

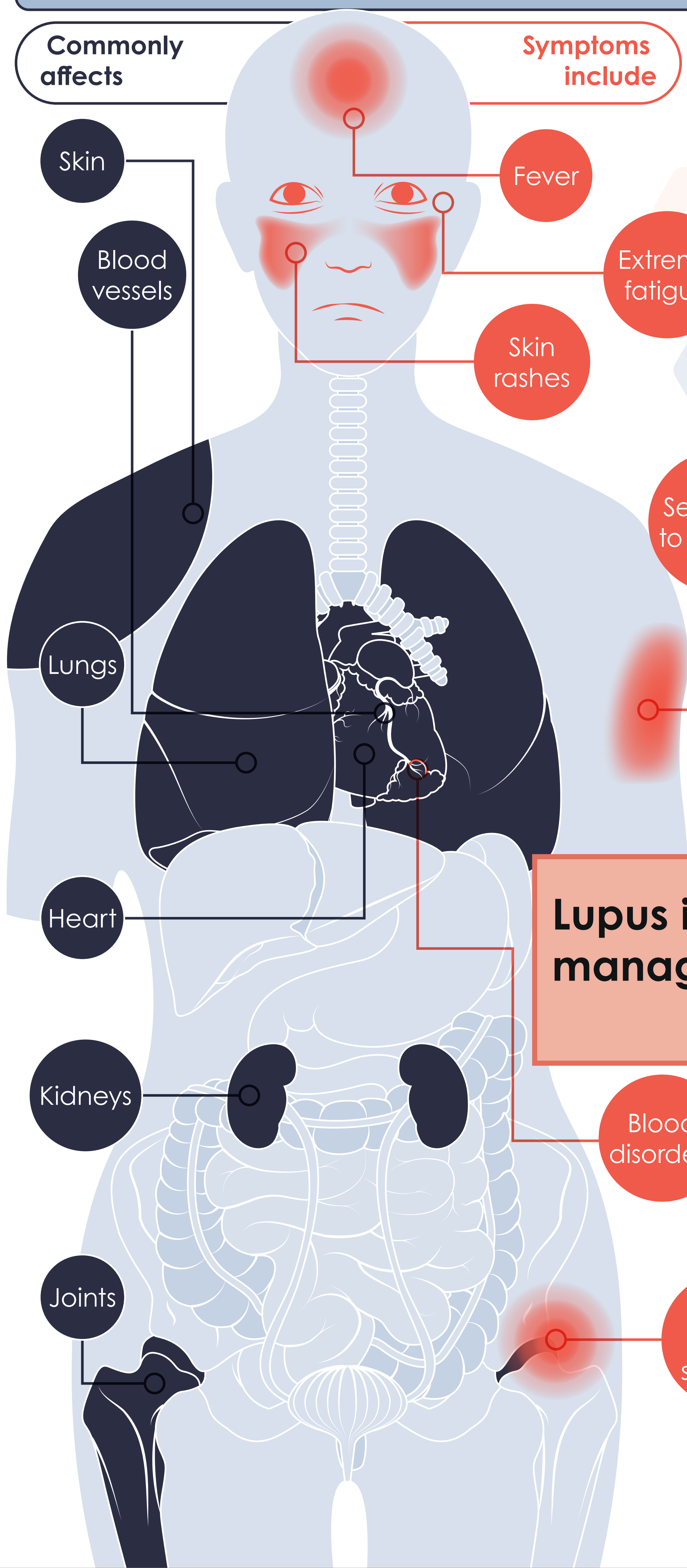
Living with Lupus

Lupus is a lifelong autoimmune disease, whereby your immune system attacks your own cells. Ineffective management can result in organ damage.

Commonly affects

Symptoms include

Symptom severity can change over time. Sometimes symptoms may be absent or barely noticeable and at other times symptoms may worsen (flare)



Educate your family and friends:

Share your experience
Explain lupus to family, friends and colleagues

Stick to your agreed treatment plan:

Treatment can prevent organ damage and control symptoms
Treatment can reduce frequency and severity of flares
Some treatments take time to work, so don't give up

Participate in treatment decisions:

Keep a diary of treatment effects, prepare notes for your appointment, and ask questions:

- "What are my treatment options?"
- "Are my treatment options safe?"
- "How can I manage side effects?"
- "My treatment isn't working"
- "What else can I try?"

Manage triggers:

Avoid excessive sun exposure
Prepare for stressful situations
Find a good balance between rest and activity

Lupus is manageable!

Create a support network involving:

Medical care team
Mental health support
Family and friends
Other patients
School and work

Communicate with your medical care team:

Share your concerns:
"I'm not coping"
"Where can I find mental health support?"

What do I need to know about my treatment options?

Antimalarials:

Disease-modifying medication used to suppress disease activity and help to relieve symptoms

NSAIDs:

Non-steroidal anti-inflammatory drugs used to reduce inflammation and pain

Immunosuppressants:

Suppress the activity of the immune system and help to reduce symptoms and the risk of flares

Steroids:

Reduce inflammation and pain in acute flares as well as managing disease activity in the long-term

Biologics:

Used when antimalarials and immunosuppressants are unsuccessful in treating symptoms

It is important that you ask your doctors about possible side effects of these medications and see your doctors regularly for monitoring of your symptoms, disease activity and medication side effects.

Where can I find more information about lupus, lupus management and support?:

- World Lupus Federation. <https://worldlupusfederation.org/>
- Brigham Health Patient Resources. <https://lupus.bwh.harvard.edu/community/community-resources/>
- The Lupus Initiative. <https://thelupusinitiative.org/patients-caregivers/>
- Lupus Europe. <https://www.lupus-europe.org/>
- Lupus UK. <https://www.lupusuk.org.uk/>

How can I help to promote lupus awareness?:

<https://worldlupusday.org/tool-kit/>