

Schools failing pupils with sickle cell disease

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A new study suggests young people with a serious genetic blood disorder are not getting the right help at school, especially pupils who miss lessons due to sickness.

Research funded by the Economic and Social Research Council (ESRC) at De Montfort University, the University of York and Loughborough University reveals that most children with [sickle cell](#) disease (SCD) do not feel supported by schools in catching up on absences from class.

Sickle cell is an inherited condition affecting around one in every 2,000 children born in England. The majority are from ethnic minority backgrounds and those with the disease may develop abnormal shaped [red blood cells](#) which block [blood vessels](#). This can lead to [chronic pain](#), [organ damage](#) and even strokes.

A common assumption has been that raising awareness in teachers about sickle cell is enough. Yet Professor Simon Dyson from De Montfort and the research team found no link between a school knowing a pupil has SCD and the child reporting improved experiences at school.

The study also found that [young people](#) are divided on whether others at school should be told they have SCD. Some believe this will lead to help, other [pupils](#) feel it will intensify bullying.

"Many schools are failing to keep young people well, and are not supporting them to catch-up any schooling they miss through illness," says Professor Simon Dyson who works in the Unit for the Social Study

of Thalassaemia and Sickle Cell at De Montfort.

Professor Dyson and his researchers have developed a policy guide for schools on supporting children with [medical conditions](#). The Department for Education have since used this information in a health and safety leaflet targeting educators.

The guide highlights examples of good practice where schools have adjusted their approach or policies to improve support for young people with SCD. Often this includes providing assistance but without drawing attention to pupils with the condition and not labelling pupils with SCD as 'truants' if they are persistently absent, or not forcing children who are tired or in pain to take exercise.

One school instigated a system of issuing the young person with a laminated card stating that the young person has the right to excuse themselves during lesson in order to go the toilet. Another school has a policy of regular twilight catch-up sessions after school. This learning centre is staffed on a rota basis so that any pupil who has missed a lesson for any reason can catch up in the presence of teachers, which doesn't single out the SCD student.

The impact of SCD on the educational experiences of young people is an under-researched area. Schools do have a duty to ensure the health and safety of pupils under the Health and Safety at Work Act, but previous studies have shown that pupils can miss weeks of schooling a year if schools and colleges do not have the correct support in place.

Professor Dyson comments: "Good practice consists of changing the wider school environment in the background without drawing attention to the young person with sickle cell as different from others. Being seen as different is something young people with sickle cell hate".

Provided by Economic & Social Research Council

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