NHS SCOTLAND

SPAH
SCOTTISH PAEDIATRIC AND ADULT HAEMOGLOBINOPATHIES NETWORK

Patient Information

Sickle cell disease (SCD) - caring for your unwell child at home

This document has been prepared by Public Services Delivery Scotland (PSD Scotland) on behalf of the Scottish Paediatric and Adult Haemoglobinopathies Network (SPAH). Accountable to Scottish Government, PSD Scotland works at the heart of the health service providing national strategic services to the rest of NHS Scotland and other public sector organisations to help them deliver their services more efficiently and effectively. The SPAH Network is a collaboration of stakeholders involved in care of patients with haemoglobinopathies, who are supported by a PSD Scotland Programme Team to drive improvement across the care pathway.

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Coming to hospital when your child is unwell can be stressful and upsetting for both your child and your family. If possible, your haematology doctor or nurse will try to keep your child at home and can offer advice to help you do this.

This leaflet will help you to understand when and how to care for your child at home. It will also explain when it is important to bring your child to hospital.

It may be useful to follow the Sickle Cell Disease Pain Flow chart given with this leaflet. This may help you decide when your child can be cared for at home or when they may need to come to hospital.

Emergency admission

You should ring 999 for an emergency ambulance if your child:

- **suddenly collapses, loses consciousness or cannot breathe**
- **is confused, their speech changes or is slurred, they cannot move, or they lose the feeling in their face or limbs**
- **they have a fit (seizure)**

When speaking to the emergency call handler, you should try to remain calm, answer all questions clearly and follow the instructions they give you.

Remember, the ambulance may take your child to the nearest Accident and Emergency Department, which may not be at the hospital where your child is normally cared for.

Urgent admission

If your child has any of the following symptoms, you should take them to hospital immediately.

- A fever (a temperature of 38ºC or above)
- Pain in their abdomen or chest
- Breathlessness
- Severe pain not controlled by paracetamol and ibuprofen
- Prolonged pain lasting 24 hours or more despite taking paracetamol and ibuprofen
- Diarrhoea or vomiting (or both) or not drinking enough

When this happens, you may not need to call for an ambulance, but you should contact your child's nurse for advice and attend hospital either by car or taxi (t may be useful to set aside a small fund to cover taxi travel costs if required).

It is always a good idea to call ahead to your child’s nurse or other contact number you have been given. Staff will be able to tell you anything you should do before leaving home.

Your nurse may advise you to give your child paracetamol or ibuprofen (or both) before coming to hospital. Also, they may tell you the appropriate procedure to follow to access the hospital.

If, for any reason, you are unable to speak with staff on the contact numbers provided, you should **not delay** bringing your child to hospital.

Caring for your child at home

Common symptoms which can make your child feel unwell are:

- anaemia – causing tiredness; and
- pain

These symptoms do not always mean that your child needs to go to hospital. You may find it helpful to contact your child's doctor or nurse when your child complains of any of these symptoms. You can call the contact numbers provided for advice on what to do.

Care you can give at home

Most of the time your child will feel well, but if the anaemia gets worse, they may become tired and begin to feel unwell. In this situation, you should call your child's nurse for advice.

However, you can do the following.

1. Encourage your child to rest. Activities such as reading and watching TV will help to occupy them until they recover.

2. Make sure your child has enough sleep. A good bedtime routine with a bedtime appropriate for their age will help with this. You should discourage your child from using tablets, laptops or mobile phones immediately before bed as this may interfere with sleep patterns.

3. Make sure your child has an adequate diet and drinks enough. Dehydration can cause fatigue. An inadequate or inappropriate diet (for example, too much fat, junk food, little or no fruit and vegetables) can cause low energy levels.

If these symptoms last for a long time, perhaps more than three to four days, you should contact your nurse for advice. They may ask that you bring your child to hospital to be checked.
If these symptoms are new (especially in children under five) you should feel for your child's spleen, if you have been shown how. If it feels bigger than usual, you should bring your child to hospital to be checked.

Pain

Pain is a common symptom of sickle cell disease. Painful episodes are also known as a painful crisis or a sickle cell crisis. They happen when very small blood vessels get blocked by 'sickled' red blood cells (blood cells that change shape). These episodes can last from a few hours to several days and can vary from person to person.

If your child has pain, you may be able to care for them at home if they do not have:

- a fever (a temperature of 38ºC or more);
- abdominal or chest pain;
- diarrhoea or vomiting (and are drinking good amounts); or
- severe pain

In this situation, you may still want to call your child's nurse for advice. However, you can do the following.

1. Give your child paracetamol and ibuprofen, following the instructions on the bottle or box

Paracetamol can be given every four to six hours, no more than four times in 24 hours.
Ibuprofen can be given every six to eight hours, no more than three times in 24 hours.
It is important to use pain medication labelled for your child.
You should make sure that you always have a supply of this medication at home.
Your GP should be able to provide this medication on repeat prescription at no cost.

2. Encourage your child to drink more

Your nurse can tell you the appropriate amount your child should drink for their age and weight. Warm drinks (not hot) can be helpful in giving relief from pain.

3. Encourage your child to rest and keep warm (but not hot)

This may mean they have to stay home from school for a short time.
Give your child warm clothing or blankets (or both). A warm bath may also help.
Careful use of hot-water bottles or heat pads on the painful area can sometimes help ease the pain.

4. Give your child comfort and reassurance

A certain amount of stress or anxiety can sometimes help us to perform well. However, in SCD, too much can trigger a painful crisis or make it worse.

When children are in pain they tend to tense up and take short, shallow breaths. This may increase or prolong their pain. Help them to relax by teaching them to:

- think about something they like and imagining how that makes them feel;
- listen to some soothing music; and
- distract themselves with restful activities (for example, reading, puzzles or TV)

5. Reassess your child's pain regularly

If your child's pain continues or increases, you should contact your doctor or nurse for advice.
If your child's pain improves, continue to give the pain medicine as prescribed for 24 hours, then gradually reduce it over two to three days.

For more information about SPAH and other helpful resources:

SPAH Website: www.spah.scot.nhs.uk
Email: nss.spah@nhs.scot

If you need this leaflet in another format (such as large print), please:

- Email: psd.contact-us@nhs.scot
- Phone: 0131 275 6000
- Contact: BSL ContactScotlandBSL at contactscotland-bsl.org.

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