

BPS MATTERS

AUTUMN 2025

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

The Behçet's support co-ordinators continue to provide vital support for patients and families living with Behçet's.

They do this through offering advice, guidance, signposting and referral services based upon "What matters to the patient."

From practical help with benefits and housing, to workplace advice and emotional wellbeing, their work reflects the wide range of challenges our patients face.

In this issue we have encompassed recent *"Patient Feedback"* 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.

Helping Patients with Work, Study & Life Goals

Our Behçet's support coordinators continue to support patients in staying employed, returning to education, or exploring new opportunities. Whether it's writing letters for employers, helping with training applications, or simply offering encouragement, they're making a real impact.

"Support excellent, advice very helpful."

"Big difference in support and I feel well advised."

We've seen great outcomes for patients in retail, IT, banking, and public services, with many reporting successful workplace adjustments. Employer booklets are still popular, and we're regularly asked to provide letters for schools, colleges, and universities—especially with the new academic year underway. We're also helping patients navigate the switch from ESA to Universal Credit, particularly those facing language barriers.

Benefits, Legal Support & Advocacy

Navigating benefits can be overwhelming, but our Coordinators are right there beside patients—offering guidance, writing supporting letters, and connecting them with trusted agencies.

"Support Coordinator has helped me with PIP forms, housing and general queries. She is someone I can rely on and is so kind and friendly."

We are seeing more patients use private firms for PIP support. Legal advice around workplace rights is on the rise, and we've made successful referrals to EHRC and other agencies. We are also supporting Disability Student Allowance applications and helping patients gather the right evidence.

Clinic Days & Patient Conversations

Clinic days are all about connection. Our Coordinators endeavour to greet every patient, offer private chats, and offer support. After appointments, they can help patients make sense of what was discussed and provide signposting to other support systems and helplines.

"Support Coordinator is always great at checking in and providing a reassuring chat."

"Her friendly chats always make visits to the clinic much more enjoyable."

Emotional support is a big part of our role, and the introduction of patient wellbeing newsletters have been well received.

Housing & Everyday Support

From housing letters to liaising with occupational therapists, our Coordinators are helping patients feel safe and supported at home.

"I cannot thank her enough for the support she has given over the years."

Patients have been helped to secure funding for essentials such as a washing machine, laptop, cooker, and even specialist beds where council provision was limited.

There has also been close liaison with occupational therapists to arrange home adaptations.

Wellbeing & Community Connections

We're helping patients find support and connection beyond the clinic—whether it's through social prescribing, respite applications, or community events.

"She makes a real difference, and she CARES. She is brilliant."

We've supported applications to Vasculitis UK's Respite Cabin and the Willow Foundation, and we are promoting the Quality of Life Survey and BUK AGM.

New partnerships with charities and agencies are opening doors for better housing, welfare, and wellbeing support.

Teamwork & Training

Behind the scenes, our Coordinators are keeping things running smoothly and staying up to date with training and collaboration.

"Support Coordinator is amazing—she has been an incredible support system for me since I was diagnosed with Behçet's."

They work closely with Clinic MDT teams, liaising with visiting consultants, and building links with other charities to improve access to advice and support.

The months ahead bring exciting opportunities:

- The **Quality of Life Survey** promotion continues, with strong patient engagement.
- Preparations are underway for the **Behçet's UK AGM**, including a joint patient-co-ordinator presentation.



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

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ANNUAL REPORT AND ACCOUNTS AVAILABLE FOR DOWNLOAD [HERE](#) FOR FINANCIAL YEAR 2024/2025

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.