



Sarcoidosis Patient Compass

Instructions:

- This is an interactive tool to help guide you through your sarcoidosis journey. It will help you understand which questions to ask your doctor.
- The importance of each point will be determined by the type of your sarcoidosis, and your understanding of your condition.
- Read and be aware of all the points but consider carefully only those points which are important for you at this current time.
- You are encouraged to use the tick boxes and to refer back to the compass over time.

Section 1 - Basics

- 1 I understand what sarcoidosis is and which organs might be affected. I know where to find additional information.
- 2 I understand that sarcoidosis might affect my quality of life (particularly fatigue) and my mental health. I know where to look for support with these issues.
- 3 I understand how to recognise a 'flare-up' and I have been given advice about what to do if my symptoms get worse, or if I start experiencing new symptoms.

Section 2 - Treatment

- 4 I understand the different treatments that are available to help me manage my sarcoidosis (as it is currently affecting me) and that my sarcoidosis may not require treatment.
- 5 I know what all of my sarcoidosis medication is for and I know when and how best to take my medication. I know that it is very important to not suddenly stop taking my medication, particularly corticosteroids (e.g. prednisolone).
- 6 I have discussed with my doctor what we are hoping to achieve with my treatment plan, both in the short- and long-term.
- 7 If I am taking immunosuppressants, I understand how I can reduce the risk of infection and the importance of this.
- 8 I understand the main potential side-effects of my treatment and where to look for more detailed information on these side-effects. I understand this might include check-ups with other specialists.
- 9 If I suffer from breathlessness, I have discussed treatment options available (including oxygen, pulmonary rehabilitation therapy and inhalers).



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Section 3 – Healthcare

- 10 I know the importance of taking responsibility for my own health by eating healthily, avoiding smoking, taking regular exercise and having an annual flu vaccination.
- 11 I understand that new symptoms, including lumps, may be unrelated to sarcoidosis and that I should discuss these with my GP / family doctor if I am concerned.
- 12 I have spoken to my GP / family doctor about any other healthcare services that might be available to help me manage my sarcoidosis symptoms (e.g. physiotherapy, mental health services, dietary advice).
- 13 I know who my lead sarcoidosis doctor is and the best way to get in touch with the hospital or my doctor regarding any complications.
- 14 I understand how my lead sarcoidosis doctor will communicate with other specialists who are treating my sarcoidosis and with my GP / family doctor.
- 15 I understand that I can request for all clinical correspondence or test results to be copied to all my doctors and to myself.

Section 4 – Further symptoms

- 16 I have requested an annual eye exam (whether I have problems with sight or not).
- 17 If I have cardiac symptoms, these are currently being investigated or I have been referred to a cardiologist with sarcoidosis expertise.
- 18 If I have neurological symptoms, these are currently being investigated or I have been referred to a neurologist with sarcoidosis expertise.
- 19 If I have other symptoms which could be related to sarcoidosis in other organs, these are currently being investigated or I have been referred to a relevant specialist.

(For 17, 18 and 19 refer to www.sarcoidosisuk.org for a comprehensive list of organ involvement and associated symptoms.)

Section 5 – Advanced sarcoidosis

- 20 If I have 'advanced sarcoidosis' (worsening disease that is unresponsive to therapy and has continued for 2+ years) I understand that my condition is potentially dangerous (with risk of organ failure) and my treatment plan is reflecting this.



The Compass reflects what most people with sarcoidosis should be aware of following diagnosis. Not all the information in the Compass may be relevant to you, ask your doctor to explain what applies to you.

The Sarcoidosis Patient Compass was developed by a team of expert doctors, patient organisations and patients.

More detailed information about sarcoidosis and links to national patient organisations can be found at:
www.europeanlunginfo.org/sarcoidosis.