Patient Information Leaflet on COVID-19 & Influenza

Aim

To provide summary guidance relating to issues arising for patients with Behçet's disease as a result of COVID-19, encompassing guidance in the context of seasonal influenza as we approach winter.

NB: There may be regional variation and guidance should ultimately be tailored to the individual patient (due to factors such as differing clinical manifestations, medication, social circumstance, work etc).

Consultation

As necessary you should consult with:

- GPs and clinicians if not on the books of Centres of Excellence
- Clinical representation (e.g. lead consultants and other clinical staff e.g. sub-specialists, nurses, psychologists) from each Centre of Excellence
- Behçet's support co-ordinators
- Patient groups

Advice

General advice

If you develop symptoms of COVID-19 (i.e. new continuous cough, fever, loss of smell or taste):

- Call 111 to seek immediate advice (attend A&E or call 999 if symptoms are severe)
- Call 119 to get a test. Do not delay. A test should be performed within 5 days of onset of symptoms.
- Do not stop your Behçet's medication. Call your respective Behçet's Centre of Excellence helpline for advice on continuing or stopping them; or for patients not on the books of a Centre of Excellence, your GP or specialist clinician.
- If you test positive for COVID-19, please also let your Behçet's team know.
If a member of your household develops symptoms of COVID-19:
• Both they and you should get tested as soon as possible and self-isolate for 14 days.
• As above, ensure you seek immediate medical help if you have severe or worsening symptoms, or other symptoms (including those relating to your Behçet’s) causing concern.

If you attend A&E, or are admitted to hospital for any reason, including COVID-19:
• Ensure you take your Behçet’s care plan with you to hospital (if you have one).
• Ensure you have a copy of your advance care plan (if you have one).
• If you are on immunosuppression, please inform A&E when booking in and ensure your doctor is aware.
• Inform your doctor of your Behçet’s diagnosis, who can then liaise with your specialist centre for further advice.

If you are having symptoms of a flare of your Behçet’s disease:
• Contact your respective Behçet’s Centre of Excellence helpline as soon as possible. We will discuss your symptoms over the phone and decide if you need to be assessed in a face-to-face appointment. If a face-to-face appointment is necessary, every effort will be made to do this in a safe environment and staff will be wearing PPE. You may have your temperature checked and will be asked to wear a mask on entering the hospital. Please note that you may not be able to bring a friend or relative with you to the appointment unless you require assistance, e.g. visual impairment. Please check with your centre beforehand.
• You may be asked to attend a “virtual” or telephone consultation (see below).
• For patients not on the books of a Centre of Excellence, speak with your GP or specialist clinician who should follow a similar process to the above.

If you have a telephone or video consultation:
• You will be sent details ahead of the consultation about how to join the appointment.
• If you foresee difficulties in attending the appointment, please ring your Behçet’s centre to rearrange and/or raise concerns beforehand.
• You may be given a specific time on a given date. However, it is a good idea to make yourself available for the whole morning or afternoon (depending on the time of your appointment) to account for any delays or difficulties.
• If you are given a video or telephone consultation, please ensure your telephone numbers are up-to-date with our team.
If you have a blood monitoring appointment:

• Please try and attend the appointment. Every effort will be made to conduct blood tests in a safe environment and staff will be wearing PPE. It is essential to have up-to-date blood tests to enable us to dispense your medications in a timely manner. Where possible, we will try and space out blood tests to reduce the number of visits required to hospital.

• If your GP organises your blood monitoring, as above, please ensure you attend in order to ensure timely dispensing of medication.

COVID-19 and Shielding

You may have been asked to shield until 1st August 2020, depending on the advice from your centre, your medication, and clinical features of your Behçet’s disease.

Having Behçet’s disease does not necessarily put you in the category of patients at most risk of complications of COVID-19. There are many factors involved in this, such as the clinical features of your disease and your medication. Your Behçet’s centre knows you best with regards to this; or for non-Centre of Excellence patients, your GP or specialist clinician.

If you are over the age of 70, or have one of these additional conditions, you are considered at greater risk of complications of COVID-19:

• Diabetes
• Any lung disease
• Kidney problems (renal impairment)
• Heart problems (angina, ischaemic heart disease)
• High blood pressure (hypertension)
• Chronic liver disease
• Chronic neurological conditions (discuss with your GP)
• Stem cell transplant
• Certain cancers (discuss with your specialist)
• Certain immune system disorders (discuss with your specialist)

You should be more cautious when considering your next steps after ending shielding, especially if you are also on immunosuppression for Behçet’s.

If you are returning to work, your workplace must conduct a risk assessment prior to this.

Carers or visitors who support you with your everyday needs can visit unless they have symptoms of COVID-19. All visitors should wash their hands with soap and warm water for 20 seconds, on arrival and when leaving, and often whilst in your home. Surfaces should also be wiped down. If your carer becomes unwell and you’re not sure who to contact for additional support, please contact your local authority.
**Flu Season**

We would advise patients to get the seasonal flu jab.

Symptoms of flu can be similar to COVID-19. Therefore, if you develop symptoms, please follow the advice in section 1 regarding medical advice and testing.

**Psychological and Other Support**

COVID-19 has been a difficult and worrying time for many, including those with conditions such as Behçet's disease. These worries may continue and increase as we exit the official shielding period. This is understandable and we, and other organisations, are here to support you.

Our Behçet's teams, including psychologists and support groups, remain available for any questions regarding issues such as social concerns and work.

**Other Concerns**

Medical and social circumstances will be different for each patient. You may therefore wish to discuss with a member of your Behçet's clinical team before trying to return to some sort of normality. Ultimately, we will let you decide on what is safest for you.