

BPS MATTERS

WINTER 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 Coordinators have continued to provide essential, compassionate and practical support to people living with Behçet's disease and their families. Their work spans employment, welfare rights, education, wellbeing and crisis support, ensuring that patients are supported far beyond their clinical appointments. Below is an overview of the impact delivered across our centres.

Employment, Education & Advocacy

Support Coordinators continue to sensitively discuss employment with patients of working age, helping them to:

- Remain in work where possible.
- Return to employment following ill health.
- Access training or education
- Work towards long-term career aspirations.

This work has become increasingly important in light of anticipated changes to the welfare system. Many patients continue to need reassurance that working is not a contraindication to receiving PIP or certain benefits.

Our Employers' Booklets remain a valued resource, helping employers better understand Behçet's disease and their responsibilities around reasonable adjustments.

During this period, a patient was supported through an employment dispute in which their Behçet's diagnosis had not been appropriately considered. The Support Coordinator provided a detailed support letter, employer guidance materials, and signposted the patient to ACAS and their trade union. The case concluded successfully, reinforcing the importance of informed advocacy in the workplace.

Support Coordinators also actively gather and share positive examples of employer support, helping reassure patients who feel apprehensive about returning to work. We are seeing particularly good practice within the public sector, NHS, IT, banking, retail and manufacturing industries.

Education & Young Person Support

Support Coordinator continues to attend the Alder Hey Behçet's Paediatric Clinic , working closely with the clinical team to support children, young people and their families. The wider Support Coordinator team also provides ongoing support outside clinic, including education advice, school support letters and help with attendance and understanding of health-related absences.

The team continues to support young people and families as they prepare for the transition from paediatric to adult Behçet's services, helping to ensure continuity of care and reassurance during this important stage.

Networking, Training & Professional Development

Support Coordinators have been liaising with adult learning providers to support patients wishing to study basic English and Maths

They provide encouragement and guidance through college application processes.

Our Coordinators ensure that they stay up to date with training and collaboration including completion of mandatory NHS training, including paediatric and adult resuscitation. They also practice their own ongoing professional development.

Welfare Rights, Benefits & Practical Support

Support Coordinators continue to provide extensive welfare rights assistance, including:

- PIP applications and reviews, particularly for vulnerable patients or those whose first language is not English.
- Writing PIP and supporting evidence letters
- Assistance setting up Universal Credit and social housing accounts.
- Support with bidding for properties.
- Housing advocacy relating to medical priority, mobility, damp and mould, overcrowding and domestic circumstances.
- Assistance with Blue Badge applications

Patients have also been supported with grant applications for essential household items such as beds, white goods and mobility-related equipment.

Referrals and Signposting

Patients have been referred or signposted to a wide range of services, including:

- Bowel and Bladder Association
- Stop Smoking services via Social Prescribing
- ECLO support
- Post-natal and family support services

- Respite and wish-granting charities.
- Specialist support for asylum seekers and refugees

Support Coordinators also assist with arranging hospital transport where possible and booking overnight accommodation for patients travelling long distances.

Wellbeing & Emotional Support

Emotional and wellbeing support remains a core part of the service, including:

- One-to-one wellbeing consultations following referral from the nursing team.
- Ongoing emotional support for patients experiencing distress, anxiety or grief.
- Support with ill health retirement.
- Family advocacy
- Conversations around physical activity, nutrition, cooking and lifestyle adjustments.
- Health and Wellbeing Newsletter

A new patient information guide continues to be sent to patients ahead of appointments and receives consistently positive feedback. It is tailored information before their first appointment to reduce anxiety and explain what to expect.

Teamwork & Patient Experience

Across all centres the Support Coordinators:

- Work closely with multidisciplinary teams and visiting consultants.
- Endeavour to meet and greet every patient attending clinic.
- Offer private appointments for in-depth discussions.
- Promote Behçet's UK (BUK) membership, website resources and peer support groups.
- Support patient involvement through shared experiences and newsletter contributions.

Ongoing Challenge: Travel Costs

Although many patients are aware of travel cost reimbursement schemes, travel remains a significant issue — particularly for those who are working but not eligible for benefits. These patients often face considerable out-of-pocket costs, with no recourse to financial support. This continues to be an area of concern raised by the team.

This update demonstrates the breadth, depth and impact of the Support Coordinators' service. Patient feedback consistently shows how valued this support is — not only for practical help, but for reassurance, understanding and kindness at often difficult times.

Patient Feedback

Patient feedback continues to highlight the importance of having Support Coordinators embedded within specialist centres:

"Always incredibly helpful and friendly whilst always being professional. It's a very helpful service to offer as part of the specialist centres."

"It makes me feel better knowing the Support Coordinator is on hand."

"It's not just the role they do well – it's how personable they are, how they listen and genuinely care."

"The Support Coordinator was very supportive and willing to extend further information and help."

"This kind of supportive approach is so important for patients."

"An amazing, friendly, helpful and empathetic presence in clinic."

"Very friendly, always smiling and welcoming – just what you need when visiting the hospital."

This update and patient feedback demonstrate the breadth, depth and importance of the Support Coordinators' work. Their commitment ensures patients feel heard, supported and empowered — not only medically, but socially, emotionally and practically.



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

Contributions By:

Denise Lavers – Operational Lead
Jean Christians – [Support Coordinator \(London\)](#)

Jacqueline Pooler - [Support Coordinator \(Liverpool\)](#)

Rebecca Hyder - [Support Coordinator \(Birmingham\)](#)

**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.