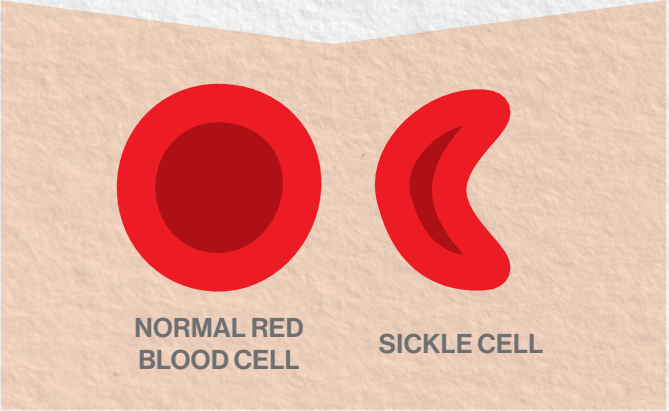
My diary

NOVARTIS

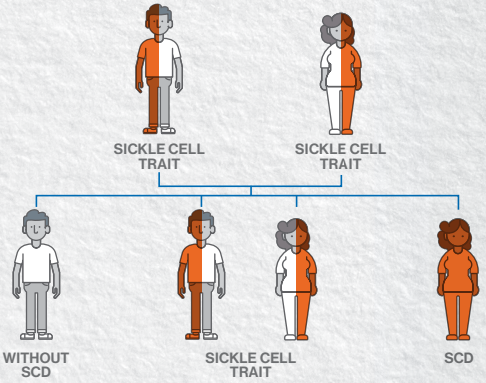
ASAFE

What is sickle cell disease?

> **Sickle cell disease** (SCD), or sickle cell anaemia, is a hereditary blood disorder caused by an abnormality in haemoglobin, the oxygen-carrying protein in red blood cells.[1]



Proteins are the result of our genes, and we receive two copies of each gene, one from our father and one from our mother. SCD is a genetic disease that you get if both copies of the haemoglobin gene are abnormal.



Since it is a hereditary disease, if you are planning to have children, you should seek genetic counselling.

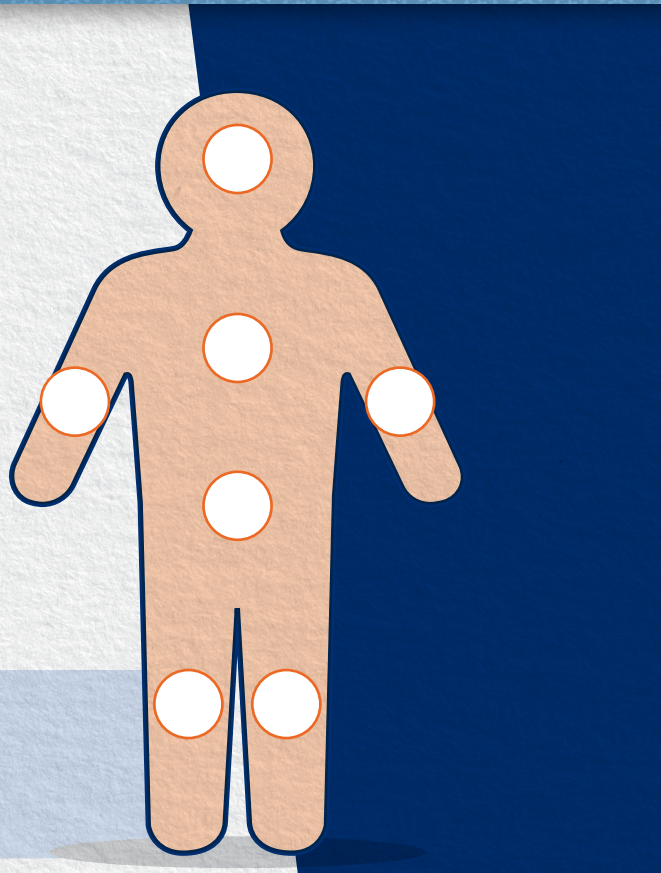
Symptoms and complications of SCD

> The main symptoms and complications are due to the destruction of sickle cells and the occlusion that they cause in small blood vessels. This may manifest as a pain crisis (vaso-occlusive crisis), but chronic, painless organ damage also occurs.

> **The severity and duration varies from one patient to another.**[4]

> **Pain can be felt anywhere in the body** and you may notice it in more than one place at a time.[4]

- Arms and legs
- Abdomen
- Chest
- Hands and feet (more typical in young children)
- Lower back



When a crisis occurs, it is important to seek professional help when the pain requires it. It is also important to tell the medical team responsible for your follow-up about any pain you have had at home.

Tips and recommendations

MEDICAL CARE:

- Make sure you receive regular medical care, not just when you are in pain.
- Seek medical care immediately if you have: fever, difficulty breathing or chest pain, neurological symptoms (severe headache, loss of feeling or movement in any part of your body), priapism (painful erection) lasting more than 4 hours, bloating and abdominal pain, severe weakness, pain that will not go away with treatment at home.
- Follow the recommendations regarding vaccination

HEALTHY LIFESTYLE HABITS: [1,4,7,8]

Eat well.

Always drink plenty of water, especially in cases of fever, vomiting or diarrhoea.

Limit the amount of alcohol you drink.

Wash your hands often and take other measures to prevent infections.

You can exercise regularly, but not strenuously. Always drink plenty of fluids.

Manage your physical tiredness and rest when necessary.

Use stress reduction techniques.

https://www.cdc.gov/ncbddd/Spanish/sicklecell/healthyliving-emer-guide.html

Treatment, check-ups and follow-up during symptom-free periods are important to prevent complications and reduce their severity, as well as to improve your quality of life.

Preventing and managing pain crises

Attending regular appointments with your medical team can help prevent complications and improve your quality of life.[6]

> Various situations **can trigger** vaso-occlusive crises, so it is best to avoid: [1,3,4,7,8]

Exposure to cold weather or cold water.

Strenuous physical exercise.

Smoking.

Dehydration.

High altitudes.

Emotional stress.

Infections.

States of hypoxia (oxygen depletion).

> To manage pain, try using a heating pad, taking a warm bath or having a massage. Physiotherapy can also provide relief. Do not apply cold.

> **Follow your specialist's recommendations** when you have a pain crisis and, if necessary, go to hospital so that you can be treated with stronger painkillers.[4]

Pain diary

> Keeping a diary of your pain crises to share with your medical team will help ensure **individualised care** and **minimise long-term complications.**.

Name and surname(s): .....

Date of birth: .....

Medical centre: .....

Doctor: .....

Phone number: .....

Date: ...../...../.....

My genotype is:

☐ HbSS ☐ HbSβ⁺ ☐ HbSC ☐ Other

My current treatment: .....

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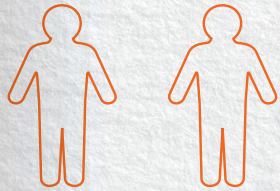
My pain diary

Where? Circle the affected areas



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(dd/mm)

Started ☐☐/☐☐

Ended ☐☐/☐☐

How intense was the pain? Circle the maximum intensity

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Mild Moderate Intense

Do you think any of the following events could be the trigger? Specify

Temperature change · Wind · Altitude · Stress · Exercise

Dehydration · Infection · Nothing

Other.....

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What relieved the pain? Specify

Pain medication · Visit to emergency department · Applying heat · Relaxation techniques

Other.....

Any other symptoms? Specify

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Other symptoms.....

If you have experienced priapism, circle the maximum intensity and specify the duration: _____

1 2 3 4 5 6 7 8 9 10

Mild Moderate Intense

Treatment: .....

What could you not do during this time? Specify

School / study · Work · Sleep · Go out with friends

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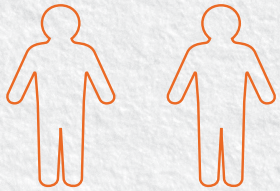

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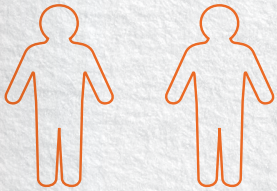

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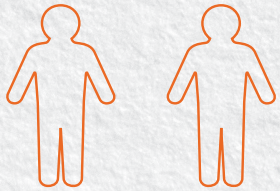

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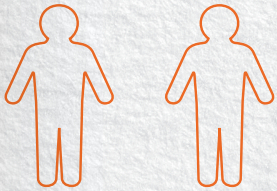

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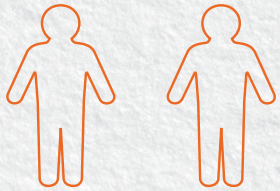

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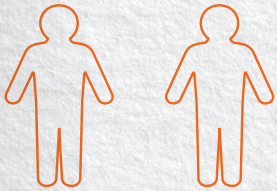

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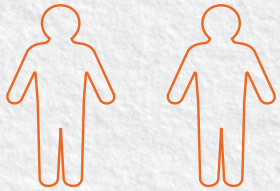

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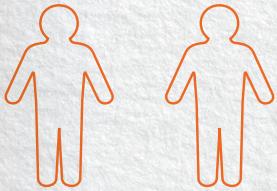

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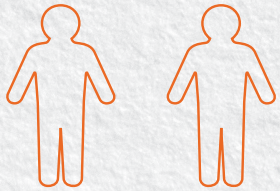

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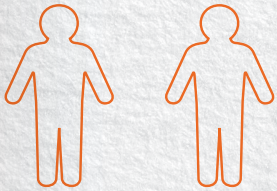

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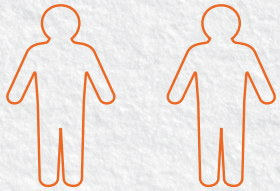

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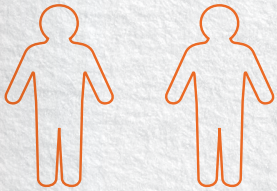

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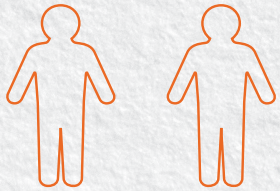

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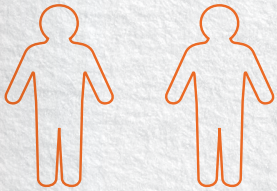

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Do you think any of the following events could be the trigger? Specify

Temperature change · Wind · Altitude · Stress · Exercise

Dehydration · Infection · Nothing

Other.....

.....

.....

What relieved the pain? Specify

Pain medication · Visit to emergency department · Applying heat · Relaxation techniques

Other.....

Any other symptoms? Specify

☐ Tiredness ☐ Fever ☐ Breathlessness

☐ Dizziness ☐ Nausea ☐ Headache

Other symptoms.....

If you have experienced priapism, circle the maximum intensity and specify the duration: _____

1 2 3 4 5 6 7 8 9 10

Mild Moderate Intense

Treatment: .....

What could you not do during this time? Specify

School / study · Work · Sleep · Go out with friends

Other.....

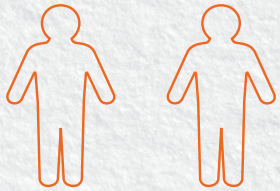
Notes .....

.....

.....

My pain diary

Where? Circle the affected areas



On what day did the pain start and end?
(dd/mm)

Started ☐☐/☐☐

Ended ☐☐/☐☐

How intense was the pain? Circle the maximum intensity

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Mild				Moderate				Intense	

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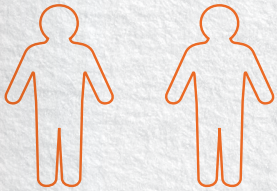

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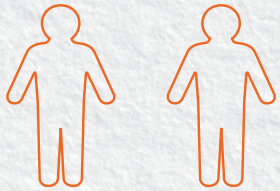

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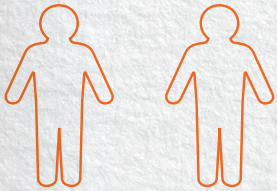

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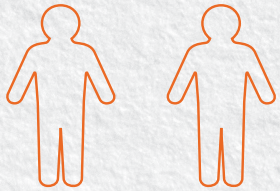

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Other.....

Notes .....

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Patient with SCD

Emergency information

Some useful information about SCD can be found via the following links:

AEAL, Spanish Association for Lymphoma, Myeloma and Leukaemia Patients
www.aeal.es

Spanish Association of Paediatrics
https://enfamilia.aeped.es/temas-salud/anemia-celulas-falciformes

Spanish Erythropathology Group
https://eritropatologia.com/

MedlinePlus
https://medlineplus.gov/spanish/sicklecelldisease.html

Spanish Society of Paediatric Haematology and Oncology
www.sehop.org

Sickle Cell Disease (SCD)
www.anemiafalciforme.es

We know that some crises require emergency care. Here is some information you can share with your doctor.

Scan the QR code or access the URL
Material for healthcare professionals

profesionalessanitarios.novartis.es/ecf-recursos-medico

References:
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2. U.S. National Library of Medicine. MedlinePlus. Sickle cell disease [Internet]. 2020. Available at: https://medlineplus.gov/spanish/sicklecelldisease.html. Last accessed: June 2020.
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4. Webmd. What Is a Sickle Cell Crisis? [Internet]. 2019. Available at: https://www.webmd.com/a-to-z-guides/sickle-cell-crisis#1. Last accessed: June 2020.
5. Centers for Disease Control and Prevention (CDC). National Center on Birth Defects and Developmental Disabilities, Division of Blood Disorders. Sickle cell disease - Tips for healthy living. [Internet]. Available at: https://www.cdc.gov/ncbddd/spanish/sicklecell/documents/A_tipsheets_5_spanish.pdf. Last accessed: June 2020.
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7. Jenerette CM, et al. Self-care recommendations of middle-aged and older adults with sickle cell disease. Nurs Res Pract 2011;270594.
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