useful in managing their treatment and care with HIV.

Manage your HIV care with EmERGE

EmERGE is a smart phone App which helps us patients to manage our blood test results, appointments and allows us to message the Lawson Unit in a familiar chat/text style.

One of the benefits of using this App is to be able to show other health professionals, such as GP's our blood test results, which can save time and



reduce repeating blood tests.

The EmERGE App is very secure and support for the App is available from a dedicated secretary, who is based at the Lawson Unit.

If you think this would suit you, or have any questions about EmERGE, ask your Lawson Unit medical professional for more details.

What is a QR code?

A QR code is a square image containing lots of dots, such as the image on the right. These are handy barcodes that can be used by a smart phone to interact with something. If your phone is compatible, a link will appear when you hover your phone camera over the QR code. Click on the link to see where it takes you. (In this case it's our last newsletter).



Drug interaction database for HIV medicines and others.

At the recent Patient Panel meeting in January 2024, we shared with each other the App called "iChart"

Have you ever been unsure whether or not an over the counter, or similar, medicine or drug would interact badly with your HIV medication?

Well, the pharmacists at Liverpool University have created a free to use App that can be used to calculate possible drug interactions.

For example; is **Doravirine** taken alongside herbal remedy **St Johns Wort** safe? The result from the database says "**Do Not Coadminister**" in a red box, (see the image on the right).



It must be said that every patient is unique, and surprising interactions may still occur, so it is always good practise to speak to your friendly Lawson Unit Pharmacy team if you want advice, especially if your interaction comes up with '**Potential Interaction**' in an orange box.

Nevertheless the HIV iChart is a useful tool, especially if you are away travelling and need advice and assurance, possibly for a non HIV specialist medical professional. The App called "iChart" is available for all smartphones that use <u>Apple</u> or <u>Android</u> operating systems.

If you are reading this online then click on the links or, otherwise, search "HIV iChart" in your search engine of choice.

If you do not have a smart phone, the database of drug interactions is available at <u>www.hiv-druginteractions.org</u>

> When browsing which app to get, select the one with this official iChart App icon



The team at **aidsmap** recently published a page about drug interactions on their website. Visit <u>this link</u> or search their site for "<u>Drug Interactions</u>"

An update from BHIVA regarding the use of statins

A <u>statin</u> is a class of drug that reduces the risk of cardio vascular events, such as heart attacks. They do this by reducing cholesterol.

On 21 November 2023, the <u>British HIV Association (BHIVA)</u> published rapid guidance relating to the use of statins for people living with HIV.

The 8-page document is in response to results from the <u>REPRIEVE</u> study published earlier this year that were also presented at the <u>IAS</u> and <u>EACS</u> conferences.

As a result of the <u>REPRIEVE study</u>, <u>BHIVA</u> now suggest that ALL people living with HIV aged 40 years or older should be offered a statin for primary prevention of cardiovascular disease irrespective of current cholesterol levels – thereby preventing cardiovascular disease **before** it occurs.

How to manage your cholesterol

Eat more:

Cut down on saturated fat

Exercise more

Stop smoking

Cut down on alcohol

Oily fish, like mackerel and salmon

Brown rice, wholegrain bread and wholewheat pasta

Nuts and seeds

Fruits and vegetables

How to contact the Lawson Unit

Telephone: 01273 664722

Email: uhsussex.lawsonunit@nhs.net

Website: www.brightonsexualhealth.com/advice/hiv-care/

For HIV related out of hours queries, please contact Ward B6 by telephone 01273 523061

HIV support services in Brighton & Hove

The Sussex Beacon (www.sussexbeacon.org.uk)

Charity Inpatient Unit and support services

Terrence Higgins Trust (<u>www.tht.org.uk</u>)

National and local support, advice and campaigning

Lunch Positive (www.lunchpositive.org)

Local peer led support services including weekly lunch club

Local LGBTQ+ mental health support

Switchboard (www.switchboard.org.uk)

Provides advice and support to LGBTQ+ people

Mind Out (www.mindout.org.uk)

Local LGBTQ+ service from the national mental health support and advice charity

Useful Web links

www.aidsmap.com

The national HIV information directory

www.i-base.info

HIV treatment information and advocacy

www.nat.org.uk

HIV rights charity







www.positivelyuk.org

Positively UK provides peer-led support, advocacy and information

www.bhiva.org

BHIVA is the leading UK association representing professionals in HIV care















