[BPS MATTERS](https://behcetspatients.org.uk/)

SUMMER 2024

BPS Matters is a quarterly newsletter that highlights the support the Behçet’s Support Coordinators are providing at the Centres of Excellence:

Published by Behçet’s Patient Support

*Behçet’s Support Coordinators support patients to help them live well with Behçet’s.*

*They do this through offering advice, guidance and referral services based upon “What matters to the patient”*

*It is important the patient has a voice and that we actively listen to what they have to say so that we may develop and improve support made available to them*

*In this issue we have encompassed patient feedback from the quarter to highlight how the range of support provided has had a positive impact on the non-medical needs of patients at varying stages of their Behçet’s journey.*

***“Always makes a difference,***

***The*** *Behçet’s* ***Support Coordinator is always reassuring and ready to offer support when needed”***

The physical and mental health wellbeing of the patient is a key factor in the flaring nature of Behçet’s. A reduction in the stress levels of a patient have been proven to reduce the frequency and symptoms of Behçet’s flares.

* We have started to offer non-medical Health and Wellbeing MOTs to patients.  These focus on ‘What Matters to You’ for a patient. They include Financial Wellbeing, Housing Support etc, but also include areas such as Movement and Physical Activity, Food and Sleep, and Social Connection
* A number of patients have been added to the Birmingham Virtual Walking Group – we are looking at creating a ‘How To’ document to make using the main features easier.

***“It was nice to check in with the Support Coordinator and I appreciated her getting in contact.”***

As the Support co-ordinators check in with the patients at the centres – they work with them to identify what their non-medical needs are and how they can assist.

There is also a ‘Checking In Service’ via telephone or text to patients living alone

We have been able to support several patients with several referrals and support letters

* 2 referrals to Vasculitis UK Summer Cabin in Scotland
* 2 Willow Foundation referrals for experiences
* 3 Referrals to Behçet’s UK for Family Fun Day
* 1 Behçet’s UK Grant Aid request
* 1 Referral to Doula UK
* Reasonable adjustment support letter for a patient’s apprenticeship assessment day.

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| ***“*A huge difference,** **I would struggle even more if they weren't available.*”*****Housing**Appropriate housing for many patients remains a major challenge. It is a key area where the role of the Support Coordinator is crucial in ensuring patients continue to have their housing needs metHousing demand continues to remain at an all-time high in London and across the regions. We have seen anincrease in patients requesting support to get on council waiting lists as opposed to private rentals.  Many London councils are now charging Social Housing residents a nominal fee for council tax, so, we are navigating this system for a number of patients who need to set up and make paymentsWe assisted 2 patients with emergency housing who are now in temporary accommodation (hostels)**Education**Being in education, employment and volunteering can have such a positive effect on the mental wellbeing of a patients.We continue to support patients to remain, enter the workplace, access training or achieve a career aspiration.We are seeing an encouraging trend where many young patients are achieving their academic and training goals. The number in paid employment, particularly younger patients, seems to be increasingWe continue to encourage and support with 1-1 sessions and support letters where needed.***“*Having someone check in like that…****it helps, it makes you feel heard and not just a number*”***There has been an increase in support provided to patients who are currently Asylum Seekers/Refugees. We have had a positive experience liaising with a charity and an NHS  funded Outreach Medical Teamthat supports asylum seekers. This has been very helpful**.**It can be a challenge locating services that support Asylum Seekers /Refugees as each area has different services, some statutory, other small charities and the approaches for providing support canvary enormously.On one occasion our Support Coordinator contacted 8 charities before finding one that could provideassistanceA need has been identified to better the pathway for Asylum Seeker /Refugee support so that we mayfurther improve the help we can offer. This is something the Support Coordinators are actively investigating.Language Line is proving to be an excellent resource when working with patients who need interpreters. It was possible to join a consultation via language line to do a holistic assessment of patients non-medical needs and take appropriate actions to support them. |
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**“I now have more of an understanding of how to claim PIP”**

The cost-of-living crisis continues to put pressure on the economic resources of Behçet’s patients. Supporting patients through the Personal Independence Payment (PIP) process remains a key function of the Support Coordinators.

We continue to assist patients completing first time PIP applications and writing general supporting letters.  We are seeing a steady increase in the number of new applications.

We continue to assist patients with Mandatory Reconsiderations for both standard and enhanced rates. Currently working on 2 appeals in this area.

We are also currently assisting several patients with debt relief.

**“As always, the Support Coordinators help and advice is invaluable”**

The Support Coordinators are constantly looking for opportunity to expand their personal and professional knowledge base - updating their skills with ongoing training and development allows them to support the ever changing and often complex non-medical needs of Behçet’s Patients.

Skill and information sharing is also an important part of what Support Coordinators do – through writing articles, sign posting and knowledge transfer.

**Training and development**

Support Coordinators continued to make effective use of the E-lfh learning platform.

Mandatory Training continues to be undertaken (in line with NHS Honorary Contract requirement)

Courses completed include:

Safeguarding 3 for adults and will be attending Safeguarding 3 for children.

**Articles**

Articles published in Behçet’s UK Newsletter

* Wellbeing MOTs
* Movement and Physical Activity
* Recipe and food articles
* ULEZ and Congestion Charge and transport for patients attending the Royal London.

Joint article with Dental Ph D student

Assisting a young patient write her story of the trials and tribulations of living with BD and through sheer determination what brilliant success and achievements she has had.

**Other support**

We have been actively involved in encouraging young patients to take part in Quality of life research at the Liverpool Centre

Patients struggling to find dental care have been supported with signposting, information and help locating NHS dentists.

Liaising with Royal London’s Eye Care Liaison Officer who has kindly provided us with information and contact details for our visually impaired patients who may need the support of the RNIB

As summer approaches there have been several Travel Insurance queries

We have seen an increase in request for…

 London transport badges to wear on public transport (not all illnesses are visible)

Behçet’s Guide for GP’s (very good simple guide)

Employment guides and support (in form of letters) explaining Behçet’s to employers/asking reasonable adjustments

***“Thank you for the work you do!!”***



[Click here for the June 2024 Update Data sheet.](https://behcetspatients.org.uk/data-sheet)

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**ANNUAL REPORT AND ACCOUNTS AVAILABLE  FOR DOWNLOAD** [**HERE**](https://register-of-charities.charitycommission.gov.uk/charity-search/-/charity-details/5029228/accounts-and-annual-returns) **FOR FINANCIAL YEAR 2023/2024**

*The Behçet’s Patients Support charity works in partnership with the relevant NHS Trust which provides medical care for patients with Behçet’s. The aim of the Centres of Excellence is to ensure that patients with Behçet’s can access timely diagnosis and receive optimal treatment across England and can access the non-medical services provided by the Behçet’s Patients Support charity staff in each centre.*