

## Newsletter

# Brotherton Wing Clinic

September 2023

### Welcome

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This newsletter was suggested by our BWC Patient Focus Groups and has been designed with help from some of our service users and our third sector partners (BHA Skyline and The Brunswick Centre). We hope you find it useful. If you have any suggestions for our next newsletter please let us know.

#### Next BWC Patient Focus Group Meetings

We run service user focus groups at least twice a year – usually in May and November. When the new dates, times and venues are finalised we will add these to the BWC webpage. If you would like to attend one of these meetings, please inform a member of the BWC team or email us: [leedsth-tr.bwadmin@nhs.net](mailto:leedsth-tr.bwadmin@nhs.net)

#### BWC Webpage

Just google 'HIV service Leeds' or use the link below:

<http://www.leedsth.nhs.uk/a-z-of-services/hiv-outpatient-service/>

Please have a look and let us know what you think.

### U25 PLWHIV & peer mentors

#### Please help our Under25 patients living with HIV (U25 PLWHIV). Call for U25 peer mentors!

Part of the privilege of working with our U25 PLWHIV is the sense of joy, potential and hope for the future that they bring.

Imagine being 5, 15 or 25 and living with HIV, whilst having to deal with taking tablets certainly bigger & less tasty than Smarties; beginning to understand your sexual or gender identity and negotiate relationships plus the worry of exams; then grappling with jobs, housing, bills and potentially starting a family of your own. Like any chronic health condition, taking daily meds may be demanding and not always your first priority. But unlike other chronic health conditions, you also don't feel free to talk to school mates, teachers, employers, or pastors to ask for understanding and help when you need it; and if there is silence and stigma about HIV at home it can be confusing and isolating. The fear of rejection by others and fears around safer sex can be overwhelming.

That's why at BWC we work closely with colleagues in children's, women's and sexual health, psychology, our local HIV support organisations, and our Yorkshire regional CHIVA support worker (Children's HIV Association) to try and provide holistic care appropriate to their level of understanding as a young person with HIV

grows up and moves from children's to adult HIV services. It's essential that they understand what's going on in their bodies, how well this can be controlled and how important it is to ask for help when they're struggling - and of course how important the trusted adults in their lives can be. If they don't have that support, how can we ensure they get the right advice on jobs, benefits, rent and cost of living issues; as well as health specific info on U=U, PEP and PrEP, contraception, and safer sex.

We hope that our U25 PLWHIV can feel empowered to tell us what they need and what's worrying them. At our Young Adult Clinic (YAC!) held in the university holidays, we're asking them how they feel about young peer mentors; what they would be looking for and whether they would want to train as one. Peer mentors share their knowledge and experience to help people improve their own understanding of HIV and treatment, take greater care of their health, and build confidence in living with and talking about HIV. If you're U25 and living with HIV and would like to train as a peer mentor please inform a member of the BWC team or email us: [leedsth-tr.bwadmin@nhs.net](mailto:leedsth-tr.bwadmin@nhs.net) or contact Karla Green, volunteer coordinator at BHASkyline: [karla@thebha.org.uk](mailto:karla@thebha.org.uk). You'd be offered peer mentor training through BHASkyline, our Leeds HIV support service, but also be offered supervision and support by CHIVA. So, if you think this might be for you, please get in touch.

## COVID-19 vaccines

Are safe and recommended for everyone living with HIV. They don't cause any HIV medication problems. Spring and Autumn boosters are recommended for all people living with HIV.

## Do You Know About U = U?

### Undetectable = Untransmittable

Did you know that having an undetectable viral load on HIV treatment (ART) stops HIV transmission? For more information please ask one of the BWC team or read:

<http://li-base.info/wp-content/uploads/2018/09/A5-factsheet-UU.pdf>

## Injectable HIV treatment...

As NICE have approved this new treatment and it is now available on the NHS, we like all other HIV services across the UK, are making plans to start our new injectable HIV treatment service.

In order to do this safely we need to start this new service in Leeds initially and then hope to be able to roll it out to our Wakefield and Dewsbury clinics as soon as possible.

Injectable treatment is not suitable for everyone. People on injectable treatment need to be able to attend clinic every 2 months for 2 injections (one into each buttock muscle) and blood tests. It is also important to be aware that recent evidence has shown that this treatment stopped working after 3 years for 1 in 40 people despite these individuals having all their injections on time.

If you are interested in, or have questions about, the new injectable treatment please ask your doctor/nurse at your next clinic visit. We also have more detailed information about this treatment for you to read in clinic and on our website.

## Research Update

### Our currently active trials are:

**LAPTOP** - an international trial which started at BWC in July 2019. This study is comparing two different HIV treatments, Bikarvy vs Symtuza, in people who are diagnosed late. We recruited 8 people. This study is now closed to recruitment.

**GenAfrica & it's Cov-Africa sub-study**- national studies investigating the genetic basis of chronic kidney disease & the impact of COVID-19 on black people living with HIV in the UK, respectively. Recruitment has now closed.

**POSITIVE VOICES 2022** - a national survey of people living with HIV. It aims to capture the lived experience and needs of people receiving HIV care in the UK. This survey has now closed to recruitment.

Thank you to all our patients who take part in our research studies. We will share the results of the above studies with you when they are available. If you want any more information about research at BWC please ask one of the team.

## Sexual health screens

**Sexual health screens** are quick and easy to do and available for all our service users at their routine clinic visits. At Leeds, please ask the doctor or nurse you are seeing, and they will help you with this when you go to have your bloods taken. You can then do your swabs yourself - the team will show you how. At Wakefield and Dewsbury please ask the doctor or nurse at your appointment and they will help you with this.

Please note: As Sexual Health screening is done via local sexual health services - Leeds Sexual Health in Leeds, Locala in Dewsbury & Spectrum in Wakefield, we will need to register you with one of these services if you would like a sexual health screen.

If you have symptoms or have been in contact with an STI and need help arranging an appointment at your local sexual health service please let one of the BWC team know and we will do everything we can to help you with this.

## Do you know about PREP?

PREP is for HIV negative individuals who are at high risk of being infected with HIV and is available free on the NHS. If you are not taking HIV treatment yet, have recently started treatment or you are struggling to take your HIV treatment, then your partner(s) may benefit from PrEP. Please ask one of the BWC team if you have any questions about PrEP.

## Would you like to talk to someone else living with HIV?

Our peer mentors are people living with HIV who have been trained by BHA Skyline through a nationally recognised scheme. They offer peer support to anyone accessing care at BWC. If you think you would benefit from talking to someone else living with HIV, please ask the BWC team or BHA Skyline staff about the peer mentor service.

## Personal Stories from People Living with HIV

Celebrating some of the voices of our LGBT+ community from the LHTT staff network - Episode 4 'In conversation with Nas': <https://www.leedsth.nhs.uk/about-us/podcast-voices-lgbt-community/>

If anyone else would like to share their personal story about their HIV journey, please let us know. These can be anonymous. If anyone would like to share their personal story please let us know. These can be anonymous.