

Epilepsy support in schools

Survey of young people with epilepsy and their parents and carers

May 2019

Introduction

Since 2014 state schools in England¹ have been legally required to support children with medical conditions such as epilepsy to ensure they can participate in all aspects of education.² Young Epilepsy conducted an online survey of young people³ with epilepsy and their parents and carers⁴ to find out whether schools are providing support that complies with Government standards.

Department for Education statutory guidance⁵ explains what schools should be doing to support young people with medical conditions, including having a specific medical conditions policy. The standards set out in guidance mean that all young people with epilepsy should have an Individual Healthcare Plan (IHP) and school staff should be trained to meet their needs. Schools also need to take into account how a young person's condition might affect their learning.

Under the Equality Act 2010, young people with epilepsy are protected from disability discrimination. Schools are also required to make reasonable adjustments for disabled young people to ensure that they are not at a substantial disadvantage compared with their peers.

The survey findings show that many young people with epilepsy are not being adequately supported at school. 1 in 3 children with epilepsy, for example, still do not have an Individual Healthcare Plan to ensure they are safe and included. Young Epilepsy is using the evidence gathered from this survey to campaign for improvements in epilepsy school support. We have also developed a free online guide for schools:

www.youngepilepsy.org.uk/guideforschools

Epilepsy

On average, epilepsy affects one young person in every primary school and five in every secondary school.⁶ It is one of the most common long term conditions in childhood. There are more than 40 different types of seizure which affect the brain and every young person's epilepsy is unique to them.

Most seizures stop without the need for emergency treatment. However, it is crucial that schools have the information they need to keep a young person safe and to determine

¹ Including academies

² Children and Families Act 2014, section 100

³ In this document, 'young people' refers to both children and young people who currently attend school

⁴ Hereafter referred to as 'parents'

⁵ Department for Education (2015) *Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*

⁶ 1 in 220 young people under the age of 19

Joint Epilepsy Council (2011) *Epilepsy prevalence, incidence and other statistics*

when to administer emergency medication or call an ambulance. Prolonged seizures can result in a potentially fatal condition known as status epilepticus.

Epilepsy can have a profound and wide-ranging impact on young people, even if seizures are controlled. Young Epilepsy research shows that a significantly high proportion of young people with epilepsy have difficulty in at least one area of cognition or behaviour.⁷ These difficulties are often missed because of the pressing medical needs of epilepsy.

Survey

Young Epilepsy's school support survey launched on 13 December 2018 and closed on 13 February 2019, receiving a total of 565 responses.

356 respondents were young people with epilepsy who attend a state school in England, or their parents.⁸ The survey findings presented below are based on the responses of this group. Of these 356 responses:

- 58% represented young people at primary school and 42% represented young people at secondary school.
- 12% represented young people at special schools and 88% represented young people at mainstream schools.

Key findings

- 1 in 3 young people with epilepsy do not have an Individual Healthcare Plan (IHP) at school to ensure they are safe and included (37%).
- Only 4 in 10 IHPs include how epilepsy might affect young people's learning (39%).
- Only 61% of families said their school had a medical conditions policy in place.
- Only half the families said that school staff had been trained to support a young person with epilepsy (50%).
- 1 in 6 young people with epilepsy are excluded from activities or opportunities at school (17%).
- 1 in 3 families are not confident that the young person with epilepsy receives the necessary care and support in school to allow full participation in school life (33%).

⁷ Young Epilepsy (2014) *The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) study*

⁸ Of the 356, 9% were young people and 91% were parents or carers. State schools in England are required to comply with section 100 of the Children and Families Act 2014.

Individual healthcare plans

Individual Healthcare Plans (IHPs) *'provide clarity about what needs to be done, when and by whom'*⁹ in order to support a specific child with a medical condition. They set out key information to ensure a child is safe and included at school.

Schools are advised that IHPs are essential for conditions that fluctuate or where there is a high risk that emergency intervention will be needed. Given that epilepsy meets this criteria, all children affected by the condition would be expected to have an IHP. However, our survey found that **1 in 3 young people with epilepsy still do not have an IHP at school (37%)**.

"[The IHP was] only recently put in place after a seizure was dealt with very badly at school. I found out there was no care plan in place, even though the school had all up to date information."

"It took me 2.5 years to get [an IHP] for my son as the school didn't take his epilepsy seriously. I had to really fight to get support for him. I even ended up doing research on the local council website, found a drop in centre and got some information. The school failed to provide anything."

"[The school] said because [my son] doesn't take medication he doesn't need [an IHP]."

"School told us he is too old at 15 [for an IHP]. This is an example of the incorrect info handed out by schools."

Government guidance states that:

*[IHPs] should be developed with the child's best interests in mind and ensure that the school assesses and manages risks to the child's education, health and social wellbeing, and minimises disruption.*¹⁰

A high proportion of young people with epilepsy have difficulty in at least one area of cognition or behaviour.¹¹ However, our survey showed that only 4 in 10 IHPs include how epilepsy might affect learning (39%).

"[The school are] ignoring (or are ignorant of) any impact on [my son's] learning."

Medical conditions policies

State schools in England are required to have a policy on supporting pupils with medical conditions. However, **only 61% of families said their school had a medical conditions policy in place**.

"[The school] should have one and I've pointed this out to them on several occasions but no policy is in place as yet."

⁹ Department for Education (2015) *Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*, p. 10

¹⁰ Ibid.

¹¹ [Young Epilepsy \(2014\) The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools \(CHESS\) study](#)

Government guidance states that a school's medical conditions policy should be "readily accessible to parents", but **1 in 3 respondents to our survey did not know if their school had one in place (36%)**.

Staff training

Schools are expected to provide suitable training to staff who are supporting children with medical needs.¹² However, **only 50% of families said that school staff had been trained to support a young person with epilepsy**.

Training came from a range of sources including school nurses, epilepsy specialist nurses and parents. In one instance a parent said they had paid for the school staff to be trained.

"A variety of staff - including midday supervisors - are trained with refresher (and her new class teacher) each year"

Concerns around training included:

- Insufficient numbers of staff being trained.
- Insufficient seizure first aid training.
- Lack of awareness of the impact epilepsy and medication has on learning even when seizures are controlled.
- Insufficient understanding and recognition of different types of seizure.

"After a tonic-clonic seizure a teaching assistant administered [my child's] EpiPen in error."

"Not enough is understood by teachers and support workers about how epilepsy affects learning, mental health and confidence. It's not just seizures."

"[My daughter] is often labelled as lazy, they don't understand that epilepsy can still affect learning even if there is no seizure happening. Side effects of medication make her tired and she gets quite a short attention span."

"Staff are not trained to notice the different types of seizures ... my daughter has absence seizures and no one has ever noticed it during two years because they didn't know what it looks like."

Exclusion of children with epilepsy

Schools are required to ensure that young people with medical conditions are supported to enable them to have 'full access to education, including school trips and physical education'. Under the Equality Act 2010, young people with epilepsy are also protected from disability discrimination. However, our survey found that **1 in 6 young people with epilepsy (17%) are excluded from activities or opportunities at school**.

Some young people are unable to take part in activities due to specific medical advice. However, in most circumstances young people with epilepsy can be included with the right support in place.

¹² Department for Education (2015) *Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*, p.

"[The] school worked well with me and [the] epilepsy nurse to put arrangements in place to allow my child to go on the school residential."

Our survey found that young people with epilepsy are being excluded from activities and opportunities including:

- Outside play
- Visits
- Swimming and other sports
- Cookery
- Science experiments
- Design and technology
- School plays
- School discos
- After school clubs

One parent told us that they had to accompany their child on a trip as the school refused to administer the child's emergency medication. Other parents said:

"Any sign of [my daughter] being poorly and she is sent home."

"[My daughter] has not been fully included in PE ... Instead she is kept in a room to be kept safe from any injuries she 'may' suffer from a seizure."

"[My child] is not allowed to do any after school clubs."

"My child is not allowed on school playground equipment during breaks."

"Every school trip they try to exclude [my son] by saying they haven't got the staff to cover, or he can go on the trip if I go along too."

Parental confidence in school support

Government guidance states that *'[it is] important that parents feel confident that schools will provide effective support for their child's medical condition and that pupils feel safe'*. However, our survey found that **1 in 3 parents of young people with epilepsy (or the young person themselves) are not confident that their child receives the necessary care and support in school to allow full participation in school life (33%).**

"Medication errors have occurred on three occasions."

"I do not feel confident that they fully understand presentation of seizures and behaviours leading to [my son] sometimes being punished for behaviour before seizures."

"My son didn't want to go to school because of his teacher as she would regularly shout at him for not concentrating, or keep him in at play time again for not concentrating. She knew he had epilepsy ... he said "I can't control this mummy, it's going to happen again and it makes me sad"."

"[I was] recently horrified to find out ... the school put a sign on the teacher's desk, for all to see, saying that my child has epilepsy. At best lazy care management which stigmatises, gives no real insight into needs and left me with an understandably very upset and confused child."

"My child's seizures are controlled at the moment but the side effects of the meds interfere with his learning and that doesn't seem to be taken seriously enough, he's not getting any support that he needs."

"I am constantly in school about my son as they fail to understand that all the medication is not working and he has around 50 plus absence [seizures] a day which affects his learning, memory and his behaviour. And they expect him to his work at the same rate as everyone else."

Notwithstanding the challenges families experience, parents also told us about their own **examples of good practice:**

"The school have been amazing... They have always followed up any changes needed in [my daughter's] care plan immediately right down to wanting to know as soon as her dosage had been increased. [They are] fully supportive of the fact that I want her to be able to do everything she was able to do before her diagnosis."

"I have a meeting with the new teacher each new school year to talk about what she should know. [My daughter's seizures are] currently controlled but as it can change the teacher needs to understand her diagnosis and the risks attached. They provide an extra teacher to solely observe her during swimming lessons. When she was first diagnosed they brought in a council nurse to help understand more what she may need while struggling with side effects. They also suggested a buddy system so a few friends would understand."

"It was through the teaching assistant at my daughter's school that actually helped us with the diagnosis of epilepsy. She noticed the signs of tonic seizures she had at school and also the absence seizures."

"Our life has been turned upside down with the recent diagnosis of epilepsy. Our school and head teacher have been excellent. They have not only supported our daughter since but also her younger sister in the year below too! I feel very confident with our daughter being at school that she will be closely watched and taken care of should a seizure occur. They have been amazing."

"My child receives very good pastoral help and care at school. All staff are regularly trained, she has had support from the school counsellor and the SENCO [Special Educational Needs Co-ordinator] (and all staff) is/are very supportive of her needs. They have also offered some recent SIBs [sibling support] talk to give to her brother."

“We were allowed to talk to the school’s SENCO prior to selecting the school for our daughter (others refused or questioned why we wished to talk to them). She has been very supportive and as a result we have a close working relationship with our SENCO and the teaching staff. We’ve encouraged lots of communication between us all and this has definitely enabled our child to thrive at school.”

“There is another child in the school with epilepsy a couple of years below. The teachers asked both sets of parents and children, if the kids could meet during the week with a member of staff. My son is very positive about the experience. Sharing their stories and their feelings.”

“In my experience it’s absolutely vital to keep talking to school. I’ve also realised that talking to school once is not enough, updating and reminding them of your child’s needs is really important. Keep an open and honest dialogue and don’t be afraid to be seen as a difficult parent!”

Improving epilepsy support in schools

Young Epilepsy is using the evidence gathered from this survey to campaign for improvements in epilepsy support in schools.¹³ We are calling for:

- Schools to ensure that all young people with epilepsy have an Individual Healthcare Plan.
- Schools to ensure they have a policy on supporting pupils with medical conditions.
- A requirement on schools to publish medical conditions policies on their websites.
- School inspections to include a routine check for support for pupils with medical conditions.

Young Epilepsy has developed a free online guide for schools on supporting young people with epilepsy, which can be found at: www.youngpilepsy.org.uk/guideforschools.

We are a member of the Health Conditions in Schools Alliance which is made up of over 30 organisations including charities, healthcare professionals and trade unions working collaboratively to make sure children with health conditions get the support they need at school.

¹³ State schools in England