

SPRING 2022



Behçet's Patients Support

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MATTERS

In partnership with the NHS and Behçet's UK

Helping people with Behçet's live well.

"BPS Matters" is published by Behçet's Patients Support.

behcetspatients.org.uk/

Behçet's Patients Support is provided by Behçet's Patients Centres
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PATIENT CONTACT

- Support Coordinators have continued to receive COVID related work enquiries from patients eager to continue to work during the pandemic.
- Support letters for benefit applications remained a key responsibility of the role of the Support Coordinator.
- A number of patients employed as teachers have contacted the Support Coordinator about their working hours, either taking sick leave or working reduced hours.
- Educational Support letters especially for patients attending Secondary schools continued to be a key role of the Support Coordinator.
- Some contact from patients, for travel, accommodation and other subsistence payments to help fund their visit to a Centre of Excellence.
- Ongoing support being provided to a patient undertaking a 3-year training programme.
- Support Coordinators continued to support patients with through the Personal Independence Payment (PIP) process from application, assessment and reviews.
- Supported young patients at Alder Hey who have moved up to the adult services at the Liverpool Centre of Excellence.
- Supported a student, linked them with the relevant University Student Support Services and signposted them for potential welfare rights assistance.

GOOD NEWS

- Successful Personal Independence Payment (PIP) tribunals... before even going to court or completing a face-to-face assessment.
- Supported a patient who completed the EU settlement scheme application process online including the renewal of their passport. All completed online to keep the financial costs down.

- Successful Behçet's UK Grant Aid requests for home equipment.
- Successful Occupational Therapy referral where the equipment, albeit simple, has really helped the patient enormously
- Supported a college student who needed adjustments for their A-Level exams.

TRENDS

- An Increase in the number of patients requesting guidance for budgeting / short-term loans.
- Support Coordinators have dealt with several patients asking about energy and water rebates.
- Increase in referrals to Clinical Psychologist for psychological intervention.
- Housing remains an issue and a consistent request for support for the Support Coordinators as the housing stock appears virtually depleted.
- The PIP landscape seems very mixed with some claimants receiving a 10 year award whilst others are finding it very difficult to get an award at all.
- Access to face-to-face appointments with charities such as Citizens Advice (<https://www.citizensadvice.org.uk/>) continues to prove difficult.

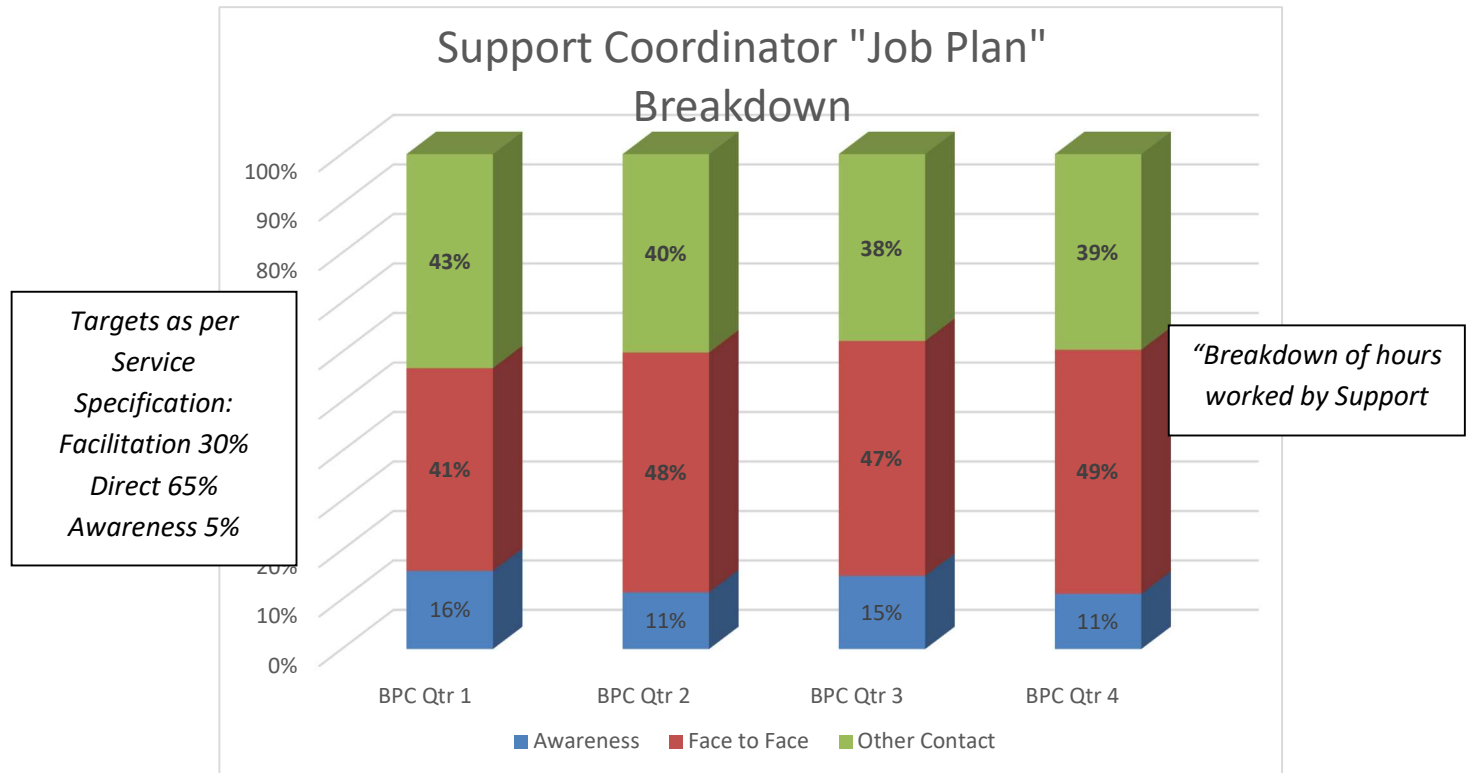
TEAM WORKING

- Articles published in Behçet's UK Newsletter. Focusing on positive aspects of "living and working with Behçet's".
- Supported and presented at the annual NHS CQUIN Behçet's service review meeting.
- Supporting children and young people attending the Alder Hey children's' clinic.
- Holding regular catch-ups meetings with the Lead Nurses at each Centre.

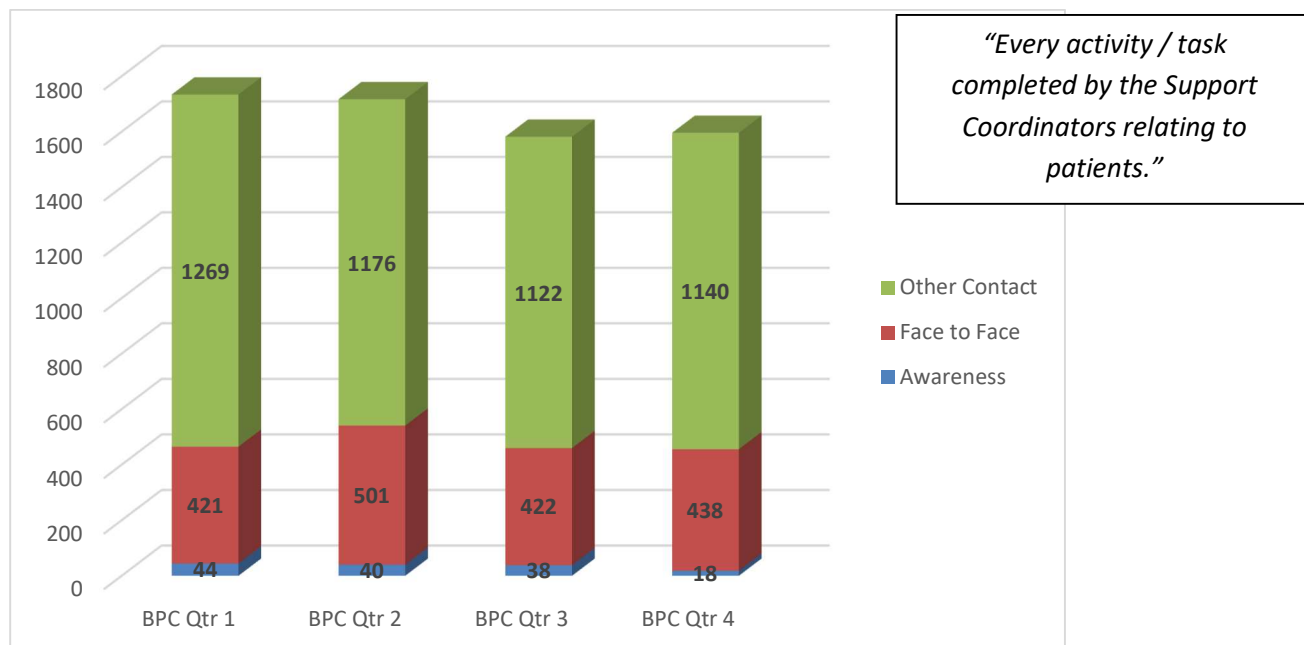
BEHÇET'S PATIENTS CENTRES

STATISTICS:(All statistics are based on the period – 1st April 2021 to 31st March 2022)

SUPPORT COORDINATOR PATIENT CONTACT BREAKDOWN



ALL PATIENT RELATED ACTIVITY

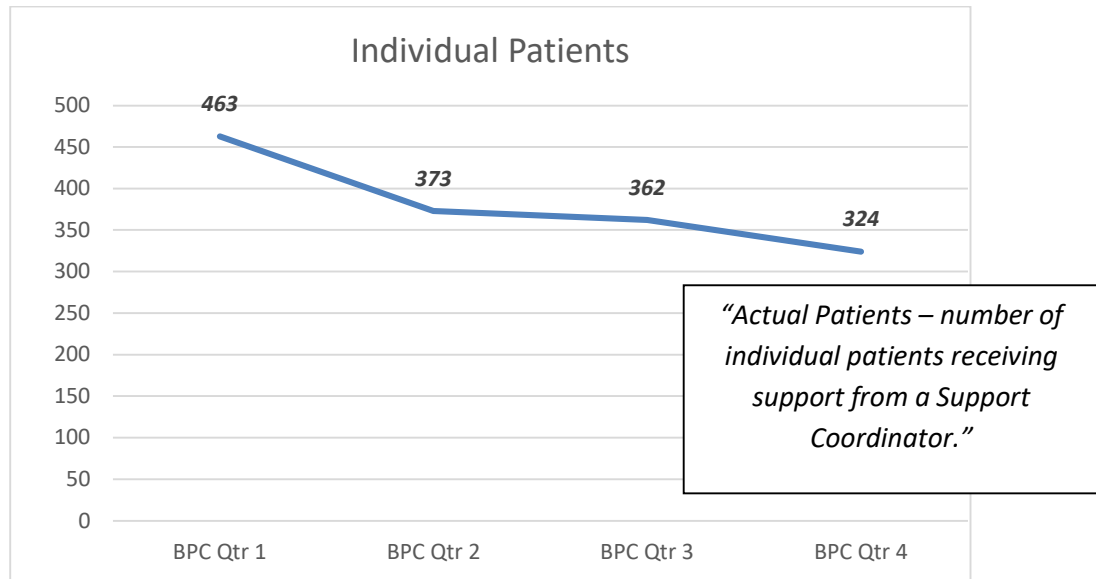


➤ Comments:

- Switch from "Other Contact" "Face to Face to", due to now supporting physical Behçet's Clinics.
- Level of overall contact with patients remains consistent, reflecting flexible nature of job role.

BEHÇET'S PATIENTS CENTRES

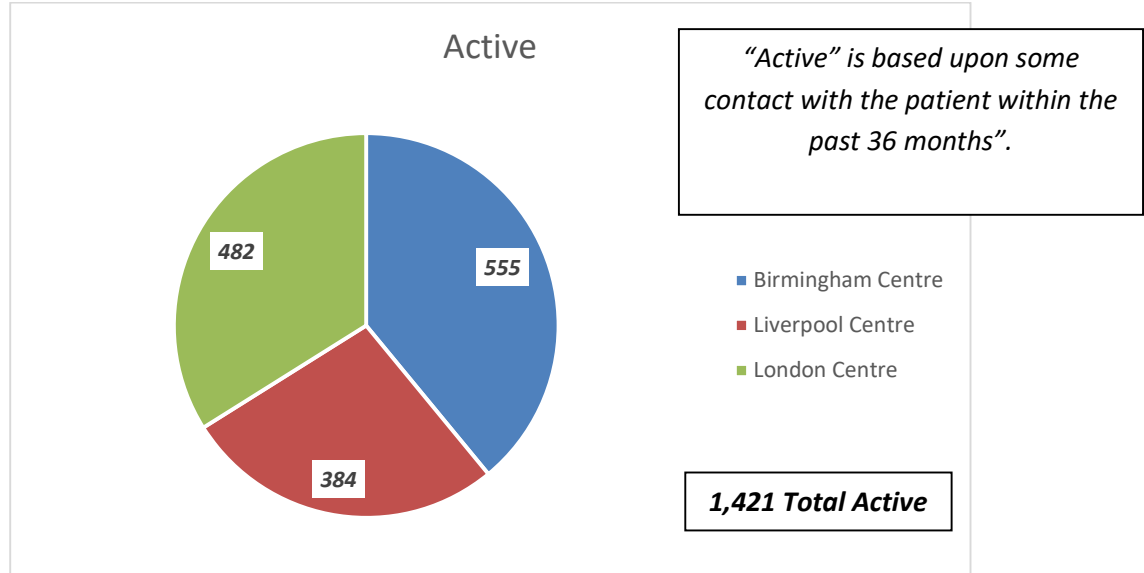
PATIENTS SUPPORTED



➤ Comments:

- Fluctuating nature of the need for non-medical support from patient.
- Quarter 3 & 4: fewer patients supported as we move back to supporting physical clinics but consistent level of activity / contact with patients.

TOTAL NUMBER OF ACTIVE PATIENTS ON DATABASE (as of 31st March 2022)



BEHÇET'S PATIENTS CENTRES

PATIENT FEEDBACK

- The Support Coordinator went out of her way to contact me and make me feel welcome.*
- Just a message, email or phone call away. Or if in clinic Support Coordinator always checks I am OK and asks if I need any support.*
- Support Coordinator is such an amazing and hardworking person, who cares for her clients. She has helped my father since the beginning and after 10 years later, I had contacted her seeking help for my father's benefits and few housing issues, she went beyond to help my family, she is always there to help, and her research skills are second to none! The help and support the Support Coordinator has provided whether it be helping me fill out a form or guiding me in the right direction has helped my family immensely and I am very thankful for her help!!*
- Both I and 2 sons have Behçet's, Support Coordinator has been brilliant over the years last week we got younger one's diagnosis and are having problems with the school and the disease Support Coordinator has done support letters for the school she has also helped with other things over the years.*
- Support Coordinator has been extremely helpful with understanding what benefits and support is out there for me, I am already in receipt of what was suggested but she offered further support in travelling to appts, accommodation and how to claim back expenses. I know I can reach out to Support Coordinator at any time, and she will offer the best advice and support.*
- Support Coordinator helped me by consulting with medical staff regarding a trial I had taken part in. I was frustrated at the lack of communication.*
- Support Coordinator empathised with my frustrations. It is so reassuring to know that she is always at the end of the phone/email.*
- It made the process easier, and I know I now have someone I can reach out to for support. And someone who understands what I am going through and the help/ guidance I may need.*
- It is always a pleasure to see Support Coordinator at the CoFE, we have built a fantastic rapport over the years. Support Coordinator also introduced me to other patients and promotes the BUK England support group.*
- Coming to the clinics and seeing and speaking to Support Coordinator helps you connect with other patients there.*
- I cannot speak highly enough of Support Coordinator. She is always so kind and supportive. As well as offering professional, practical support, she also is also genuinely interested in you as a person. I cannot say I particularly look forward to my CoE appointments but having a friendly face there always makes me feel less anxious.*
- Without the patient Support Coordinators many patients would struggle to get the support they need. Support Coordinator has been a fantastic support to me over the years.*

CONTRIBUTIONS BY:

(All statistics are based on the period – 1st April 2021 to 31st March 2022)

John Mather – Operations Manager
Jean Christians – Support Coordinator (London)
Jacqueline Pooler - Support Coordinator (Liverpool)
Rebecca Hyder - Support Coordinator (Birmingham)

BPC REPORTING PERIODS:

BPC Qtr. 1: 1st April to 30th June

BPC Qtr. 2: 1st July to 30th September

BPC Qtr. 3: 1st October to 31st December

BPC Qtr. 4: 1st January to 31st March (Financial Year End)

ANNUAL REPORT AND ACCOUNTS AVAILABLE FOR DOWNLOAD [HERE](#) FOR FINANCIAL YEAR 2020/2021



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For further information about Behçet's Patients Support, please visit behcetpatients.org.uk/