



The FiSCD Study: Understanding Fatigue in Children and Young People with Sickle Cell Disease

SHORT REPORT

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We carried out a study to find out how children and young people with sickle cell disease (SCD) experience fatigue. We interviewed 12 children/young people, 5 parents and 10 health professionals. This is what we found:

Children and young people



- Fatigue is a big part of their everyday life with SCD.
- Fatigue means they have less energy for everyday activities like walking and going upstairs.
- They struggle to “keep up” with friends, school, work, and at home. This makes them feel isolated, sad and worried.
- People do not understand SCD fatigue, including families, doctors, nurses, teachers and friends.
- People see their fatigue as laziness or unfriendliness and tease or punish them for it. To avoid this, children/young people try to hide the fatigue from others.
- Children/young people deal with fatigue by doing less and resting more, which is sometimes hard to do at school, work or home.
- Fatigue means “missing out” on life and dreams.
- Health professionals do not ask about fatigue or provide any support for it.
- They want health professionals to talk to them about fatigue and provide help.

Parents



- Fatigue is a big part of their child’s SCD that parents don’t fully understand.
- Fatigue means their child misses school sometimes and spends more time alone and indoors. This makes parents feel worried and anxious.
- Parents deal with their child’s fatigue through healthy meals, hydration and encouraging them to do fewer activities and rest more.
- Health professionals don’t inform parents about SCD fatigue and how to support their child. Parents want that to change.

Health professionals



- Fatigue does not get attention in current SCD care and education.
- Health professionals need to talk to children, young people and parents about fatigue.
- Health professionals need to pay attention to fatigue to help improve children’s and young people’s quality of life.
- Interventions and treatments are needed to help children, young people, and parents deal better with fatigue.

What happens next?

1

We have written a report based on what everyone told us. They will be sent to doctors, nurses, psychologists, social workers, charities and other professionals who look after children and young people with SCD. We hope it will help people understand how fatigue affects children and young people with SCD.

2

We will use what everyone told us to develop a programme to help children and young people with SCD deal with fatigue better. We will do this together with children, young people, parents, health professionals and charities.