

BPS MATTERS

SPRING 2025

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

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Behçet's Support Coordinators support patients to help them live well with Behçet's. They do this through offering advice, guidance, signposting and referral services based upon "What matters to the patient."

In this issue we have encompassed "*Patient Feedback*" over the year to highlight how the range of support provided has had a positive impact on the non-medical needs of patients at the varying stages of their Behçet's journey.

'Thank you to all who offer help & support on this rare complex and lifelong condition - knowing I can contact someone for support is a huge comfort.'

The Behçet's Patient support coordinators play a crucial role in enhancing the care and support provided to patients.

They continue to check in with the patients at the centres – and they work with them to identify what their non-medical needs are and how they can assist. They also continue to support outside the clinic through telephone calls, message and email. They can offer regular weekly 'checking in' telephone calls.

Where possible they support new patients before their first clinic in terms of reducing anxiety, clinic process familiarisation, travel assistance and advice.

'The support coordinator in clinic is wonderful. So friendly and extremely supportive, very interested in your wellbeing and day-to-day, which really makes a difference. Clinic days wouldn't be the same without her.'

Support coordinators focus on holistic care, addressing not just the medical but also the social, emotional, and practical needs of patients. This comprehensive approach helps patients manage their condition more effectively.

Over the period the team have provided support to patients though

- Working with patients on healthy eating and increasing physical activity. Recently offering specific advice on healthy eating over Ramadan.
- Providing specific issue support on request on topics such as dementia and mental health crisis.
- Referring and assisting patients in applying for OT Home Assessments for patients who required adaptations, including wet rooms in the bathrooms and aids in the kitchens.
- Supporting applications for Willow Foundation and Vasculitis UK Respite Cabin.
- Working on a template with clinic for an easier travel claim as recent changes to guidelines for this benefit have changed, making it harder to get reimbursed for both patient and companion.

'Support coordinator is a godsend she goes above and beyond to help us if she hasn't heard from us in a while or if she has done anything to help letters or forms or calls, she always rings to see if went ok or if she needs to do anything else to help'

Support coordinators advocate for patients, helping them navigate the healthcare system and access necessary services. They assist with practical matters such as benefits advice, workplace reasonable adjustments, and educational support.

The team manage a steady flow of support letters for PIP, employers, DWP benefits, Universities, schools and housing.

Having a support letter that explains Behcet's disease as a complex and unknown condition can be very valuable. For patients who need reasonable adjustments at work or school, a support letter can provide a clear explanation of their condition.

This can help employers or educators understand the need for flexibility and support during flare-ups or medical appointments.

Patients can use the letter to advocate for themselves in various situations, such as applying for disability benefits or accessing community resources. It can also empower patients to explain their condition confidently to others.

'The most wonderful care.

They listen, care and give me great advice to help me in all sorts of ways.

I can't praise them enough.'

To ensure a more integrated and holistic approach to patient care it is important for the team to stay informed about current trends This also helps the team better collaborate with other healthcare professionals and organizations.

Trends

- Increase in requests for PIP and other welfare benefits, but much harder getting awards due to tighter government restrictions. There is a real cost of living impact on this. Many patients are no longer being awarded PIP at review time.
- Rising trend for many PIP applicants to use private firms/solicitors due to the increased government restrictions.
- Increased requests for support letters from patients for lawyers and solicitors for issues such as immigration and other legal matters.
- Increasing patient concerns about recent government announcements about proposed changes to welfare.
- Medical priority for housing continues to be a regular request from London patients.
- Travel costs are still a big issue for many patients.
- We are seeing an increase in mental health issues/difficulties and more specifically psychology discussions.

'Being diagnosed with this sickness and realising there are people like my support coordinator there to support you makes a vast difference.'

To ensure that the Behcet's support coordinators can provide the best possible care and support to their patients. It is important that they engage in continuous education to stay updated on the latest and best practices.

They endeavour to maintain and broaden their wider networks which allows them to connect with other professionals and organizations, sharing knowledge and best practices.

Team development and networking are essential for a Behçet's Support Coordinator because this enhances the quality of support provided to patients, fosters collaboration, and contributes to personal and professional growth.

Team Development

All Support Coordinators ensure they are up to date with all NHS mandatory training.

Other education has included.

- Supporting People with Health Conditions into Work: Individual Placement and Support (IPS)
- Linked In Marketing
- Safe Surgeries e-learning – improving access to primary care – Doctors of the World

Networking

The team have also sought opportunity to network across the sector in the following ways.

Employment

Linking with a local Job Centre Disability Employment team to get guidance on directing a patient.

Social Care

Linking with the homeless charity 'Centrepoin't' who have been excellent in providing support to those who have either no fixed abode or are being constantly moved.

This has potentially serious implications i.e. the patient may not receive their appointments and thus not attend clinic and ultimately lose contact with the service.

By liaising with the appropriate authorities, the support coordinators have been able to minimise this occurrence.

Other Professionals

Support Coordinator attended online Webinar for Scottish Rare Diseases Group who were discussing a Nurse role for BD. They currently have no dedicated Behçet's Service. Our Support Coordinator gave an overview of the Behçet's Support Coordinator role which was well received. The professional attendees were very impressed about our role.

Contacting Doctors of the World and providing links to training and information.

Working with Headway Support Worker to support a patient in making healthier activity choices,

CQUIN

A number of the team attended the CQUIN meeting in Birmingham. It was a good opportunity to enjoy a face-to-face meeting, meet the clinic teams and discuss future planning and initiatives.

Linked In

We have recently set up a LinkedIn business page which has included developing a marketing strategy, a posting calendar and then creating posts, scheduling posts and posting on behalf of the team.

We encourage our Centre Teams to follow our page.

[Behçet's patients support | Search | LinkedIn](#)

'Keep up the great work!'



[Click here for the March 2025 Update Data sheet.](#)

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ANNUAL REPORT AND ACCOUNTS AVAILABLE FOR DOWNLOAD [HERE](#) 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.