

## Epilepsy support in schools

### Survey of young people with epilepsy and their parents and carers

October 2017

#### Introduction

Since September 2014, state schools in England<sup>1</sup> have been legally required to support children with medical conditions such as epilepsy. Young Epilepsy conducted an online survey of young people<sup>2</sup> with epilepsy and their parents and carers<sup>3</sup> to find out whether schools are providing support that complies with Government standards.

The Department for Education has published statutory guidance<sup>4</sup> which 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 the 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.

#### Survey

Young Epilepsy's school support survey launched on 28 March 2017 and closed on 8 May 2017. The online survey received 661 responses.

373 respondents were young people with epilepsy (11%), or parents and carers of young people with epilepsy (89%), who attend a state school in England.<sup>5</sup> The survey findings presented below are based on the responses of this group. Of these 373 responses:

- 62% represented young people at primary school and 38% represented young people at secondary school.
- 7% represented young people at special schools and 93% represented young people at mainstream schools.

#### Key findings

- Less than half of the families responding to our survey (45%) said their school had a medical conditions policy.
- 1 in 3 young people with epilepsy still do not have an IHP at school (36%).

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<sup>1</sup> Including academies

<sup>2</sup> In this document, 'young people' refers to both children and young people who currently attend school

<sup>3</sup> Hereafter referred to as 'parents'

<sup>4</sup> 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*

<sup>5</sup> The schools that are required to comply with section 100 of the Children and Families Act 2014

- For those IHPs that are in place for young people with epilepsy:
  - 1 in 6 do not include information on current medication/treatment (16%).
  - 1 in 9 do not include what to do in an emergency (11%).
  - 1 in 13 do not include what to do when a seizure occurs (8%).
- 2 out of 3 plans do not include how epilepsy might affect learning (67%).
- Only half the families (51%) said that school staff had been trained to support a young person with epilepsy.
- Concerns around training include:
  - Staff lacking confidence to deal with epilepsy.
  - Lack of understanding of the danger of prolonged seizures.
  - Insufficient understanding of different types of epilepsy.
  - Lack of awareness of the impact of epilepsy and medication on young people's learning.
- 1 in 6 young people with epilepsy (18%) are excluded from activities at school, including:
  - Assemblies
  - Outside break times
  - Swimming and other sports
  - After school clubs
  - School trips
- 1 in 6 families (17%) are concerned about home to school transport for young people with epilepsy.
  - This rises to 1 in 3 (34%) for young people at secondary school.
- 1 in 4 young people with epilepsy (24.5%) have an Education, Health and Care Plan or a Statement of Special Educational Need.

## Medical conditions policies

State schools in England are required by law to have a policy on supporting pupils with medical conditions. However, **less than half of the families responding to our survey (45%) said their school had a medical conditions policy.**

This figure adds weight to recent findings from the Health Conditions in Schools Alliance (HCSA) that only 47.5% of schools had a policy in place. It should be noted that when the HCSA subjected these policies to further analysis, it was found that only 11.5% of schools had a policy which complied with Government standards.<sup>6</sup>

Government guidance states that a school's medical conditions policy should be "readily accessible to parents", but **49% of respondents to our survey did not know if their school had one in place.**

*"I've never been given any information about how the school supports pupils with epilepsy."*

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<sup>6</sup> Health Conditions in Schools Alliance (2017) *Investigation into schools' compliance with Department for Education statutory duty for supporting pupils with medical conditions in school*

*“We have not been made aware of such a document.”*

*“We have asked to see it but been dodged.”*

This parent raised concerns about how their child’s school implements its medical conditions policy:

*“It seems a policy is in place but not enforced or followed and when challenged on how they make sure all teachers are aware of this policy then no clear answer can be given.”*

## Individual healthcare plans

Individual healthcare plans (IHPs) *‘provide clarity about what needs to be done, when and by whom’*<sup>7</sup> in order to support a specific child with a medical condition. 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 (36%)**.

*“We had to dig our heels in to get [an IHP].”*

*“We have had to fight to make sure this plan is in place.”*

*“As a parent I had to push the school to hold a meeting ... to develop an IHP for my son.”*

*“I recently found out that my daughter did not have an IHP and furthermore the staff had not been trained in how to administer her [emergency medication] nor did most of them even know basic seizure first aid ... this horrified me...”*

**Young people with no IHP were much more likely to be in a school that was not known to have a medical conditions policy (75%<sup>8</sup>) than young people with an IHP (43%<sup>9</sup>).**

For those IHPs that are in place for young people with epilepsy:

- **1 in 6 do not include information on current medication/treatment (16%).**
- **1 in 9 do not include what to do in an emergency (11%).**
- **1 in 13 do not include what to do when a seizure occurs (8%).**

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.*

Epilepsy can have a profound and wide-ranging impact on children. Young Epilepsy research<sup>10</sup> has found that 95% of children with epilepsy have a significant difficulty in cognition or

<sup>7</sup> 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

<sup>8</sup> Does the school have a policy on supporting pupils with medical conditions? (Young people with epilepsy with no IHP) No: 10.4%, Don’t know: 64.9%

<sup>9</sup> Does the school have a policy on supporting pupils with medical conditions? (Young people with epilepsy with an IHP) No: 2.6%, Don’t know: 40.1%

<sup>10</sup> Young Epilepsy (2014) *The identification of educational problems in childhood epilepsy: The Children with Epilepsy in Sussex Schools (CHESS) study*

behaviour. This need is not being reflected in children's IHPs, however, as our survey showed that **2 out of 3 plans do not include how epilepsy might affect learning (67%)**.

*"The school were reluctant to acknowledge that [my daughter] would have any educational needs as part of her type of epilepsy."*

*"Always struggled to get [my daughter's] primary and now secondary school to acknowledge she is struggling with memory, learning and grades."*

## Staff training

According to Government guidance, schools are required to provide suitable training to staff who are supporting children with medical needs. However, **only 51% of people responding to our survey said that school staff had been trained to support a child with epilepsy**.

Training came from a range of sources, including school nurses, epilepsy specialist nurses and parents:

*"If it wasn't for me pushing and demanding that they be aware, our son would be at risk every day. Training was given by me as the school felt money could not be spent on ensuring the safety of our child."*

*"Our local epilepsy nurse specialist is fantastic and is always willing to train teachers and carers [on] how to assist my son during a seizure and give [emergency medication]."*

A number of parents expressed concern at the limited numbers of staff being given training:

*"I had to push for [training], the staff decided they didn't need it, when I found out I insisted they did but not all necessary staff were trained!"*

*"Had to fight to get school to realise they needed more staff trained. Because in secondary school more teachers [have a] larger area to cover if there was a problem."*

Some families were concerned at school staff's **lack of confidence in dealing with epilepsy**:

*"They seem to find epilepsy quite scary, they panic if they think I might have a seizure."  
(young person)*

*"The training is completely insufficient and they are all terrified of his seizures, if he is not well and has a few [myoclonic or absence seizures] he gets sent home."*

*"They send [my daughter] home if she has enlarged pupils, one of 20 seizure symptoms. It's ridiculous, something needs to change."*

*"[As] soon as [my son] says he feels ill, they send him home then raise questions about his attendance."*

Parents were also concerned about the **lack of understanding of the danger of prolonged seizures**, which can result in a potentially fatal condition known as status epilepticus. Young people with epilepsy may have been prescribed emergency medication which needs to be administered within a specific time frame. One parent explained that the school *"cannot get training to give emergency drugs so an ambulance will need to be called"*, potentially delaying the administration of medication. Another parent said:

*“The ignorance and failure to disseminate information which is so critical to [my daughter’s] health is shocking, my daughter has been in status [epilepticus] in the past and the school seem unaware of how critical a condition this can be.”*

Another parent explained that, despite training, *“quite often [emergency medication is] forgotten on day trips or left to go out of date.”*

**Different types of epilepsy are not always being understood or recognised** by schools:

*“Sometimes when I have [absence seizures] they just brush that aside and even tell me off for not paying attention - like what the hell?”* (young person)

*“Staff only seem to recognise tonic clonic seizures. They do not report [my son’s] focal seizures to me even though he is incontinent during these. It’s almost like they don’t think focal seizures are important.”*

*“One teacher excluded my daughter in a competition because they thought she was being silly (she was 6 then) but she told me she was having a seizure at the time.”*

*“[The school are] continually focusing on [my son’s] ‘lack of focus’ on school reports when he suffers from absence seizures!”*

However, there were some examples of good practice in relation to understanding different types of epilepsy:

*“[We] explained that if she has an absence seizure she can lose the thread of what the teacher is saying. The school said it would ask the teaching assistants to make sure she understands what to do.”*

Although families spoke about training covering what to do in the event of a seizure, some parents highlighted a **lack of understanding of the impact the condition and medication can have on young people’s learning**:

*“Whilst my daughter has [an individual healthcare plan], I had to fight to get the school to understand that as her epilepsy was nocturnal it was the impact of the seizures and the medication on her cognition, memory and processing speed that was the main problem in school. Staff need more training on the impact of medication as the focus seems to be just the seizures. Staff are also unaware of the link between mental health and epilepsy.”*

*“It has been a constant struggle to get help. [My daughter] is behind but they keep saying she is fine. She is failing her exams. How can they not admit they need to do something ... One teacher said she was playing on having epilepsy for memory loss!”*

*“On one occasion due to lack of understanding of the condition I got told by my daughter’s old teacher “I don’t think she has epilepsy she just chooses not to do her work” this was after a meeting a specialist epilepsy nurse had gone into school to help give school a better understanding of her condition!”*

*“[The school] do not make allowances for how tired my daughter is at times after having had a bad night of seizures. The staff genuinely do not seem to have a clue about how to best support her...”*

*“They tried to put me on disciplinary action because of my low attendance, which was due to my epilepsy.”* (young person)

## 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'*. However, our survey found that **1 in 6 young people with epilepsy (18%) are excluded from activities 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:

*"[My daughter is] fully involved particularly in sport and [has] been on two ski trips and other residential trips too."*

*"[My daughter] has been on two residential trips involving outdoor activities and has been fully included in all of them, including climbing and zip wire."*

*"[My] child was included on a residential trip abroad."*

*"My son is made welcome and provided for at all of [the extra curricular activities]."*

*"[My son] has never been prevented from doing anything."*

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.

Despite evidence of good practice, our survey also showed that **young people with epilepsy are being excluded from a range of activities, including assemblies, outside break times, swimming and other sports, after school clubs and school trips.** One young person was excluded from a particular subject because lessons were held upstairs. In another instance, however, a school was able to move lessons downstairs to accommodate a young person with epilepsy.

Lack of understanding about epilepsy's impact appears to be a factor in some cases:

*"My daughter has on many occasions been excluded from activities because of her apparent behaviour which me and the [Epilepsy Specialist Nurse] explained it's her epilepsy not her being naughty."*

Other young people experienced a lack of support:

*"I could not participate in a catering GCSE because it was too dangerous, but children of all different conditions are provided with [Teaching Assistants] so they can do any subject. If a child in a wheelchair couldn't fit through the door they would have to provide an alternate route yet they couldn't do that for me." (young person)*

One parent explained that a school had tried to charge them for one to one support in swimming lessons as part of the curriculum. Other parents have had to provide support to ensure their child was included:

*"[My son] isn't allowed to do residential trips and I attend the majority of all others which is making a huge impact on everything. I'm unable to work also now too."*

*“Although [my daughter] has never been told she cannot go on trips I am always encouraged to go as well, being told they are struggling for staff as my daughter needs closer attention paid.”*

## Home to school transport

Local authorities are required to provide home to school transport for children ‘*who cannot reasonably be expected to walk to school because of their mobility problems or because of associated health and safety issues related to their special educational needs or disability*’.<sup>11</sup>

Our survey found that **1 in 6 families (17%) are concerned about home to school transport for young people with epilepsy. This rises to 1 in 3 (34%) for young people at secondary school.**<sup>12</sup> This older group are often expected to travel further and/or independently to get to school.

A number of families spoke about their concerns that seizures might go unnoticed on school transport and have had to adjust their schedules to enable them to take their children to and from school:

*“[We] have had to ensure that there is always someone around at either end of the school day - we have changed working patterns which has had an impact on our finances and lifestyle.”*

Families raised concerns about taking public transport or walking alone due to the risk of seizures:

*“I don't get the school bus anymore. I don't know what they would have done if I'd had a seizure on the bus.”* (young person)

*“My son travels to school alone which is very worrying. It's hard to balance his safety with the importance of his independence as he needs to learn to live with and manage his epilepsy.”*

*“I can't allow him to walk to and from school as I don't know when a seizure could strike.”*

*“I am worried about my daughter crossing roads because she has absence epilepsy.”*

Concern was expressed by a number of parents about the lack of training for transport staff, including on the use of emergency medication:

*“We fought for four months for the [emergency medication] to be included into his transport plan.”*

*“I know that friends whose children have epilepsy worry because of the lack of training of both drivers and chaperones and that there is no legal obligation for training to take place.”*

## Additional support for special educational needs

Epilepsy can have a profound impact on learning and behaviour. Other conditions that young people have (alongside epilepsy) may also result in needing a higher level of support at school.

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<sup>11</sup> Department for Education (2014) *Home to school travel and transport guidance to schools*

<sup>12</sup> 8% for young people at primary school

Our survey found that **1 in 4 young people with epilepsy (24.5%) had an Education, Health and Care Plan (EHCP) or a Statement of Special Educational Need.**

*“My son has a full time [Teaching Assistant] as a result of the [EHCP] which has made the world of difference to his experience at school. He is so much happier, knows who to go to if he has a seizure and gets all the support he needs with his learning.”*

Responses from families show the challenges they face in getting an Education, Health and Care Plan in place to provide sufficient support for young people with epilepsy:

*“Still trying to get an EHCP in place - she is year four now and have been trying since reception.”*

*“[My son’s] paediatrician would like him to have an [EHCP] but the school are dragging their heels.”*

*“Was told by SENCO that an EHCP was not needed unless we wanted our child to go to a special school. Disagreed with this so applied for EHCP ourselves and got one.”*

*“Fighting for an EHC. The school just focus on the educational part. They don’t have a clue.”*

*“School have been amazing and done everything they can but our LEA have been impossible. Because it’s a rare type of epilepsy he doesn’t really fit their criteria so getting his learning needs met has been impossible. He’s now 2 years behind as we were told (he’s 6) that until he’s functioning at a 12 month level (he’s currently at about 3/4 years) they will not even consider an EHCP.”*

## Other concerns

Parents and young people raised a number of other concerns in their responses to our survey.

Stigma:

*“[My daughter] was asked to wear a sash on the playground so she was easily identified when playing. We made it clear that a member of staff would need to be in close proximity to her so should know where she is without having to ‘label’ her!”*

Safety concerns:

*“They won’t let me wear my medical alert bracelet.” (young person)*

*“I wrote the risk assessment for her swimming lessons after the blanket one they did was awful and totally useless. Her ‘watcher’ at swimming was helping another child with their hat when mine had an absence [seizure] in the pool.”*

Limited funding for support:

*“Only the [Learning Support Assistants have been trained]. [I’m] worried though, as these jobs are becoming fewer and staff made redundant to save a few pence (they are woefully underpaid).”*

*“She’s been unable to attend swimming lessons with her class as the school hasn’t been able to secure funding for her to have 1 to 1 in the water.”*

*“In the past 8 months the level of care/supervision he receives has reduced. School have advised they cannot afford the one to one supervision at play times.”*

*“School have said they have no spare staff to give 1:1 supervision. This means she will grab hold of nearest child during seizure. She has pulled them both to the ground on occasions.”*

Lack of clarity on funding responsibilities:

*“Due to funding between health and education, [training] cannot be provided by the children's epilepsy team. This seems stupid when the aim is to prevent serious complications and the time it takes to call an ambulance will exceed the time before she needs her emergency drugs putting my child in harm.”*

### **Other positive experiences**

Despite a number of concerns being raised, there were many examples of parents and young people experiencing good quality support. One school, for example, had a named governor for supporting children with medical conditions.

Regular communication between the school and parents:

*“My son's school have been amazing since his diagnosis last year even booked up a course to learn more and the school nurse has a regular meeting with us and my son's [Teaching Assistant] and the SENCO teacher my son works with to update his care plan and offer us advice.”*

*“The school my son goes to is amazing. They're so supportive of him and his needs. They update me regularly and I keep them up to date.”*

*“Home school communication via home school book completed daily so staff are aware of how my son is before each day starts and can also provide us feedback on events during the day.”*

Whole school approach:

*“[The school] have a yearly assembly so [my daughter] and the head teacher can tell the school community about epilepsy and what they need to do if she has a seizure. They are great.”*

*“I asked [the teacher] to show [a film] and talk to my daughter's friends after she had a seizure in the playground. It made a huge difference to my daughter feeling 'normal' and helped her friends feel less frightened and know what to do.”*

Holistic support from the school:

*“The secondary school contacted us ahead of him joining them as they had received paperwork from the school nurse. In the summer term ahead of him joining in the September, we met with them and they drew up a comprehensive IHP and every teacher who would teach him was given full details of his condition and details were also passed to the SENCO and the emotional welfare department. An open communication system has meant that we have been able to update and be updated regularly by email/telephone.”*

*“I have a radio and so does [the first aider] and if I ever have a seizure he can be called through the radio and he will assist me. He also does one to one with me for revision and coursework catch up. The students and teachers are really supportive there. They have adjusted my timetable in the hope of reducing the seizures so I now do a shorter day at school. I also have many people I can talk to if I need to ... In terms of exams all my needs have been met ... [I will be given] extra time, be allowed to have breaks and will be in a calm environment supervised by my first aider ... The teachers are also very understanding. They are helping me with revision so helping me work through it and making it less stressful. I also feel safe at school.” (young person)*

Responsiveness to changing needs:

*“My daughter’s school have been amazing ... Anxiety is a trigger for her seizures and ongoing increasing and changes of meds have made things tricky at times. My daughter has two people she can go and see at any time who know her and get her and have made the difference to her. From experience of recent [exams] where I ... worried she’d trigger a seizure, one quick email to the key stage head and she acted and in my mind avoided a seizure. A plan was then put in place to alleviate further anxieties during the [exams]...and all was good. As a parent it is so important someone takes your child’s condition seriously.”*

*“[My daughter’s] teacher has consulted medical professionals and spent time with us to understand how to respond to a seizure as the situation has developed and has worked out special ways for [my daughter] to alert her if she feels like she may have a warning of a seizure e.g. pointing to a particular sign rather than putting her hand up to tell staff as she can feel shy.”*

## **Improving epilepsy support in schools**

Young Epilepsy is using the evidence gathered from this survey to campaign for improvements in epilepsy support in schools.<sup>13</sup> 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 is 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.

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<sup>13</sup> State schools in England