

WINTER 2020



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.**

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## COVID -19: INFORMATION

- Behçet's Patients Support continue to work with Behçet's UK to provide non-medical support to their patients and members.

<https://behcetspatients.org.uk/covid-19-information>

<https://behcets.org.uk/coronavirus-covid-19/>

## PATIENT CONTACT

- Support Coordinators give patients the same standard of care, support and experience as per face-to-face consultations in clinic.
- Continue to support the patients in a way that suits them.
- Adopt a flexible approach to contacting patients; text, phone calls, emails and letters. All new patients contacted to introduce service of the Support Coordinator.
- Follow up every patient who have 'clinic' appointments- contact from the Support Coordinator much appreciated by patients.
- Reacting to the changing COVID-19 situation with emotional support via a listening ear even where Support Coordinator could not change anything.

## GOOD NEWS

- Supported patients who have successful tribunals / appeals; plus, patients have been contacted with the positive news before having to attend hearings.
- Helped a young patient to successfully apply for Universal Credit; support letter was crucial in providing relevant information about Behçet's.
- Provided travel training and support to a patient anxious about getting to the hospital for clinic appointment.
- Speaking to and supporting parents concerned about sending children back to school and the risk to themselves.
- Supported a patient through pregnancy and onto having her baby.
- Helped a patient avoid a cap on water usage by explaining their Behçet's situation and the impact on daily life.

## TRENDS

- Support Coordinators are receiving a high number of calls from patients, who are feeling lonely, just for a chat. Support Coordinators retain a list of these vulnerable patients to check in with on a regular basis.
- Increase in number of enquiries from patients who are concerned about whether they are classed as Clinically Extremely Vulnerable or not; potential impact on employment and vaccination roll-out programme. Patients are redirected by the Support Coordinators to the medical teams at their individual centres so they can obtain the appropriate advice.
- Feedback from patients about delays in obtaining prescriptions from Centres.
- Some patients feeling frustrated about not being called on time for phone / video consultations. Many patients are working from home, doing home schooling etc and must juggle appointments around work and education.
- Patients who have suffered the loss of family members due to COVID-19 do contact their Support Coordinator to inform them of their loss and to chat. BPS have produced branded cards to acknowledge patient life-events; "Hello There" and "Thinking of you".

## TEAM WORKING

- NHS colleagues regularly refer patients to the Support Coordinator for non-medical support.
- Regular contact with NHS Centre Psychologists to discuss and refer patients as necessary to each service.
- Articles published in Behçet's UK Newsletter. Focusing on positive aspects of "living and working with Behçet's".
- BPS Team support, invaluable support to each other during these difficult times.
- NOW LIVE: Online survey to obtain feedback about the impact of COVID-19 on Behçet's patients;  
<https://www.surveygizmo.eu/s3/90267605/BEH-ET-S-CENTRE-COVID-19-Patient-Survey>

# BEHÇET'S PATIENTS CENTRES

## PATIENT FEEDBACK

- *Always helpful and stays in contact with me.*
- *Support Coordinator has been a fantastic support to me from day one of me visiting the Centre of Excellence, she is also a friendly face when visiting the centre.*
- *I contacted her for help I always do; she always helps me.*
- *I only found the Support Coordinator in lockdown and she was amazing.*
- *Always in contact with me by phone once a week Thursday or Friday to see if I need any help if I do not answer always leaves a voicemail message and if I forget my voicemail, she phones me later that day phone or texts.*
- *Support Coordinator has been brilliant. She has provided information to school & university and has also contacted them when necessary.*
- *Helped me regarding returning to work Support Coordinator was very helpful to me understands my fears.*
- *Support Coordinator explained what was available and that I was able to contact her whenever required. She still regularly catches up with me to make sure that I do not need any help.*
- *Everything and anything I have ever needed help with (that is within her remit) she has done. She does so with a very positive, sensible and conscientious approach. She is also able to be simply supportive, understanding and listen. She is the best thing about the CofE. She carefully and professionally tries to help resolve the many problems that patients face. We really need her.*
- *I did not need any at the time. However, Support Coordinator contacted me to check and was friendly and amiable and assured me that if the time came when I did need it that she was there. She was encouraging thoughtful and positive.*
- *I spoke with Support Coordinator on a few occasions with a few concerns I had regarding my condition and the current COVID situation. She was helpful and give me some great advice and helped in receiving and obtaining some information and documentation needed for my employer.*
- *A big difference with Support and Advice.*
- *The support provided over the years has been absolutely second to none, it is always nice to have a chat when attending the CofE.*
- *This is a fantastic charity that really goes out of its way to support patients & families. Support Coordinator is an absolute gem. She is so helpful & so kind and really builds up a good relationship with patients and families. She always responds to queries & really cares.*
- *Having access to support from Support Coordinator is such an asset, I have not needing support often but knowing it is there is reassuring.*
- *Support Coordinator is worth her weight in gold. Nothing us ever too much trouble and always done with a smile. Always at the end of the phone for anything.*
- *Thank you for providing a service that has been very helpful and knowing having a rare disease that not many people understand, there is someone who does understand, and help is there should we need it.*
- *The Behcet's Support Coordinators play a major role in patient's journeys, from being a friendly face at clinic visits, right through to supporting us with financial matters and more.*

**CONTRIBUTIONS BY:**

*(All statistics are based on the period – 1st January 2020 to 31st December 2020)*

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: 1<sup>st</sup> April to 30<sup>th</sup> June  
BPC Qtr. 2: 1<sup>st</sup> July to 30<sup>th</sup> September

BPC Qtr. 3: 1<sup>st</sup> October to 31<sup>st</sup> December  
BPC Qtr. 4: 1<sup>st</sup> January to 31<sup>st</sup> March (Financial Year End)

**ANNUAL REPORT AND ACCOUNTS AVAILABLE FOR DOWNLOAD [HERE](#) FOR FINANCIAL YEAR 2019/2020**