

Patient Journey Sarcoidosis



1. First symptoms

As multi-system disease possibly affecting any organ:

- flu-like symptoms, night sweat
- fatigue, memory issues
- reddish skin, nodules, rash, rosacea
- shortness of breath (dyspnoea)
- heart pain, arrhythmia
- swollen lymph nodes, glands, joints
- dry mucosa (mouth, eyes, cough)
- neuropathic (autonomic) malfunction
- chest and muscle pain
- blurred vision, uveitis, cataract
- kidney stones

Need:

Support for presented symptoms.
Frequent misdiagnoses:
Psychological, burnout.

Ideally:

Recognition of symptoms of an unusual condition and prompt transfer to a specialist centre with a minimum number of cases proving expertise.

2

... diagnosis ...

2. Diagnosis

Is a matter of exclusion.

Unexplained organ problems prompting the patient to be seen by many doctors until proper diagnosis.

Necessary biopsies are not always taken from easy to reach tissue.

Even severe symptoms may be intermittent and be missed by tests.

Need:

Diagnosis needs to be quick, timely and well managed: time from first symptoms, to professional guess, to confirmed diagnosis.

Ideally:

Defined pathway of care from mapping the affected organs to coordinated treatment including psychological and quality of life factors.

3

... treatment ...

3. Treatment

Symptoms from established, remitting or progressing disease (strength and organ involvement).

Problems from side effects of treatment as well as comorbidities and strategy to minimize long-term adverse events.

Treat to avoid organ danger and to maintain quality of life.

Need:

- Continuous diagnostic support is needed because of changing presentation and organ involvement and other upcoming diseases/comorbidities.
- Systemic affliction requires holistic care with a defined leading /coordinating doctor.

Ideally:

- Holistic care with a defined leading coordinating doctor.
- The individual prognosis is unknown, and the coordinating doctor will therefore monitor and ask the patient and take complaints seriously.

4

... follow up ...

4. Follow-Up Care

Because of the lack of prognostic parameters, the risk of relapse and unobserved progression follow-up is needed.

For many sufferers, care is more a continuous diagnosis and treatment management task. Longer lasting disease often results in neglected social and economic burden.

The doctor might see an excited and brave patient for a moment only, but the patient might be suffering 24x7.

Need:

Option for longer-suffering patients to be seen in a specialist centre for treatment or for a second opinion.

Ideally:

- In remission - the patient's GP knows the specialist doctor and transfers the patient to the specialist if needed or upon patient's request.
- Periodic continuous education for patients to improve health competence and collect feedback on open needs.