



Sickle Cell & Thalassaemia NEU guidance for members, reps and local officers

This briefing provides information to school staff to support the uninterrupted education of children with sickle cell disorder and thalassaemia. It is important that all staff, including supply teachers and agency workers, are regularly briefed about the needs of pupils with sickle cell disorder, as with other medical conditions.

What is sickle cell disorder (SCD)?

Sickle cell disorder (SCD) is a collective name for a series of serious inherited chronic conditions that can affect all systems of the body. It is one of the most common genetic conditions in the world and affects around one in 2,000 of all babies born in the UK. These sickle cell disorders are associated with episodes of severe pain called sickle cell painful crises.

Many systems of the body can be affected, meaning that different key organs can be damaged and many different symptoms can occur in many different parts of the body.

What is beta thalassaemia major?

Beta thalassaemia major is a serious inherited blood condition in which the red blood cells are nearly empty of haemoglobin, the key part of the blood that carries oxygen around the body. The first life-saving step of treatment involves children having blood transfusions every three to four weeks for the rest of their lives. This extra blood introduces extra iron into the body that the body cannot get rid of easily. The second step of treatment involves drugs that get rid of the excess iron.

How does someone get sickle cell disorder or beta thalassaemia major?

Sickle cell disorders and beta thalassaemia major are inherited. They are not infectious diseases and cannot be caught like coughs or colds. Sickle cell or thalassaemia carriers are sometimes referred to as having sickle cell/thalassaemia trait. Carriers have a normal and an affected gene. Carriers are usually perfectly healthy themselves, and may not know they have the trait unless they have a blood test. If someone is a carrier it cannot turn into sickle cell disorder or beta thalassaemia major. If both partners are sickle cell carriers, then in each pregnancy there is a one-in-four chance that they could have a child with sickle cell anaemia; a one-in-four chance of a child with normal haemoglobin (haemoglobin AA); and a one-in-two chance of a child who is a sickle cell carrier.

How can the symptoms of sickle cell disorders be prevented?

Certain factors have been identified as more likely to precipitate a painful sickle cell crisis. These include infections, colds and/or damp conditions, pollution, dehydration, strenuous exertion, stress, sudden changes in temperature, alcohol, caffeine, and smoking.

Water

Young people with SCD need to be well hydrated to reduce the likelihood of becoming ill. This means that they need a ready supply of fresh drinking water available at all times



and need to be able to access drinking water in class. Schools need to ensure that water fountains are working and kept in the highest state of cleanliness so young people with SCD are not put off using them, and the risk of infection is kept to a minimum.

Using the toilet

People with SCD produce large quantities of dilute urine and need to go to the toilet more often so will need frequent toilet breaks.

Tiredness

A child with SCD may experience severe anaemia. This may mean they feel tired, lethargic and unable to concentrate. Young people with beta thalassaemia major are likely to be tired towards the end of their four-week cycle of transfusions. It is important that staff do not mistake serious medical symptoms of SCD or beta thalassaemia major for laziness. Climbing several flights of stairs several times per day to get to and from the classroom is physically demanding for some young people with SCD.

Physical exercise

A child with SCD will need to avoid hard physical exercise that could precipitate a sickle cell crisis. Young people with SCD will come to know their own safe limits of physical activity. For children with SCD, cold or wet weather, or exposure of the skin to cooling wind, may all be a trigger to episodes of illness. Obligatory sports and gym sessions outdoors in cold and wet weather is a potent stimulant to crisis for some children. It is important to listen to the child and parent, and follow advice from their specialist medical teams about this.

Infection

Young people with SCD and thalassaemia may have a damaged or missing spleen (the organ that helps to fight infections). Safe storage and dispensing of any antibiotic drugs prescribed for the young person with sickle cell disorder or thalassaemia is essential.

Temperature

Young people with SCD need to avoid activities that require outdoor work in cold or damp conditions as well as under-heated classrooms, especially mobile classrooms. They may need to wear a coat in class and should be allowed to stay inside at break times in cold or wet and windy weather.

Individual health care plans

All children with SCD or beta thalassaemia major will have individual health care plans, which should be reviewed yearly. As both SCD and beta thalassaemia major have numerous possible complications affecting many systems of the body, it is important, where possible, to include a specialist sickle cell or thalassaemia nurse in drawing up this plan.



Further information

Research

The research evidence underpinning the production of the full version of this guidance is available at: dmu.ac.uk/research/research-faculties-and-institutes/health-and-life-sciences/sickle-cell-education/sickle-cell-education.aspx

The site includes resources for schools including a guide to school policy, a booklet for teachers, a booklet for pupils, and advice for teachers who have a pupil with thalassaemia – see other resources below.

Sickle cell voluntary groups

The Sickle Cell Society

sicklecellsociety.org

Organisation for Sickle Cell Anaemia Research

Birmingham – oscarbirmingham.org.uk

Sandwell – oscarsandwell.org.uk

Sickle Cell Young Stroke Survivors

cyss.org

Thalassaemia voluntary groups

UK Thalassaemia Society

ukts.org

Other resources

NHS Sickle Cell and Thalassaemia Screening Programme available at: gov.uk/topic/population-screening-programmes/sickle-cell-thalassaemia

SCOOTER Open Education Resources For Sickle Cell And Thalassaemia, available at:

dmu.ac.uk/documents/health-and-life-sciences-documents/sickle-cell/schoolpolicysicklecellandthalassaemiaversion1paper.pdf