Understanding of epilepsy by children  
with, or without, epilepsy  

Funded by Epilepsy Action  

Final report  

May 2007  

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Acknowledgments

Our thanks to Epilepsy Action for funding this project and for having been extremely supportive and encouraging throughout. We have consistently received warm and constructive support from across the organisation; including Trustees, research, technical, conference, media and support staff. We have very much valued this trusting and open relationship which has underpinned, and greatly benefited, the research.

Our thanks also to the pupils and staff of participating schools and colleges, as well as Local Authority personnel who have contributed so enthusiastically to the project. They are not named here for ethical reasons.

We are also grateful to staff and students at Sir Jonathan North Community College, Leicester for their enthusiastic involvement.

Finally colleagues at the University of Birmingham, particularly Dee Fellows, (secretary to the project), Caroline Baxter (discussions concerning parental perspectives) and Paul Edwards and Geraint Evans (technical support for e survey) have helped to ensure that tasks were completed well and on time.
Acknowledgments

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Understanding of epilepsy by children with, or without, epilepsy

Summary

This one year project (2006-7) focused on the understanding of epilepsy by children with, or without, epilepsy. It encompassed two overlapping sets of data collection (informed by a literature review): (1) an e survey of 44 self-selected children and young people with epilepsy and (2) interviews (mainly individual) in mainstream schools with (i) 22 children/young people with epilepsy and (ii) 22 classmates, matched with child with epilepsy; by age, gender and broad ability level. The findings are highly relevant to mainstream schools but also have implications for promoting the wider social inclusion of children and young people with epilepsy; for example, in youth groups, sports foci, arts orientated groups and informal social networks.

Findings concerning children and young people with epilepsy

Overall, children and young people (ages 7-18) with epilepsy were clear about the nature of their condition, including seizures. However some of the younger primary age children were confused about causes while, with age, young people became more phlegmatic about having epilepsy. A majority of participants reported that they were taking medication for their epilepsy, although there was some confusion amongst the youngest children about the function of their medication. A frequent reference across all age groups was to tiredness, either as a side effect of their medication or arising from the epilepsy itself. For this reason, if no other, it is vital that mainstream schools have good knowledge both about individual pupils with epilepsy and about the condition more generally.

For many children and young people, there was an implicit reluctance in accepting epilepsy as a ‘part of them’; self-reported feelings of secrecy, stigma and shame abounded. This raises important issues concerning the silence around epilepsy in mainstream schools which, ironically perhaps, may be reinforced by successful medication for pupils there with epilepsy. The lack of role models in public life may be reinforcing a tendency to feel embarrassment about epilepsy.

Many children and young people felt worried and uncomfortable about their epilepsy in school contexts and wanted teachers to have a better understanding and awareness of the condition. More widely, the majority (possibly reflecting our mainstream school focus) felt that their epilepsy had a fairly limited impact on participation in activities outside of school. The differences across age groups suggest developmental patterns which reflect the impact of a combination of: knowledge and acceptance of epilepsy, adjusting of medication and cognitive trajectories. Overall, young people wanted more information about epilepsy to be available in the public domain and this needed to be presented in a variety of formats.
Findings concerning classmates- children and young people without epilepsy

Children and young people without epilepsy had varying levels of awareness of the condition with some being close friends with someone with epilepsy and others believing (incorrectly, see methods) that they did not know anyone with the condition. Despite these differences, an overwhelming finding was that the majority of children and young people knew very little about epilepsy. However, their attitudes towards people with epilepsy were positive and understanding, although characterised by uncertainty due to a lack of information or knowledge. Importantly, those who had friends with epilepsy had come to know more about the condition.

A majority of participants said that there was little or no discussion about epilepsy at their schools. Many wished to be better informed about epilepsy and they made thoughtful suggestions for ways in which this could be done through schools. Suggestions included teachers having greater awareness of the condition, implementing a ‘buddy’ system to support younger students, and providing information about epilepsy in a range of formats and always in age-appropriate and accessible language (see recommendations).

Methodological points

The portfolio of methods developed in other work (Lewis et al 2005, 2007) was drawn upon here so that diverse children and young people were able to share their views. This approach of individualising methods to maximise contributions from children and young people was successful in generating responses, even from children as young as 7 or 8 years old, and eliciting a range of (generally well-supported) views.

Taking a qualitative methodological approach, as well as providing space for open responses on surveys, revealed important insights into complex concepts like stigma. This was illustrated in children and young people’s readiness to talk about their feelings of ‘difference’ in relation to others when given the opportunity to do so sensitively.

Future work might usefully apply the approaches used here to exploring further the views of pupils with epilepsy in special schools (likely to experience co-occurrence of epilepsy with other conditions) and understanding about epilepsy, for all children with or without epilepsy, in the wider community.
## Understanding of epilepsy by children with, or without, epilepsy

### Recommendations (draft)

<table>
<thead>
<tr>
<th>Children and young people’s feelings about…</th>
<th>Key points from findings</th>
<th>Recommendations</th>
</tr>
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<tbody>
<tr>
<td>epilepsy at school</td>
<td>- Children and young people with epilepsy feel more anxious about their condition at school compared to home.</td>
<td>For schools:</td>
</tr>
<tr>
<td></td>
<td>- Children and young people with epilepsy worry about how other people at school will respond to their condition and this sometimes means that they are reluctant to talk about it to others.</td>
<td>- plan and provide opportunities to listen to the views of pupils with epilepsy (and their parents) to find out how they would like their epilepsy to be supported at school.</td>
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<td></td>
<td>- Children and young people without epilepsy are unsure about the condition and worry about what to do if someone had a seizure at school.</td>
<td>- ensure pupils are told which teachers know about their epilepsy, and what they know about it.</td>
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<td></td>
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<td>- reassure pupils that they are valued members of the school and that they will be fully supported.</td>
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<td>- integrate basic First Aid/epilepsy awareness in health curricula.</td>
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<td>- keep a systematic and regularly updated record concerning pupils with epilepsy and share with relevant staff.</td>
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For Epilepsy Action:

- develop materials to help friends of children with epilepsy to understand the condition and know how to respond.
- promote importance of general First Aid classes in schools (which include information about seizures).
- develop interactive area of EA website addressing these issues.
<table>
<thead>
<tr>
<th>Whether information about epilepsy should be taught in schools</th>
<th>For schools:</th>
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<tbody>
<tr>
<td>- Children and young people feel that schools should do more to promote understanding and awareness of epilepsy amongst the student population.</td>
<td>- adopt a committed, whole school policy to supporting pupils with epilepsy and other health conditions and disabilities/impairments.</td>
</tr>
<tr>
<td>- Children and young people, with and without epilepsy, want to know more about various health conditions, including epilepsy.</td>
<td>- involve the School Council in making decisions about how topics like this should/could be approached in school.</td>
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<tr>
<td>- There are different ways in which awareness can be raised and schools should consider making a range of approaches available (see below).</td>
<td>- utilise a range of approaches for displaying information and raising awareness (see below for suggestions).</td>
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<table>
<thead>
<tr>
<th>What other people need to know about epilepsy</th>
<th>For schools: (as above)</th>
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<tbody>
<tr>
<td>- Children and young people were very clear about the information they thought people (including themselves) should know about epilepsy.</td>
<td>For Epilepsy Action:</td>
</tr>
<tr>
<td>- They thought it was important for people to know this information; suggestions included:</td>
<td>- as part of awareness raising in schools, develop a project that involves young people with epilepsy (perhaps FE or HE students) in supporting training sessions in schools. This could be via large group sessions.</td>
</tr>
<tr>
<td>- <strong>Nature:</strong> the causes of epilepsy, including genetic links; whether it is a fatal condition; whether it is contagious; hearing the views and experiences of young people with epilepsy and how they cope.</td>
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<tr>
<td>- <strong>Prevalence:</strong> statistics about how many people are affected by epilepsy.</td>
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<td>- <strong>Impact:</strong> how epilepsy affects people.</td>
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<tr>
<td>differently (seizure types, syndromes); triggers of epileptic seizures; how epilepsy may or may not have an impact on activities and future career choices; how epilepsy affects people at home and school</td>
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<tr>
<td>Intervention: how taking medication can help and what the medication is for; impact of medication and seizures on tiredness at home and school (and resultant impact on work and learning); importance of diet, sleep, and exercise; surgical interventions and efficacy of these; practical advice about what to do to help someone having a seizure</td>
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<tr>
<td>assembles as well as small group work and individual support for students</td>
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<tr>
<td>- identify gaps in existing information and resources to ensure that these aspects of epilepsy are adequately covered and information is available in a range of formats (including e formats), using clear and accessible language</td>
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<td>- consider epilepsy awareness needs in specific context of schools/children from minority ethnic groups</td>
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<td>how information could best be presented</td>
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<tr>
<td>- Children and young people had different preferences concerning how, and where, information should be presented</td>
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<tr>
<td>- They felt very strongly that information, in any format, should be available in clear and accessible language</td>
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<tr>
<td>Suggestions for formats included:</td>
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<tr>
<td>- Internet information sites, chat forums, ‘MySpace’</td>
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<tr>
<td>- Videos showing young people talking about their experiences</td>
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<td>- TV advertising and inclusion in range of programme types (fiction, news, documentary, arts, sports etc)</td>
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<td>- Radio (as above)</td>
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<td>- Magazines and newspapers (‘mainstream’ and epilepsy-specific)</td>
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<td>- Leaflets and posters available in schools, doctors’ surgeries, hospitals and ‘everyday’ contexts like supermarkets</td>
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<td>- Books in schools and libraries</td>
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<td>- Opportunities to talk to young people with epilepsy directly to find out more</td>
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<tr>
<td>For schools:</td>
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<td>- ensure that a range of information, in different formats, is available for children and young people</td>
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<tr>
<td>- designate a ‘safe space’ or ‘corridor’ to which pupils can go for sensitive information, help and support</td>
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<td>For Epilepsy Action:</td>
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<tr>
<td>- develop some video footage that shows diverse young people talking about their epilepsy and how they deal with it. This could also show them taking part in a range of activities and ways in which they ‘take control’ for themselves. Could be co-produced with a group of young people and directed by them. This could be available as stand alone DVD or in downloadable clips from the internet. Needs to utilise popular sites for young people also including MySpace. Targeted external funding may support this.</td>
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<tr>
<td>- Develop some simple, funky leaflets using age appropriate language</td>
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| what schools can do to help | Children and young people made a number of suggestions for how schools could provide support for young people with epilepsy; suggestions included:

- **Staff awareness:** ensuring that teachers are adequately trained and aware about epilepsy; understand about the need to take time off for hospital and doctor's appointments; offer one-to-one discussions with a teacher at the school in order to talk about how epilepsy affects the student and what they would prefer to happen if they have a seizure at school / college; ensure that all teachers know about students’ individual needs

- **Support:** implementing a ‘buddy’ system or club for children with epilepsy (and other conditions or disabilities) so that (for example) older children can support younger ones; providing support in exams, for example being aware of environmental triggers such as flashing lights and giving students

| For schools: |
| - evaluate existing provision of information and support re health conditions and disabilities to identify gaps (and include pupils in this)

- consider the implementation of a ‘buddy system’ to support vulnerable students in general

| For Epilepsy Action: |
| (see above)
the choice of whether to take exams in a different room to other students; encourage participation in activities rather than taking an overly protective approach
- **Curricular**: putting epilepsy on the curriculum so that everyone has the opportunity to find out about it
- **Information giving**: having a school notice board that displays relevant information; inviting people from organisations to come and present an assembly about epilepsy
Understanding of epilepsy by children with, or without, epilepsy

1. Background

To date, there has been little systematic published evidence concerning the views of children and young people with epilepsy, and their classmates, about their condition. Two particular gaps in knowledge and understanding are addressed by this project and relate to (1) classmates’ understanding of epilepsy and (2) the links between understanding of epilepsy (all children and young people) and the school context in which so much of children’s lives is spent.

1.1 Prevalence rates and nature of epilepsy in children

The prevalence of epilepsy in the general population in developed countries is 5-10 cases per 1000 (MacDonald et al., 2000) with the most common age of onset being before the age of 15. Rolandic epilepsy (benign childhood epilepsy) constitutes about 15-17% of all childhood epilepsies and is not associated with major long term (5 years post seizure) cognitive difficulties (Lindgren et al 2004). Epilepsy is the most common neurological condition in adolescents with a prevalence of 1.5-2% amongst that age group (reported in Baker et al., 2005). This means that in an average secondary school with 800 students on roll, there could be as many as 12 to 16 students with epilepsy.

1.2 School context: knowledge and perceptions of peers and teachers

For children and young people with epilepsy, school experiences have been shown to be a key factor in students’ current and future quality of life (Williams, 2003). Galletti et al (2004) concluded that about one third of children with epilepsy (even if cognitive functions are normal) underachieve in school. However it was unclear from this work whether under-achievement was due to the epilepsy, medication for epilepsy (especially if prolonged) and/or school factors.

Children with epilepsy who expressed negative attitudes towards their condition have been found to be more likely to have poor academic attainments compared with children with epilepsy who had more positive attitudes (Austin et al 1998). This suggests that children’s feelings and perceptions about their condition play an important role in shaping their experiences and ability to cope. In addition, teachers and other students at school play a crucial role in children and young people’s experiences of living with a chronic condition. This is important in relation to a social model of disability in which the social context has a profound influence on the impact of impairments or conditions.

1.3 The views (about epilepsy) of children and young people with epilepsy

Several research groups have worked with young children (age 6-10) in exploring understanding of their epilepsy and life experiences generally
Houston et al concluded that it was striking how even young children were already aware of the stigma associated with epilepsy. On a more positive note, however, most of the children reported few restrictions on their participation in activities.

Wilde and Haslam (1996) involved 24 participants, aged 13-25, in in-depth individual interviews about their experiences of epilepsy. A majority of participants reported experiences of prejudice and discrimination and this was most likely to occur at secondary school and by peer groups. Nearly all reported that their close friends knew about epilepsy and their support was very important. Many also associated disclosure of the condition with apprehension and anxiety about how others would respond. Working with similar age groups having epilepsy, Eklund and Sivberg (2003) and McEwan et al (2004b) reported adolescents’ feelings of being different from their peers. Interestingly, some said this was in part due to the lack of knowledge about epilepsy in the wider society.

1.4 The views (about epilepsy) of children and young people without epilepsy

There is evidence that young people without epilepsy have a limited understanding of epilepsy and view epilepsy as a negative and stigmatising condition (Fernandes et al 2005). Further, Cheung and Wirrell (2006) (working with 13-18 year olds) found that epilepsy was perceived to have greater adverse physical and social impacts than did other named chronic conditions (apart from Down syndrome). Reluctance to befriend a young person with epilepsy was attributed to: fears about what to do if a seizure occurred; worries about catching epilepsy; and the perceived weight of responsibility in being a friend of a person with epilepsy.

These results suggest a worrying prejudice towards young people with epilepsy, which could also explain – from the opposite perspective – the feelings of stigma and shame young people with the condition say they experience. That is, perhaps it is not surprising that young people feel the need to maintain secrecy about their epilepsy given the negative attitudes and perceptions that abound in the general population.

1.5 Methodological issues arising from previous studies

1.5.1 Source of interview foci

While there is a sizeable research literature that examines Quality of Life (QoL) in children and adolescents with epilepsy, children and young people have rarely been involved in the generation and construction of factors appearing in the scales. Instead these may be based on proxy responses of parents/carers or adapted from QoL scales for adults with epilepsy or generic (not specific to epilepsy) child-based scales of QoL (McEwan, Espie & Metcalfe, 2004a). This means that some QoL scales for children and young people with epilepsy may be of limited validity because they are not grounded
in, and generated from, the personal views and experiences of young people with epilepsy. It is likely that young people will have views and concerns which differ from those of adults; further, young people with epilepsy will also have distinctive experiences and concerns compared with those of young people without epilepsy.

1.5.2 Use of educational contexts

Given its importance in young people’s lives, it is surprising that experiences of epilepsy in educational contexts do not figure more prominently in research. Some of the above qualitative studies include school as one of the many factors in children’s QoL, but there is a need to find out more detail from young people directly about their views and experiences of epilepsy in school.

1.5.3 Familiarity with people with epilepsy

It is unclear from some studies (e.g. Cheung & Wirrell 2006) whether any of the participants without epilepsy who were interviewed about epilepsy knew anyone with the condition. This could be a highly influential factor in young people’s responses as direct experience of people with the condition could positively influence perceptions (as suggested by Lowe-Pearce & Camfield, 2005).

1.5.4 Parallel interviewing of children with, and children without, epilepsy

Linked with this, we have not found any studies which explicitly interviewed children and young people with and without epilepsy from the same schools and classes, thus having a shared educational context on which they were drawing. For example, peers were not included in any of the qualitative studies above, but given the importance of peers’ attitudes for friendship and support, it is essential to gather their views within a similar context.

1.5.5 Participation rates

McEwan et al (2004b) reported a high rate of non-participation of those invited to take part. The data obtained from those who did participate was very powerful, but the low sign-up rate suggests that a different, or combination of, methodological approach(es) may be needed to encourage wider participation.

The distinctiveness of the project reported here lies particularly in the rich, qualitative data generated by the selected methods, the collecting of views from children with or without epilepsy (from the same schools and classes) and a focus on epilepsy as experienced by children and young people in mainstream schools.
2. Aims and research design

This work builds on the findings summarised above as well as taking into account the methodological points arising from earlier work.

Our aims for this one year project (2006-7) were:

1. To explore the understanding of children and young people (ages 7-18), in mainstream schools, of the nature, causes and prognosis of epilepsy. The focus on mainstream schools, reflects EA’s mission concerning inclusivity.

2. To use this information to produce recommendations concerning the most effective ways for teachers and other professionals to integrate, in an inclusive school context, children with epilepsy.

3. Methods (summarised) (see appendices 8.6 for further details)

The project encompassed two overlapping sets of data collection (informed by a literature review):

Stage 1: an e survey of children and young people with epilepsy; the invitation to participate being distributed via EA and relevant e-groups; and

Stage 2: interviews with (i) children/young people with epilepsy and (ii) classmates, matched with child with epilepsy; by age, gender and broad ability level.

3.1 e-survey

An e-survey was used to gain responses from a wide group of young people with epilepsy, including those who preferred to take part anonymously rather than be interviewed face to face (see below).

Foci for the e-survey were the perceived impact (of having epilepsy) on schoolwork, home and leisure activities of having epilepsy; and feelings about this with particular reference to independence, friendships and aspirations (parallel versions for younger [Primary- 11 years and younger] and older [Secondary- 11 years +] respondents). The survey was deliberately uncomplicated in format and anonymous in order to encourage completion. The link to the survey was advertised through EA, the University of Birmingham, epilepsy clinics, specialist epilepsy nurses, and contacts through a range of relevant organisations (such as Contact a Family and the SENCO Forum). The e-survey was accessible between August 2006 and January 2007.

We received 57 (18+39 for under 11 and over 11 respectively) returns in total of which 44 were usable (11 returns from the Primary age survey, with stated ages of respondents ranging from 3 to 11 [mean age 7 yrs 3 months] and 33 usable responses from the Secondary age survey, with ages of respondents
ranging between 11 and 23 [mean age 16 years 9 months]). Forms excluded from analyses were: incomplete or blank (9), from an adult aged 51 years (1), duplicates of another entry (3). The latter possibly reflected some confusion about when or how to return the e-form having completed it.

Nearly half of the e-survey respondents reported that they had begun to have epilepsy when they were under 5 years old (19/44, 43.2%) while the remainder had a varied time of onset spread across later age groups (onset at ages 6-8: 7/44, 15.9%; onset at ages: 9-11 5/44, 11.4%; onset at ages 12-15: 6/44, 13.6%; onset at ages 16-18: 5/44, 11.4%).

Respondents were clearly self-selected and had to be proficient and competent in using the internet and responding to the survey form. This thus excluded children and young people with epilepsy who also had severe learning difficulties although some children in this group were able to complete (with parental support) the e-survey or hard copy of the survey form. It is also likely that children and young people who were uncomfortable about their epilepsy will not have chosen to complete the e-survey. Given the sampling and self-selected respondents, the results need to be regarded as indicative rather than generalisable to all children and young people with epilepsy.

3.2 Interviews with children and young people

Interviewees were identified via a cross section of five Local Authorities. One region was selected specifically because it included a high percentage of families from minority ethnic groups. The other four authorities spanned city, rural and urban areas. Schools agreeing to participate were given an EA schools information pack as a gesture of thanks.

Participants were recruited via mainstream primary and secondary schools in those authorities, and interviewed there, rather than through clinics or hospitals, as is usually the case. This helped children and young people to consider school-related factors more readily than would have been the case had they been interviewed in more medically oriented settings. Children and young people both with, and without epilepsy from the same schools were included in the study. Informed consent to participate was checked at the outset with all the children and young people interviewed. All interviews were audio recorded and fully transcribed. Transcripts were coded using the software package Nvivo, which facilitates the storage, manipulation, categorisation and retrieval of qualitative data. Individual children and young people interviewed were given a £10 ‘Love to Shop’ voucher (exchangeable at a wide range of high street stores; participants were not told of the vouchers before the interview) and (if the school requested this) a certificate recognising their participation.

The main foci for the interviews for children and young people with epilepsy were: understanding of their own epilepsy, school-related issues, peer acceptance, independence, identity and aspirations. For matched children without epilepsy, the interview focused on their perception of these things (as
appropriate) for a child with epilepsy. The rationale for these foci was based on our literature review (notably McEwan et al, 2004b), emerging e-survey findings and our recent research into the views of disabled children (Lewis, Parsons & Robertson, 2007).

Through these methods we recruited 22 children and young people with epilepsy and the same number (matched participants on the basis of sex, age band and broad ability range) of children and young people from the same schools who did not have epilepsy. (See appendices 8.5 for further details.)

The rational and justification for this project (see above) concerned the fostering of inclusion and the placement of children with epilepsy in mainstream schools. It is therefore interesting to note the considerable difficulties we encountered in locating such children. Many schools (see appendix 8.4 tables) initially expressed support for the project, but later said that they could not take part as there were no children with epilepsy attending their school. Further, responses from one child have had to be been omitted because epilepsy was not explicitly mentioned during the interview (at the parents’ request, as the child had not been told that they had epilepsy) and consequently the interview procedure was not comparable to that used with other children. This raises important issues about the invisibility of epilepsy (see discussion 6.2).

4. Findings concerning children with epilepsy

In order to present a clear overview, we have grouped findings from the e-survey and the child interviews together under six themes to which both sets of data collection were referenced. These themes were: epilepsy-specific matters, identity, school-related issues, peer acceptance, independence and autonomy, and ambitions and aspirations. We present these first with reference to children and young people with epilepsy and then in relation to classmates who did not have epilepsy. Within both these sets of material, we present the findings and discussion for each theme in a developmental context, moving through the findings with reference to pupils of primary school age (ages 6-11 years), then secondary (ages 11-16/18 years) and FE (interview data only, ages 16-18).

(For further details, please see methods (3.1 and 3.2) and the appendices-extracts from tables for the e-survey).

Extracts below from e-survey responses are noted as (P/WEB = primary – web/e-survey; S/WEB = secondary- web/e-survey); and extracts from interviews are noted as P/INT = primary – interview; S/INT = secondary – interview; FE/INT).
4.1 Epilepsy-specific matters

4.1.1 Explanations and knowledge of epilepsy

Overall, children and young people (ages 7-18) with epilepsy were clear about the nature of their condition, including seizures. However some of the younger primary age children were confused about causes while, with age, young people became more phlegmatic about having epilepsy.

Many primary age children (both e survey and interviews) provided convincing descriptions of their experiences of epilepsy and those interviewed were willing to talk about epilepsy explicitly. This was despite, in some cases, the researcher being told by teachers that a diagnosis of epilepsy was doubtful. Seven out of the eight primary school children with epilepsy, interviewed individually, had heard of epilepsy (one was not sure). All the children had heard of headache, six said that they had heard of asthma, three had heard of eczema and two had heard of diabetes. Given the relative frequency of these conditions, these results have face validity.

Many of the primary age children gave descriptions of having a seizure which sounded authentic and credible, although some of the younger children struggled to express what they had experienced:

\[\text{(Like) it is raining in my head. Like when it is thundering outside} \]
\[\text{(P/WEB)}\]

Some of these primary age children were confused about the causes of epilepsy. For example, three thought that epilepsy could be caught from other people. One child associated seizures with pale skin and pale skin with contagion:

\[\text{When I had it [seizure] my mum decided I couldn’t go to school ... cos I kept on. I went whitish. I went really whitish...[epilepsy] can be caught.. say your cousin comes over right ... and you’ve got a big white hand [during/after seizure] then you touch your cousin, they they’ve got it, right (P/INT)}\]

Others had apparently idiosyncratic misconceptions:

\[\text{I have ice-cream in the fridge to keep my belly cold when I have a fit} \]
\[\text{(P/INT)}\]

These types of misconceptions were not found with older pupils. One comment (S/WEB) noted the misperception of epilepsy as being
characterised by grand mal seizures (this was a common view, also expressed during individual interviews).

Most of the young people (age 11+), when asked in the e-survey what they said to friends to explain epilepsy, provided clear, matter-of-fact explanations including information either about what causes seizures or what happened when they had a seizure (or both):

_I tell them what happens when I have a seizure and what to do. I was told it’s like a chemical imbalance in my brain so that’s what I tell other people._ (S/WEB)

Understanding of seizures was probed further in the interviews. Most of the secondary age (11-16) students interviewed (6 out of 7) described a limited awareness of their seizures as they happened at night; only one student described some seizures during the day (she also experienced nocturnal seizures):

_I get a lot of eye twitching and I’ll blank a minute and in some tests I get to go in a different room and get extra minutes and that…normally it’s the eye twitching and blank stares. I haven’t had a grand mal seizure in a long time now so it’s getting better_ (S/INT)

Many of the oldest students interviewed (FE age group, ages 16-18) also described a feeling of not knowing what was happening to them during their seizures and, in relation to these, relying on other people to support them or to let them know what had happened. One described his seizures as ‘the whole lot’, suggesting he experienced grand mal seizures; others described their seizures in different ways, for example:

_Well, I don’t actually have full epilepsy, I just like blank out_ (FE/INT)

Five of the seven young people in the secondary group felt that there had been a gap in the provision of information about their epilepsy; whilst they could describe their seizures and knew some of the basic facts, they would have liked more information, for example, a biological explanation about why seizures occurred. By contrast, knowledge of epilepsy across the FE group was good and many talked in some detail about their condition; there was a sense in which these young people had grown accustomed to their epilepsy, and the terms used to describe it, over a period of time.
4.1.2 Medication

Overall, a majority of participants said they were taking medication for their epilepsy, although there was some confusion amongst the youngest participants about the function of their medication. Many made reference to side-effects suggesting that there were still unpleasant or undesirable aspects to taking medication even if it was successful in controlling seizures.

Virtually all the children and young people responding to the e-survey were taking medication for their epilepsy (only one [secondary age group]) was not doing so. The large majority (36/44, 81.8%) took medication twice a day compared with relatively few taking their medication once a day (2/44), three times a day (4/44) or once a week (1/44). (Others gave a ‘don’t know’ or nil response to this question.)

Information concerning medication of children and young people interviewed is given in appendix tables (8.5) and taken directly from interview data (schools preferred to keep information about students confidential).

Half (four) of the primary age children interviewed said that epilepsy could be helped by taking medication:

> If I don’t take my medicine, if I forget, then it happens that night. When I’m awake and I’m ready it won’t happen but when I’m in bed it happens, when I’m asleep (P/INT)

There was, however, some confusion amongst these younger children about different types of medication and why it was being taken. Some had other conditions for which they were taking medication and they were not clear which medicine was being prescribed for which condition.

Interestingly, one child interviewed was concerned about the mixed ‘healthy eating’ messages she was receiving; on the one hand that sugar was bad for her yet she was being urged to take her epilepsy medication as this would ‘do her good’. Of the two primary age children who said medication was not helping them, one boy was very clear about the fact that, at least for him, medication was not helpful for epilepsy:

> It’s something that sometimes you can control, and some things make it worse, and I’ve got the one where the thing that most makes it worse is medicine! And I have to go every six months…in [PLACE] hospital…and I was under their head epileptic specialist and I found out that I’ve got the type that they can’t control with medicine (P/INT)
Four of the seven secondary age pupils interviewed were currently taking anti-epileptic drugs; three had previously taken medication but had stopped. Most were accepting about taking the medication but two did not like having to do this:

*It bothered me that I had to take all the tablets. It's annoying…and I get moody about taking tablets when they stick in the back of your throat and they taste disgusting and you can't get rid of the taste…my Mum has to remind me [to take them] because I am a bit forgetful* (S/INT)

All five of the FE age (16-17) students interviewed with a confirmed epilepsy diagnosis were taking anti-epileptic medication and some had experienced changes and adjustments in their dosage, type or combination of medication over time. One of the female students talked about her weight gain as a result of being on her medication and this had made her feel very unhappy. Another female student said she had been told she might gain weight but this had not happened. One other student said his medication had affected his memory so ‘I forget things quick’. One student mentioned that she was careful about how much she drank when out with friends because of her medication.

### 4.1.3 Tiredness

A frequent reference across all age groups interviewed was to tiredness, either as a side effect of their medication or arising from the epilepsy itself.

Four primary age children said epilepsy made them very tired; six said it made them go to bed at a certain time. Comments from two primary age children interviewed provided more details which suggest that these children felt that their nocturnal seizures could have a significant impact on their daytime activities, due to the subsequent tiredness:

*When I have a fit, my mum brings me some water and we go to the hospital and have a bit of a check and then come to school because I don’t want to miss school, then when I’m at school I sometimes feel a bit sleepy and I try to wake up and then I ask if I can out cold water on my face and I feel a bit awake…* (P/INT)

Tiredness also featured in accounts by the older students (e survey and interviews) although, interestingly, only one (out of six) of the FE students interviewed mentioned feeling tired after experiencing a seizure and needing to sleep for a long time. By contrast, six out of the seven secondary pupils interviewed described feeling tired after a seizure or because of their medication. In addition, 32/33 respondents to the secondary age e-survey provided information about whether their medication had any side effects and 25 of these suggested they experienced some side effects. Eleven mentioned tiredness/drowsiness/lack of sleep making this the most commonly reported side effect (often in conjunction with others).
4.1.4 Control

The unpredictability of seizures was frustrating for some young people because it meant a lack of physical control over their bodies. Finding other ways to exert some control in their lives was important, such as whom they told and how they coped with the early signs of a seizure.

Several young people (age 11+) replying to the e-survey made powerful comments associated with epilepsy and a consequent lack of control:

[Epilepsy] is taking over my body because it freaks me out because i don't know whether i am going to have a fit or not (S/WEB)

[epilepsy is] ruining my life i was to take gcse exams today 24 nov but had a seizure in the morning could t go to school so now i will be put down on exam as failed (S/WEB)

One FE male student talked about the importance for him of taking control over his seizures; he had disciplined himself so that he could stop some of his seizures from developing:

Saliva in the mouth starts bubbling and you try to control that… I can control that and… I used to make hand movements but now if I clench my fists it's like you're stopping it in effect, breathing through them and recently I feel as if I'm going deeper into a fit and I'm coming through it… I've been able to control them and stop them from the start but now I'm going into the fit and can control them from there so hopefully if I can control the whole thing (F/INT)

For some students (see ‘disclosure’ section 4.2.2 below) it was also important to be able to have some control over whom they told about their epilepsy and how other people ‘came to know’; having seizures in front of others was considered embarrassing.

4.2 Identity

4.2.1 Importance of epilepsy

Children and young people had very individual notions of the way in which epilepsy was, or was not, an important part of their identity. Some minimised its importance, most tried to find a balance, but for a minority, epilepsy was an all-consuming experience. For many, there was an implicit reluctance in
accepting epilepsy as a ‘part of them’ since feelings of secrecy, stigma and shame were common.

Seven of the eight primary age children with epilepsy interviewed individually acknowledged that epilepsy was something they had themselves. Amongst these younger children, ‘fits’ was the more commonly used or understood language in relation to epilepsy. Three children said they had heard of ‘seizures’ and two said they had experienced them; six said they had heard of ‘fits’ and five said they had experienced them. Children tended to know one or the other term rather than both, for example both children who said they had ‘seizures’ had not heard of ‘fits’ and all five who said they had ‘fits’ had not heard of ‘seizures’ (or were unsure).

In the e-survey and interviews, primary age children did not generally see epilepsy as the most important thing about themselves or as being central to who they were. Four of the eight primary age children interviewed and 8 of 11 in the e-survey disagreed with the statement that epilepsy was the most important thing about themselves; for example:

Don’t really like it but I can deal with it (P/INT)

In contrast, three of the primary age children interviewed and two of the e-survey respondents said that epilepsy was the most important thing about themselves:

It is what makes me, me (P/WEB)

Children’s feelings about having epilepsy were explored in interviews with primary age children using eight cards showing a word and a picture as illustration. The feeling with which they agreed most frequently, in relation to their epilepsy, was ‘embarrassed’ (half, four children), followed by ‘sad’ (three children) and ‘OK’ (three children). The fact that half of the group already felt, at this young age, embarrassed about their epilepsy suggests that the associated stigma exerts an early and powerful influence. This was also apparent in discussions with two of these children:

Sometimes people take the mickey out of it and I don’t like it, so I’ve just kept it to my best friends (P/INT)

Is people finding out and you being embarrassed about it something that you worry about? Yes. I wouldn’t want that to happen (P/INT)

One quarter of the comments by young people in the secondary e-survey suggested that epilepsy was not an issue or problem when they were ‘out and
about’ (‘I don’t think about it’; ‘is really not an issue’). However, an identical proportion of comments also conveyed worry or concern about seizures occurring and a further 21% of comments suggested young people made negative social comparisons between themselves and others, often feeling odd or different compared with their friends (see ‘peer acceptance’ 4.4 below).

There were 30 written-in responses to the statement in the e-survey: ‘epilepsy is the most important thing about me’. Many of the young people (53%) simply said ‘no’ or were in emphatic disagreement with the statement:

    No! I am the most important part of me, not my condition! (S/WEB)

Some were more ambivalent about how epilepsy related to their identity or had affected them (33%):

    It's a new way I can define myself, but it's not the most important part. Artists, Daughter, Girlfriend, College student, then epileptic is somewhere in there  (S/WEB)

Others (a minority – 13%), whilst not agreeing explicitly with the statement, provided more anguished responses, suggesting that epilepsy had dominated their lives.:

    Because it messes with my head and has stolen my childhood and teenage years. My life only seemed to start at 17 because I didn't have to be dependent on my mother as I started a further and higher education college and she wasn't allowed to be with me and I had to learn to be without her. She was always with me in high school working in the office or sitting outside the classroom door.

None of the secondary aged pupils with epilepsy who were interviewed thought their epilepsy was the most important thing about themselves and there were no suggestions in additional comments that epilepsy was an overwhelming or all-consuming experience, unlike some of the secondary e-survey respondents. Note that epilepsy was clinically inactive in four of the seven secondary students interviewed and so this is likely to have influenced feelings about the condition (Austin et al., 1996); there was certainly relief that the epilepsy had gone:

    I feel like I'm a bit more free now to do what I want and I don't have to think twice if my friends say ‘do you want to sleep over’ …. It’s like a weight off your shoulders and not having to remember to take your medicine as well, worrying when you haven’t taken it (S/INT)
Other young people were not very concerned about having epilepsy and minimised it:

I don’t really think ‘Oh I’ve got epilepsy, all my friends should know!’ It’s not something I want to hide either. I don’t really care…I’m more worried about other things than my stupid epilepsy (S/INT)

One pupil suggested she had undergone a journey of acceptance in relation to her epilepsy and had incorporated it, positively, as a ‘part of her’:

[I had my first fit at] about 6 months old, it went on from there, got worse and then better and I’m OK with it now…I thought well never mind, let them know, this is who I am and they’ve got to accept it whether they like it or not (S/INT)

Another, the youngest in this group (aged 11) was finding it more difficult to accept:

I wish that I never had it…I don’t like telling that many people (S/INT)

She also referred many times to feeling upset about teachers’ attitudes and their lack of understanding about the impact of epilepsy on her academic abilities; these attitudes were evident at both her school and her local mosque:

Obviously the mosque teacher has to know because if I get low marks then they shout at me and I feel upset and I tell them. They know that I need help but they can’t say sorry…I get into trouble because I get low marks…this is like really upsetting that when we get school reports, they wrote that my writing is like a 6 year olds and it’s really upsetting. My reading is not proper for my age and I got upset (S/INT)

A number of the FE students interviewed used words like ‘scared’, ‘shocked’ and ‘worried’ to describe their feelings about epilepsy, especially at the time of onset and diagnosis. The female student whose diagnosis was uncertain at the time of interview illustrates powerfully some of the feelings of fear and confusion that can occur:
I’m a bit scared because one of my friends was talking about narcolepsy and said it could be that…it’s like when you faint but you don’t have a fit…’cause I’m getting some information from my friends and some off the web and it’s all a bit confusing because you don’t know what to trust (FE/INT)

However, most of the students in this FE group had accepted their epilepsy over time and developed a balanced view of their condition in relation to other pressures that existed for them:

I realise that I’m going to have to get used to it because it is going to be with me for the rest of my life so I’ve got to get used to it and be able to tell people (FE/INT)

Finally, FE students had various approaches to coping with their epilepsy. Being able to talk to supportive and understanding friends and / or family was essential for some young people. One relatively simple, but effective, approach was to wear an epilepsy ‘Medic Alert’ so that others would know about the condition if a seizure occurred in public:

Normally, I have my Medicare necklace and just wearing it gives me more confidence because I know that if something was to happen to me in the middle of the street when I was walking home by myself, then if anyone phoned for an ambulance they would be able to recognise it (FE/INT)

In addition to physically taking control over a seizure (see 4.1.4) one FE student talked about taking psychological control over his epilepsy and this played a central role in his resilience in dealing with the condition on an everyday basis:

I stand up for somebody and I’ll say something, perhaps gets me into trouble a couple of times, but you’ve got to be committed and do something about things. I got into the cadets and it’s more discipline and you’ve got to be able to discipline yourself and that builds your confidence all the time (FE/INT)

For the other male FE student in this group, physical activities were important in helping him deal with his epilepsy.
4.2.2 Disclosure

Many children and young people had told at least one close friend about their epilepsy but some had not told anyone. Having some control over who knew about their epilepsy was important for young people. Similarly, having honest and straightforward communication about epilepsy was valued. Despite growing more used to telling people as they got older, disclosure was still tinged with anxiety and concern over how others would react.

Children were asked what they said to their friends to explain epilepsy. Three of the primary age group in the e-survey said that their friends did not know and, for one, this was because medication was proving successful at keeping epilepsy under control:

\[ \text{Haven't had to explain yet as my drugs keep it under control (P/WEB)} \]

Young people responding to the e-survey also referred to secrecy around epilepsy:

\[ \text{[At school I always feel that my epilepsy] will be found out, that my friends will let it slip out, or my teachers will mention it because they think it important for my school year to know! (S/WEB)} \]

A few respondents (S/WEB) mentioned partial or selective disclosure in relation to either what information was given, or to which people were told, about epilepsy:

\[ \text{It makes you shake and have accidents in the night but I would only tell the last bit to my very close family (S/WEB)} \]

The invisibility of epilepsy occurred at home as well as in school:

\[ \text{[At home I sometimes feel that my epilepsy] is not discussed as much as i would like (S/WEB)} \]

Three out of the seven secondary age young people interviewed said that at least one close friend knew about their epilepsy. The others said they had not told friends about it. Of those who had told at least one friend, two said that other classmates, outside their immediate friendship group, did not know about their epilepsy. Some felt apprehension about disclosing their epilepsy to others even, or especially, when friends were close:
I don’t think there’s any way to make it easier ‘cause it’s always going to be a hard thing and I think it’s easier with people you don’t know in a way because they’re always going to judge you…but people who you really know, you’re scared of them judging you because they do know you and I don’t think you can make it easier apart from just telling them (S/INT)

I told them not to spread it around and I told my best friend and told them not to spread it around. One did spread it around and I was really upset (S/INT)

One was more pragmatic and felt that telling friends could be a good thing because they would then be better informed and so would know what to do should a seizure occur:

I think they’ll be a bit more aware if I did come into a seizure (S/INT)

Another student had found an internet chat forum helpful because it had put her in touch with other people going through similar experiences. Another participant said how important her family had been in helping her cope, mainly through being open about it and encouraging discussion.

The issue of disclosure took on a slightly different hue for the older group of students (16-18 year olds) compared with the secondary school pupils; the latter were more apprehensive about disclosing their epilepsy whilst this slightly older group were either frustrated about the need to explain epilepsy to others or more open, pragmatic and accepting:

It was helpful [that some friends knew] because at least I didn’t have to go round explaining it all over again because when it first happened you were just hitting puberty as well and you are shy, it’s something else you have to tell (FE/INT)

I don’t mind explaining about it, I really don’t mind, because I think once you have been diagnosed you can probably explain it a lot better than your neurologist (FE/INT)

An important and valued aspect of disclosure for two of the FE students was the feeling of being in control over whom they did, or did not, tell about their epilepsy:
You always have to tell them what to do, but that’s the same with everything really…then the people you want to know, know instead of everybody knowing (FE/INT)

Importantly, though, despite evidence of more pragmatic, accepting attitudes towards their epilepsy it was clear that feelings of embarrassment and fear of discovery were undercurrents in young people’s commentaries. There was still evidence of epilepsy being experienced as a stigmatising condition, requiring secrecy:

What really gets you is if they see you having a fit. I find that really embarrassing, my hands start getting all jerky and then I just get really self-conscious of it and that can be really embarrassing (FE/INT)

4.3 School-related issues

4.3.1 Learning

Most of the primary aged children did not think their epilepsy had a significant impact on their learning at school, although many of the secondary pupils (in interviews and open survey responses) felt that it had to some extent. Older students had succeeded in spite of their epilepsy through a combination of hard work and appropriate additional support in schools.

For the large majority of primary age children with epilepsy, their epilepsy was seen as having no, or little, impact on either their learning generally in school or on their reading specifically. This was a strong finding, applicable across both the e survey and individual interviews. Similarly, we found across both e survey and interviews that more of these children considered, in relation to schoolwork, that it was their writing rather than their reading which was affected by their epilepsy.

For a majority of the 33 secondary age pupils completing the e survey (see tables in appendix 8.8), epilepsy was thought to have no or little effect on their reading, writing or (less strongly) learning generally (91%, 94%, 76% respectively) although in open comments, many of the students seemed more conscious of the possible impact of their epilepsy on learning:

At school I always feel that my epilepsy…. 

hinders me when I have petit mals, because then I don’t catch all the information. (S WEB)
is the cause of my not wanting to be with new people and not get on at school (S/WEB)

ruined my education (S/WEB)

Six of the seven secondary-aged pupils with epilepsy interviewed, also said that their condition had an impact on at least some aspect of school-related activity (reading, writing, or learning) either due to difficulties with concentration or through tiredness and needing to take time off school. The semi-structured interviews and open-ended questions on the survey allow participants to provide more nuanced responses about their experiences, which could explain the contrast with closed responses.

However, four out of five FE students interviewed felt their condition had not impacted negatively on their academic abilities despite, in some cases, having to spend some time in hospital. These students were all educationally successful (being in the first or second year of A-level study) and adequate support had been put in place at school for some, for example, through having additional time in exams. This suggests that the direct impact of epilepsy on academic achievement for these older students may have been ameliorated through good educational provision as well as experience of educational success.

In line with this, one female student noted the negative impact of her epilepsy diagnosis on her self-esteem and confidence and this had a knock-on effect on her participation in activities at school, suggesting that both the direct and indirect effects of epilepsy on learning should be considered:

I had quite a lot of time off school because I felt very self-conscious, I couldn’t do any drama or anything like that, ‘cause I still wasn’t sure about the medication and I couldn’t go away that Easter like I was planning to and that’s when the dynamic changed with my friends as well…I think it made a difference with my GCSEs because I had to miss school

The FE student currently undergoing diagnostic tests to determine whether she had epilepsy echoed this difficulty; having to miss college because of hospital appointments was very stressful, especially at a time of ‘high stakes’ during A-Level study.

4.3.2 Teacher attitudes

Many children and young people felt worried and uncomfortable about their epilepsy in school contexts and wanted teachers to have a better understanding and awareness of the condition. Understandably, children felt
reassured when teachers knew about their epilepsy and handled situations sensitively.

There were noticeable differences between primary age children’s feelings about their epilepsy in home and school contexts. When completing the sentences ‘At home/school I always/sometimes feel that my epilepsy…’ (P/WEB) children almost always provided comments that suggested epilepsy was not ‘scary’ or a problem at home, but was more difficult for them at school. Although some children said that sometimes at home their epilepsy was annoying or weird, these responses were much more common when asking about school and were stronger in representations of negative feelings or experiences.

Seven of the eight primary age children interviewed said that their teachers knew how to help them and, in line with the confidence in parents at home (see section 4.5 below), children who were more confident about their school situation also noted teachers’ understanding of their condition. Conversely, problems in the school context were linked to adults’ attitudes and a lack of understanding. This suggests that it is important, not merely for teachers to be aware of epilepsy and appropriate interventions, but also that children recognise that teachers hold this knowledge (see discussion 6.3) (a distinction noted explicitly by two secondary school interviewees).

Young people (aged 11+) responding to the e-survey also suggested that school was not a particularly comfortable place for them with nearly three-quarters (71%) of comments indicating worry or concern over academic-related aspects, friends, or epilepsy ‘getting in the way’ more generally:

\[ \text{Gets in the way of my start at 6th form college-travelling etc (recently changed from minor absences to major seizures)} \]

In line with this, secondary pupils interviewed felt that there was room for improvement in teachers’ awareness. For example one said that she did not feel she could go and talk to a teacher about her epilepsy if she needed to and would have preferred it if the teachers could ‘come over and ask me something’. The FE students with epilepsy expressed broadly similar views, with some having experienced helpful and supportive attitudes but others feeling that awareness needed to be raised.

A personal approach to understanding and supporting students was important; either through someone who had personal experience of the condition or, at the very least, taking the trouble to find out how students’ were feeling and coping.

This suggests that teachers need to have a better understanding of the full impact of having epilepsy on their students; firstly in relation to physical effects such as tiredness and poor concentration, and also in terms of impact on self-image and esteem and willingness to seek additional support.
4.3.3 Strategies

Young people wanted there to be more information about epilepsy available in the public domain and this needed to be presented in a variety of formats, including using a style that was accessible to them. Hearing the views of other young people with epilepsy was also considered a potentially powerful and helpful strategy, linking with the importance of having good role models of people who have epilepsy in society more generally.

In terms of what schools could do to help students with epilepsy, comments emphasised the need for teachers to take an informed and sensitive approach to the condition (see recommendations). Students (age 11-18) were helpful in identifying what aspects of epilepsy should be conveyed or highlighted in order to assist teachers with developing a more informed approach, these included: impact of medication and seizures on tiredness at home and school (and resultant impact on work and learning); the wide range of different physical manifestations of seizures; awareness that it was a more common and wide ranging illness than most think; (‘anyone can get it at any age and I don’t think people know that’) and knowledge of practical ways of spotting and dealing with seizures. Of key importance, wherever and whatever information was presented, was the use of appropriate language:

\[
\text{I don't know because you see leaflets on other things...and they use all these really posh words and I think 'what the hell?' and I think there should be a leaflet that people my age should be able to understand...the internet again tends to use those really weird words (S/INT)}\]

Interviewees were asked how and where information about epilepsy could best be presented in order to maximise its accessibility for young people generally. Perhaps unsurprisingly, many suggested the internet as a good place in which to present information. Other suggestions included having more books about it as well as having a school assembly and / or an independent person come to the school to help pupils find out more about epilepsy. Newspapers, television and radio were also suggested as useful media for presenting information. The important point about the provision of information is that young people have varying preferences for the way in which information is presented and accessed.

4.4 Peer acceptance

Children and young people were very concerned about how other people viewed epilepsy and many had experienced unhelpful and hurtful comments from others about the condition. Young people were very aware of ‘feeling different’ from others and excluded from some social activities. Close friends were a vital source of support, both emotionally and practically.
Not being different from other children was important. Many young people completing the e-survey (age 11+) were very aware of, and apprehensive about, the impact of their epilepsy on friends and peers. Just over a fifth (21%) of responses to questions about how young people felt about their epilepsy when they were ‘out and about’ suggested worry about the reactions or perceptions of others and negative social comparisons:

\[
\text{Is a punishment for something. None of my friends have it, I feel like an outcast!}
\]

Some also felt they were not able to do the things with friends that they’d like to, for example:

\[
\text{I don't go out anymore because i can't do the things my friends do so why bother i stay in all the time (S/WEB)}
\]

Three of the seven secondary age pupils interviewed (S/INT) said that they had experienced unhelpful or negative attitudes from other people in relation to their epilepsy:

\[
\text{I can remember in primary school, I was off for a while and my mate asked me why, so I told her why and she just never spoke to me afterwards because she didn't believe me. She said she had never heard of epilepsy and it was a load of made-up rubbish (S/INT)}
\]

Five of the secondary age pupils interviewed also suggested that their epilepsy had had an impact on some aspects of their social life, either explicitly or implicitly. For example, two interviewees made reference to specific events which they were not able to attend (sleep-overs at a friend’s house and a trip to ‘LaserQuest’). Three pupils commented on a lack of friends generally and although they did not directly link their epilepsy to this it is striking that, in an otherwise small heterogeneous group, this was repeated. Reassuringly, there was also evidence of positive attitudes and supportive reactions from close friends both within the secondary and FE student groups. In the latter, friends played an essential role in supporting young people with epilepsy, and close friends had mostly been understanding and supportive:

\[
\text{Most people just were like ‘so what?’ (FE/INT)}
\]

\[
\text{She’s just been like really, really supportive and has always…watched out for me. Just things like little things you do, she’s been more aware,}
\]
and I think it’s just that that they are always there and it helps to know someone is watching and looking over your shoulder really (FE/INT)

The two male FE students, tended to prefer practical support and did not spend much time talking about their epilepsy with friends:

‘I’ll comment about it but we don’t talk about it…[but] friends are key… people around me at college don’t know me but they know what to do. They gave me water. I had a fit in maths and they got water and I don’t think there’s anyone in there from my High School but they knew what to do so somebody has obviously been there who knows what to do (FE/INT)

Although friends were largely supportive and understanding, there was mention by a number of young people about their friends being shocked, worried or overly protective:

My close friend worried and saw how it changed me (FE/INT)

My friends became really overprotective at times (FE/INT)

(See discussion 6.1 concerning developmental aspects of coming to terms with epilepsy.)

4.5 Independence and autonomy

The majority of children and young people felt that their epilepsy had a limited impact on their participation in recreational activities such as sports and spending time with their friends. Younger children generally reported fewer restrictions on activities than did older children. A consistent minority felt that epilepsy affected their lives substantially. For younger children especially, feelings about epilepsy were linked with a sense of security provided by parents. So responses in the e-survey to having epilepsy, tended to show greater confidence when referenced to the home context than when referenced to the school or wider community. Similarly, all eight primary age children interviewed said that their family knew how to help them.

The large majority of the primary age children responding to the e-survey said that epilepsy had little or no effect on everything they did. Similarly, over three-quarters of that group felt that epilepsy did not stop them going to after-school clubs, swimming or doing things with their friends.
Very similar comments were made by the primary age children with epilepsy who were interviewed. Six of these eight children said that their epilepsy did not get in the way of them taking part in activities outside school and four said it did not get in the way of swimming (two said it did and two were not sure). Just one child said epilepsy got in the way of playing certain sports. So overall, across both e-survey and interview data, primary age children did not seem to think that their epilepsy was having a substantial impact on their participation in various activities although there was a consistent minority of primary age children responding to the e-survey (2 or 3) who perceived epilepsy as having a significant impact on their lives, including limiting participation in physical activities and doing things with their friends. It is worth remembering the nocturnal and possibly less disruptive (more minor) nature of most of the children’s epilepsy in the primary age group interviewed.

A large majority of young people with epilepsy (N=33, ages 11+) (see tables in appendix 8.8) who responded to the e-survey stated that their epilepsy had little or no impact generally on their participation in activities. However, for all five of the home/leisure activities questions, there was between a quarter and a third of respondents for whom epilepsy had a significant impact. The largest groups in this respect were those who said epilepsy affected doing things with friends and the time they went to bed (36% in each case, 12 respondents).

The older e-survey respondents were slightly less positive than were the primary school age group in relation to whether epilepsy ‘affects everything’; 72% of the group answered ‘no’ or a ‘little bit’, with the remaining 27% saying ‘yes’ or quite a lot’. This is perhaps partly due to having lived with epilepsy for a longer period of time and therefore having more experience about how it can affect everyday life.

4.6 Ambitions and aspirations

Most children and young people hoped that their epilepsy would be non-existent in the future and that they would no longer have to take medication. Being able to drive was a key aspiration for some. Despite these points, their outlooks were predominantly optimistic. Although many knew that there might be some restrictions on their participation in certain activities, they said that their epilepsy would not substantially affect their life choices.

When primary age children were asked in the e-survey to complete the sentence ‘In the future I would like to…’, six (out of 11, perhaps unsurprisingly given the context of the survey) provided epilepsy-related responses, for example:

    In the future I hope...they [the jumps] go away because they are a bit of a pane (sic= pain) (pess go) [sic= please go] (P/WEB)

Five of the primary age children interviewed said that epilepsy would not get in the way of things they wanted to do in the future and one said that it would
(one was not sure). The boy who said it would have an impact was very specific about the nature of the activities that would be affected: driving and rock climbing.

32/33 young people (age 11+) in the e-survey completed the statement ‘in five years time I hope…’. Again, unsurprisingly, the vast majority of responses (26; 81%) included references to no longer having epilepsy and/or being free of medication:

*To have grown out of epilepsy and will not have to worry ever again about having a fit!* (S/WEB)

Two responses explicitly mentioned a hope that there would be better general understanding of the condition:

*I hope that there is a better understanding of epilepsy throughout England so other children with the condition can lead normal lives and everyone around them will understand their condition!* (S/WEB)

The students with epilepsy interviewed at secondary school were not overly concerned about the impact epilepsy would have on their futures; one said they did not think it would have any impact at all and one was not sure, one wanted to drive when she was older (and really hoped she could) but did not think epilepsy would have an impact on her career choices. Another student suggested that her lack of concern about the impact of epilepsy on her future was because medication had kept her seizures under control.

Young people in the FE group hoped that they would ‘be off’ their medication and seizure-free soon. Three very much wanted to learn to drive; this was a key goal and one student was keenly aware of the potential negative impact on this goal of ceasing his medication.

Two suggested that there might be some impact of their epilepsy on future plans and aspirations; one of the reasons that one of the students was so keen to drive was because he wanted a career in the Police or RAF and he realised that without a driving licence, this may not be possible. One of the students was careful about how tiredness could trigger her seizures and aware that this could have an impact on her job choices:

*I suppose in a way it could affect different jobs that I do because I want to go into nursing and I have to be careful that shift work doesn’t affect me because lack of sleep can trigger mine as well* (FE/INT)
The same student had some concerns about her future health needs, especially in relation to pregnancy:

*Well, it’s going to make things difficult because they’ve said the medication I’m on that you really, really can’t afford to have any unplanned pregnancies and if you want to have kids in the future it would have to be planned (FE/INT)*

Overall, however, there was no overwhelming sense that students felt their ambitions and future choices were particularly adversely affected by their epilepsy. The pragmatic attitude of one young man captures this well:

*I have to be careful with what jobs I want to do and stuff like that…[but] I don’t want to do them jobs anyway! (FE/INT)*

5. Findings concerning children without epilepsy

Children and young people without epilepsy had varying levels of awareness of the condition with some being close friends with someone with epilepsy and others believing (incorrectly, see methods 3.2) that they did not know anyone with the condition. Despite these differences, a strong finding was that the majority of children and young people knew very little about epilepsy. However those who had friends with epilepsy had come to know more about the condition over time.

A majority of participants said that there was little or no discussion about epilepsy at school. Many wished that this could be done so they could be better informed about epilepsy. They made many suggestions for ways in which schools could help to do this. Their suggestions included teachers having greater awareness of the condition and implementing a ‘buddy’ system to support younger students (see recommendations). So their attitudes towards people with epilepsy were positive and understanding, although characterised by uncertainty due to a lack of information or knowledge. Children and young people wanted to find out more about epilepsy and liked to have information available in a range of formats and always in age-appropriate and accessible language.

5.1 Primary age children

5.1.1. Knowledge of epilepsy

In total, nine primary aged children (without epilepsy) who had classmates with epilepsy were interviewed individually and in depth. Discussion with these children began with an exercise to explore their knowledge of various health related conditions (including epilepsy). Most (7/9) had heard of headache; 5/7 had heard of asthma and eczema (many of these children
spontaneously labelled a sibling, other family member, friend or classmate with the condition); one confused asthma and eczema. Far fewer had heard of diabetes (3/7), or nausea/vomiting (2/7).

Perhaps unsurprisingly when compared with the children with epilepsy, epilepsy-related terms were not familiar. This was despite the fact that all these children were classmates of a child with epilepsy. Just over half (5/9) had heard of epilepsy. Two of these five children had heard about epilepsy at school because a teacher had told them about it; two knew someone (their friend/classmate) who had epilepsy; while for the other child there was no information about how they had come to know about epilepsy.

Six children had heard of ‘fits’ (although there was some misunderstanding of this term: one child thought it referred to health (‘fit’) and another to ‘fits of rage’). Only two children had heard of ‘seizures’ (one said ‘no’ and two were ‘not sure’). Only one child explicitly linked epilepsy with seizures and fits: when shown the cards with the words ‘seizure’ and ‘fits’ on he said “…that is epilepsy and that is epilepsy”.

I know they have fits….I also know…cos when we go to TOWN, in case he does have a fit I’ll walk down with him, cos it’s only down the road, but just clear a space, call like an ambulance and don’t put your fingers in his mouth, get a spoon if you must…like if they’re trying to swallow their tongue (P/INT)

Understanding about the nature of epilepsy was limited. One child (age 8) thought that epilepsy could be caught from other people:

Someone might be able to catch it if they touched someone when they are having a fit (P/INT)

Three children said they thought epilepsy could be helped by taking medicine, and that epilepsy makes people very tired.

5.1.2. Impact of epilepsy

Primary age children thought, in general, that epilepsy did not have a big impact on children’s participation in activities.

It all depends really, if you’ve got a tension, you’re heading for a fit then yes [epilepsy would stop you riding a bike], in case you had a fit while you are riding, but if you were ok and there was somebody with you, yeah (P/INT)
Similarly, it was not thought to interfere with learning at school although one child (aged 6) said that epilepsy did affect this “…because they daydream”. Views were mixed or unclear in relation to the impact of epilepsy on friendships, autonomy and aspirations. Three children thought that epilepsy would get in the way of things people with epilepsy wanted to do in the future. One 8-year-old girl whose friend had epilepsy said she thought that some jobs might not be possible for people with epilepsy (driving a bus) but that others would be accessible (teaching):

Yeah 'cause it was either my Mum or Dad, they had an epileptic teacher when they were at school

5.2 Secondary age young people

Four of the seven secondary aged young people without epilepsy who were interviewed knew someone with the condition although all these young people attended mainstream schools which were also attended by students with epilepsy.

5.2.1 Explanations and knowledge of epilepsy

All except one of the seven participants had heard of epilepsy prior to their participation in this project. One participant was unsure about whether epilepsy could be caught from other people but most in this group said that it was not contagious; most also agreed that epilepsy could be helped by taking medicine. Four thought that epilepsy would make someone very tired.

It was clear that participants did not have a very broad or detailed understanding about the condition, even when they were aware that they knew someone with epilepsy. This rather scant and superficial understanding about epilepsy is illustrated by the following comment from a young woman who knew someone with epilepsy:

What exactly is it? I know a fit is when you lose control of your body but that doesn't really explain it enough… My mum says it can be visual things that trigger it off and that's one of the most common ways (S/INT)

These pupils did not feel that epilepsy was the most important thing about someone and there was only one comment that explicitly suggested young people with epilepsy could feel differently from others. This was made in the context of discussing how awareness raising could help:

And they wouldn’t make the person feel different, like an outsider from the rest of the people (S/INT)
5.2.2 School-related issues

There was no evidence from any of the secondary age participants that epilepsy was something that was talked about, or taught, at school. Two of the students noted that teachers should be more aware of epilepsy and, importantly, have a better understanding about what it means for individual students. Several felt that there is a, more general, role for schools in raising awareness about the condition:

*We learn about respect and responsibilities and all those kinds of things. I think it would fit within that category of learning and I think it should be part of the curriculum to learn about how people are affected and be taught that it shouldn’t affect their future, and to have more respect for people with difficulties*  (S/INT)

Participants were asked how, and where, information should be presented in order for it to be accessible for young people; the internet was suggested as a good place as well as leaflets. Again, in agreement with the young people with epilepsy, the importance of leaflets being targeted at, and specifically relevant, for young people was emphasised:

*You could have age-group aimed leaflets…young people would read them but not older people….teenagers, the one thing they don’t want to do is read , the only thing they want to do is text their boyfriends!* (S/INT)

These students also made a number of excellent suggestions about how schools could help young people with epilepsy and these are incorporated into our recommendations. Briefly, their ideas included implementing a ‘buddy’ system through which older students could support younger ones, having assemblies, talks and taught lessons about epilepsy, and encouraging greater awareness amongst teachers.

5.2.3 Peer acceptance

Feelings about epilepsy were mostly positive and understanding, although there was still some uncertainty about the condition:

*I think when people hear the word epilepsy they think it’s like really bad whereas if you heard about asthma it would be like ‘oh they’ve just got a problem with breathing’; it’s not that big, but epilepsy sounds worse because you don’t know about it* (S/INT)
Participants did not report any knowledge of negative attitudes towards epilepsy, although one thought that this could be a possibility:

_"I don’t know how [she] deals with it because I bet she gets picked on sometimes but [she] is a very strong person...because we are at an all girls school...they are very, very bitchy and will use anything against you...trust no-one! (S/INT)"

Reassuringly, however, secondary school age participants were sympathetic and responsive when asked how they do, or would, help a friend with epilepsy, even if they were not entirely sure about what was a ‘correct’ response. Three of the participants in this group were aware of the need to approach the topic sensitively and let their friend with epilepsy discuss their condition when they wanted to:

_"I think the people they are telling have got to respect that there’s a certain part of it that is private, like you don’t want to tell people all the details! They’ve got to kind of understand that if they don’t want to talk about it they don’t have to (S/INT)"

### 5.2.4 Independence and autonomy

Secondary school students, like primary age pupils, did not generally think that epilepsy would stop people being able to choose things for themselves or impact on most activities. However four members of this group thought that epilepsy would influence participation in some forms of extra-curricular activity, including sports and swimming. Four participants said that epilepsy would have an impact on socialising with friends; and two mentioned that it may preclude joining in with the school disco.

### 5.2.5 Ambition and aspirations

Two of the seven participants in this group were not sure whether epilepsy would have an impact on things that people wanted to do in the future, but four thought it might do and provided a number of suggestions about how this could happen:

_"If you had epilepsy, if you’re like an actor, say if your brain told you to do something, probably would ruin your job and you’d probably get fired  (S/INT)"

_"I don’t think they would be able to do stuff like discos or basically anything with flashing lights  (S/INT)"
It could get in the way of things at University - they might find it too hard (S/INT)

It could do [get in the way of future choices] because people see it as a disease rather than an illness if someone was employing you or something but I don’t think it should (S/INT)

5.3 FE Students

There were six students in this group of FE students without epilepsy (3 females, 3 males) aged 16-17 years who were interviewed. All were studying A or AS levels at a sixth-form college and were chosen for participation in the project by their friend with epilepsy (or uncertain diagnosis in one case). Note-questions for this group focused on their views and experiences of supporting a friend with epilepsy rather than on their perceptions of how epilepsy impacted on their friend.

5.3.1 Explanations and knowledge of epilepsy

Three of the friends of students with epilepsy had witnessed their friend having a seizure; two of which were not grand mal seizures:

They weren’t your typical sort of fits where you go unconscious and you fall on the floor and start to twitch and shake, so I wasn’t so worried about her causing herself damage (FE/INT)

She’s got really minor epilepsy, and she was sitting there and I realised she wasn’t paying attention and I asked her if she was OK (FE/INT)

These comments highlight that an essential aspect of awareness raising, echoed throughout comments from most of the groups of young people involved, is addressing the common misperception that grand mal seizures represent ‘typical’ epilepsy.

General knowledge and awareness amongst this group was reasonably good in the sense that many had sought out additional information about epilepsy because they had a friend with the condition. However, most admitted to knowing very little about it before they knew their friend had epilepsy. Interestingly, one comment suggested that the reason people might think of grand mal seizures as ‘proper’ epilepsy was because this was the type of seizure most commonly depicted in the media:
You know when you say typical it wouldn’t be so dramatic in a TV show to just have someone trying to shake (FE/INT)

One was glad that a first aid course had helped him remain calm whilst helping his friend during a seizure. For another student, gaining a proper understanding of what epilepsy means for people had happened over time as he had gained experience of being with his friend in different situations:

‘cause there are so many things that can trigger epilepsy, like watching TV, and I don’t know the full extent of how bad his epilepsy is, I know it is brought on by flashing lights and things like that, so I do get worried when we watch like a video or something, but when he’s finished watching it and he’s OK there’s a growing awareness that he’s OK and is not really going to be affected by it (FE/INT)

5.3.2 College-related issues

All six of the students in this group said that, to their surprise, epilepsy was not discussed at school or college. So unsurprisingly, participants felt that general awareness of epilepsy was low both amongst fellow students and the wider population. One student, in his first year at the college, pondered the possible implications of this and was concerned that a lack of knowledge could lead to someone not being helped in the best way:

I wonder how many people around the college are epileptic? There must be people that you mingle with and any number of them could have something wrong and you just don’t know so if I fell over and started shaking would people know I was epileptic? Would people know what to do? If someone just came over and sat there and tried CPR.. they might do the wrong thing because they won’t know exactly what was wrong...(FE/INT)

Across the group there were various suggestions about how schools could improve their provision for students with epilepsy, as well as raise awareness amongst the wider school population, these included having people come to the school to talk about different health conditions; incorporating teaching about health conditions into the curriculum and encouraging better relationships between staff and students so that young people felt they could talk to teachers about any difficulties (these, and other comments, from young people about how schools can help are incorporated into our recommendations).

Improving the general awareness about epilepsy across all members of staff was considered important so that knowledge was not confined to only one or two teachers. In terms of information about epilepsy specifically, there were a
number of things that students wanted to know, or thought others should know, about the condition including: what an epileptic seizure may look like; environmental and physical triggers of seizures; biological explanations about causes of epilepsy and associated features; and personal experiences of epilepsy. (See recommendations.)

The importance of personal experiences with epilepsy, through being friends with someone with the condition, emerged as a recurrent theme in these young people’s comments. Whilst they understood and appreciated the need for, and value of, general awareness raising in school, they were alert to the fact that knowing someone with epilepsy was the best way of finding out more about it:

*For me personally I think it was a lot more beneficial to have someone who has experienced it, to tell me what it is like, so looking at symptoms, and obviously the book can’t tell you what they were feeling and experiencing and things like that (FE/INT)*

Finally, suggestions for where and how sources of information about epilepsy should be available mostly echoed those from the secondary school group although, again, their preferences differed across the group: Internet, television (including documentaries about the condition and adverts), practical information on first aid boxes, leaflets, posters, newspapers and magazines. One suggestion focused on utilising emergent and popular internet sites as a way of targeting information at young people:

*Maybe if you picked a website like MySpace or something, where a lot of young people are on it, you could have some advertising space or something (FE/INT)*

However, two other students felt the Internet was not the best place for accessing information about epilepsy:

*The internet is not really accessible to everyone is it? (FE/INT)*

*To be honest I don’t think the internet is that helpful because you can’t have a conversation with a piece of paper. It is about talking it through more than just reading the screen (FE/INT)*

5.3.3 Peer acceptance

Five of the FE students interviewed knew someone with epilepsy. As with the secondary school group, attitudes about epilepsy were accepting and
understanding because friends had grown used to, and found out more about, the condition over time. However, when they first found out about the condition, they admitted having felt worried, largely because they did not have a very good understanding concerning the nature of epilepsy:

*I was confused because I didn't know about it and I was quite shocked what had happened and then finding out that he wasn't at school for a few days, I was quite worried about that* (FE/INT)

There was no mention of any negative attitudes from others towards their friends with epilepsy. Of those who had a friend with epilepsy, all were very understanding and recognised the importance of their own role in relation to supporting their friend:

*I think definitely as the role of a friend, you’ve got to be aware of it and know what he is going through with it and be able to be on a close personal level so you can discuss what he is going through and if he does have an epileptic fit to know what needs to be done in that time... willing to put the time aside to research it and find out lots about it* (FE/INT)

Sometimes this was difficult to manage and one friend wished that there could be some support for herself in order to help her understand the condition better and, implicitly, cope with some of the worry that she felt in supporting a friend with epilepsy:

*it would be quite nice for me to have someone to talk to who wasn’t [friend with epilepsy] because obviously you need some outside perspective once in a while on it and it would be nice if there were people you could go an talk to...there’s no-one to support me the other side. Because I know there’s nothing I can do for her, and I talk to her about stuff, but there’s nothing the other side to help me to understand it* (FE/INT)

6. Discussion

6.1 Developmental issues

Children and young people tended to have varying ideas and feelings about their epilepsy across the age span. (Note that as this study was cross-sectional, developmental extrapolations are made with caution.)

Young people (12-18) (unlike primary school age children interviewed) said that they were scared about, and fearful of, their seizures when they first
occurred. This is understandable given that some also said that they knew nothing about epilepsy at that time. At least two possible explanations for this difference between the primary school and older age groups can be considered. First, young people may have retrospectively recalled their experiences of seizures as being more fearful than they had been found to be at the time. There is evidence from the psychological literature on resilience that battles conquered tend to be recalled as having been more fierce than they were felt to be at the time. Second, the social context may have changed, such that epilepsy is now treated more matter of factly. Given the relatively short time scale involved and that many young people mentioned a current lack of open communication about epilepsy, the latter explanation seems unlikely.

Other comments also point to the former interpretation. Recalling seizures as significant may have helped young people to incorporate having epilepsy into part of their identity. However there was also a (sometimes) unhappy realism of coming to terms with the implications of having epilepsy (medically and physically, as well as socially and academically) in relation to a denial of access to activities and opportunities. It is possible that a retrospective reappraisal of diagnoses and early experiences reflected this ‘felt realism’, which was missing from the relative optimism and positive experiences of the younger children interviewed. In line with this, young people’s recollections conveyed a strong sense of ‘getting used to it’, for the person with epilepsy as well as for their friends and family. This is consistent with research on children’s experiences of chronic illness (Stewart, 2003) as well as other qualitative studies into children and young people’s experiences of epilepsy (McEwan et al., 2004b; Eklund & Sivberg, 2003).

Our findings emphasise the importance of the acceptance of epilepsy for children with the condition, but, importantly, extend this to their friends also. Over time, these classmates developed both general and person-specific knowledge and understanding about epilepsy as well as confidence in supporting the friend. This highlights the need to ensure that friends (in and out of school) and other classmates are aware of what epilepsy means and can provide sensitive practical and emotional support (see also Elliott et al., 2005).

This has implications for service providers also and they need to ensure that the information and support needs of the friends of young people with epilepsy are adequately catered for. They carry out an essential role, as reflected in a comment from one of the young people interviewed here:

Because any problems [FRIEND] has, I know about them, and I think about them; but I have nobody who can advise me on them

There are parallels with recent work on young carers and the important support which they provide, largely unrecognised, and often alone. Epilepsy Action has potentially an important support and information role for such
children and young people in the context of their help to friends (and family members) with epilepsy.

6.2 Invisibility and identity

Historical figures known, or believed, to have had epilepsy include Pope Pius IX, Lenin and Prince John (son of King George V and Queen Mary); scientists with epilepsy have included Alfred Nobel; arts-linked figures with epilepsy have included Edward Lear, Dostoyevsky, Laurie Lee and, more recently, Richard Burton, Bruce Lee and Truman Capote. Curiously perhaps, epilepsy has been attributed without supporting evidence to some major figures including Pythagoras, Hannibal, Isaac Newton and Agatha Christie. In particular, many religious figures (in positivist cultures) have been suspected of having temporal lobe epilepsy, perhaps reflecting an attempt to provide a rational explanation for mystical experiences.

It is not easy to identify contemporary politicians, scientists, sports people, artists, poets, dramatists and writers with epilepsy. Exceptions include Max Clifford (publicist); the actors Danny Glover (The Color Purple and other films) Martin Kemp (East Enders) and Rik Mayall; Rabbi Lionel Blue and the athlete Florence Griffith Joyner ('Flo Jo').

Perhaps reflecting the rise of the pursuit of ‘celebrities’ by photographers, the two most high profile examples recently concern famous people whose children have epilepsy and so the parents have expressed concerns about the possible impact on the child of recurrent high flash photography (David Cameron re his son, Ivan; David and Victoria Beckham re their son, Romeo). While it is important that epilepsy is spoken about publicly, the apparent rationale for the publicity about these cases may unwittingly reinforce stereotypical views of epilepsy.

It was notable that, for our participants with epilepsy, there was an almost complete absence of epilepsy from most contexts of their everyday life (including schools, television and, even sometimes, family discussions). Some of them deliberately sought to maintain this invisibility and were reluctant to disclose or discuss epilepsy. They wanted greater awareness about the condition amongst the general population so that attitudes might become more understanding and accepting.

In this sense there was a ‘cycle of invisibility’ perpetuated by a lack of information plus a limited willingness to be open and honest. That is, many young people disliked the silence surrounding their condition but were also, because of their concerns about how other people would react, actively maintaining that invisibility. Some research (eg. Jessop & Stein, 1985) and commentators (Friedman, 1988) note the difficulties experienced more generally by people whose disabilities are invisible or ‘marginal’ rather than visible or (often) physical. That is, those with hidden disabilities tend to suffer more emotional problems and experience greater difficulties with psychosocial adjustment compared with those whose disabilities are more immediately apparent. Indeed, a key aspect of the comments from young people in the
The present study was of the felt need for secrecy around the condition due to feelings of being different from peers. There was a strong sense from many children and young people with epilepsy about not feeling ‘normal’, or able to do all the things which their friends could do (found also in Elliott et al., 2005; Eklund & Sivberg, 2003). These positions reflect a social model of disability in which it is others’ reactions or lack of understanding, rather than any intrinsic impairment or condition, which is effectively disabling.

Johnson and Thomas (1999) suggest that schools may (inadvertently) support this view through a tendency to ‘over-medicalise’ the condition. One example of this in their findings was through the giving of responsibility for storing and handling of medication to one or two staff members only. In those circumstances, medication was often viewed problematically as something ‘administered to’ children rather than (e.g.) pills which the child could take in order to help them better manage their condition. In addition, information given to teachers about individual children’s epilepsy tended to focus on their medication and any activities in which they could not take part. The authors concluded that epilepsy needs to be reconceptualised as “…just one amongst many factors that affect pupils’ lives” (p.16).

We have hypothesised possible links between invisibility and openness concerning epilepsy as a part of reflexive individual identities in the school context. This study did not set out to test such links explicitly and research designed to explore these would be needed to demonstrate such connections. Links between epilepsy, identity and openness might also be explored in the context of formal social identity theory and recent applications of this in the disability context (Lewis and Crisp 2004). That work highlights the role of group membership in sustaining particular identities while rejecting or playing down others. For example, an organisation such as Epilepsy Action, is likely to be important to young people who are working towards their social identities (i.e. being in or out of particular groups) because it exemplifies both what it is to be ‘in’ or ‘out’ of that group (‘people with epilepsy’).

### 6.3 Information and Support

Children and young people without epilepsy, and those with epilepsy at the point of diagnosis, said that they knew very little about the condition and expressed feelings of worry, anxiety and uncertainty. This was also true for friends of young people with epilepsy who sometimes felt ill-equipped to help their friends (at least initially) due to a lack of information and understanding. Over time, their understanding and confidence developed but this was almost solely through direct experience of witnessing seizures or talking to friends about their epilepsy rather than through any additional mechanisms for raising awareness, either formally or informally.

Overall, the reactions and attitudes of friends and peers exerted a powerful influence on children and young people (in agreement with findings from Wilde & Haslam, 1996; Eklund & Sivberg, 2003; McEwan et al., 2004b; Elliott et al., 2005); even those who had grown accustomed to, and accepting of, their epilepsy often expressed feelings of embarrassment or fear of discovery.
The support and understanding of close friends (and family members) were essential in young people’s accounts of coping with their epilepsy, both practically and emotionally. Nevertheless, many young people with epilepsy also said they would have liked to talk to, or hear from, other young people with epilepsy who would presumably have a greater, and more personalised, understanding of challenges faced.

In addition, children and young people with, and without, epilepsy felt there was an important role for schools to play in terms of disseminating information and raising awareness for staff as well as students. Some teachers were described as knowledgeable and approachable – and this was reassuring – but others were ‘off-limits’ and not informed or empathic. This suggests that it is not just important for teachers to be aware of epilepsy and appropriate interventions, but that (especially younger) children recognise that teachers hold this knowledge. One suggestion from young people was for schools to implement a ‘buddy’ system, focused on either additional support needs/disabilities, or more generally for everyone in the school. Similar systems are already in place in some schools and have worked well (for example, in association with CHIPS [ChildLine in Partnerships]).

The importance of supporting children and young people in ‘child-friendly’ and accessible ways was emphasised through participants’ wishes for information to be available in appropriate language that they could understand and in a variety of formats (internet, leaflets, books, posters, advertising). The images, views and experiences of other young people with epilepsy could play an essential role in this as well as important high-profile role models (such as sports and pop stars) who could promote awareness and understanding. We have built directly on their specific suggestions in our proposed recommendations.

6.4 Methodology

The portfolio of methods developed in other work (Lewis et al 2005, 2007) was drawn upon here so that diverse children and young people were able to share their views. This approach of individualising methods to maximise contributions from children and young people was successful in generating responses, even from children as young as 7 or 8 years old, and eliciting a wide range of (generally well-supported) views.

Our deliberate focus on mainstream schools meant that children educated in special schools (whose epilepsy may have co-occurred with severe learning difficulties or autism [for example]) were not included. Those groups are also likely to have been excluded in the e-survey as the ‘primary age’ version of the survey would still have been difficult for them to complete. We were contacted by several parents of such children who asked that future research include these groups also. While this was outside the scope of this project, it would be valuable to explore whether there is a more open approach to epilepsy in special schools and the possible consequences for school/community attitudes and inclusion more widely.
The e-survey and interview data sometimes presented conflicting findings. For example, a majority of secondary age pupils responding to the closed questions in the e-survey said that their epilepsy had little impact on their learning. However, in open responses about general impact of the condition, these same young people were likely to mention some impact on their school-related activities. Most of the young people in individual interviews did feel that having epilepsy had some effect on their lives. This demonstrates that open-ended questions (in surveys and interviews) may generate more detailed and nuanced responses than do those available through structured surveys and interviews with very limited flexibility, thereby supporting the qualitative approach taken here.

In support of this point, it is noteworthy that in a review of studies examining the concept of stigma in the lives of young people with epilepsy (MacLeod & Austin, 2003), only quantitative studies were considered and conflicting results across studies were found. The authors suggested that stigma is a complex concept that may not be amenable to investigation through direct questions and survey instruments. However, it is clear from the present research, that taking a qualitative methodological approach can reveal important insights into complex concepts like stigma. Children and young people talked openly about their feelings of ‘difference’ in relation to others when given the opportunity to do so. This suggests that children and young people are willing to talk about difficult and personal issues in the context of research projects, provided the approach is sensitive and ‘person-centred’ enough to elicit views in a safe and supportive context.

It is likely that the anonymity offered by the e-survey was an additional important factor here (compared with, for example, an ‘anonymous’ survey being carried out by the clinic to which young people go regularly for check-ups and prescriptions). It was noticeable that many of the e-survey responses from young people (compared with interviewees) suggested greater unhappiness about, and difficulties with, their epilepsy. This indicates that young people may have felt able to express more negative views through the anonymous and individualised digital space of an online survey, which may not have been so forthcoming in a face-to-face meeting. So taking a combination of approaches in seeking children’s and young people’s views offers possibilities for participation on their own terms and can generate (as here) a rich dataset.

In methodological terms, the field of epilepsy is benefiting from the growing mix of quantitative and qualitative paradigms both within and across studies. Further ethnographic approaches, including for example, diary or video-based accounts and reflections by children and young people with epilepsy and their community members would be innovative and valuable in providing further insights into the ways in which society can become more inclusive of all our young people.
Bibliography


CHIPS (ChildLine in Partnerships) [www.childline.org.uk/Schools.asp](http://www.childline.org.uk/Schools.asp)


Epilepsy Action (undated) *Epilepsy and Everyone* Leeds: Epilepsy Action

Epilepsy Action (undated) *Upfront: Information for Young People* Leeds: Epilepsy Action


Full report on DRC website


Schubert, R. (2005) Attention deficit disorder and epilepsy Pediatric Neurology 32 1 1-10


8. Appendices

e surveys (NOTE- paper based versions shown here)

Children and Young People with Epilepsy: Web-based survey for children and young people with epilepsy (under 11 years)

(1) How old are you?

(2) How old were you when you got epilepsy?
   5 years or under
   6-8 years
   8-11 years
   Don't know

(3) Are you the only person living in your house with epilepsy?
   Yes
   No
   Don't know

(4) What do you say to your friends to explain epilepsy?

(5) Do you take any tablets/pills to help with your epilepsy?
   Yes
   No
   Don't know

   If you do take tablets/pills, how often do you do this?

(6) Please tick one box to show us whether epilepsy makes a difference to the things you do.

   Epilepsy means that writing is hard
   No! Not at all
   A little bit
   Quite a bit
   Yes! A lot

(7) Having epilepsy stops me from going to after-school clubs
   No! Not at all
   A little bit
Quite a lot
Yes! A great deal

(8) Having epilepsy stops me from going swimming
No! Not at all
A little bit
Quite a lot
Yes! A great deal

(9) Having epilepsy stops me reading
No! Not at all
A little bit
Quite a lot
Yes! A great deal

(10) Having epilepsy stops me from learning at school
No! Not at all
A little bit
Quite a lot
Yes! A great deal

(11) Having epilepsy stops me doing things with my friends
No! Not at all
A little bit
Quite a lot
Yes! A great deal

(12) Having epilepsy means I have to go to bed at a certain time
No! Not at all
A little bit
Quite a lot
Yes! A great deal

(13) Having epilepsy stops me from playing certain sports
No! Not at all
A little bit
Quite a lot
Yes! A great deal

(14) Epilepsy has an effect on everything I do
No! Not at all
A little bit
Quite a lot
Yes! A great deal

Please tell us how you feel by finishing these sentences (questions 15 to 20).

(15) When I am at home I always feel that my epilepsy...

(16) When I am at home I sometimes feel that my epilepsy...

(17) At school I always feel that my epilepsy...

(18) At school I sometimes feel that my epilepsy

(19) When I am out and about I always feel that my epilepsy...

(20) When I am out and about I sometimes feel that my epilepsy...

Please write anything you feel when you read these sentences (21-23).

(21) Having epilepsy means that sometimes I can not choose things for myself.

(22) Epilepsy is the most important thing about being me

(23) Epilepsy stops me doing things that my friends can

(24) Please finish this sentence, 
In the future I would like to...
Some questions about you....

(1) How old are you?

(2) How old were you when you became epileptic?
   - 5 years or under
   - 6-8 years
   - 9-11 years
   - 12-15 years
   - 16-18 years
   - 19 years or older
   - Don't know

(3) Are you the only person living in your house who has epilepsy?
   - Yes
   - No
   - Don't know

(4) What do you say to friends to explain epilepsy?

(5) Do you take medication for your epilepsy?
   - Yes
   - No
   - Don't know

(5a) If yes, how often do you take this?

(5b) Does your medication have any side-effects?

Questions about the effect epilepsy has on your life... (tick box)
(6) Having epilepsy affects me writing
   No! Not at all
   A little bit
   Quite a lot
   Yes! A great deal

(7) Having epilepsy affects me going to 
    after-school clubs (tick box)
   No! Not at all
   A little bit
   Quite a bit
   Yes! A great deal

(8) Having epilepsy affects me going swimming (tick box)
   No! Not at all
   A little bit
   Quite a lot
   Yes! A great deal

(9) Having epilepsy affects me reading (tick box)
   No! Not at all
   A little bit
   Quite a lot
   Yes! A great deal

(10) Having epilepsy affects my learning at school (tick box)
    No! Not at all
    A little bit
    Quite a lot
    Yes! A great deal

(11) Having epilepsy affects me doing things with 
    my friends (tick box)
    No! Not at all
    A little bit
    Quite a lot
    Yes! A great deal

(12) Having epilepsy affects what time I go to bed (tick box)
    No! Not at all
    A little bit
    Quite a lot
    Yes! A great deal
(13) Having epilepsy affects the sports I play (tick box)
   No! Not at all
   A little bit
   Quite a lot
   Yes! A great deal

(14) Having epilepsy affects everything (tick box)
   No! Not at all
   A little bit
   Quite a lot
   Yes! A great deal

Please tell us how you feel by finishing these sentences in your own words (15-20).
(15) At home I always feel that my epilepsy...

(16) At home I sometimes feel that my epilepsy...

(17) At school I always feel that my epilepsy...

(18) At school I sometimes feel that my epilepsy...

(19) Out and about I always feel that my epilepsy...

(20) Out and about I sometimes feel that my epilepsy…

Please write anything you feel in response to the following statements (21-23).
(21) Having epilepsy affects the choices I am able to make.

(22) Epilepsy is the most important part of me.

(23) Epilepsy stops me being included in activities.

(24) Please finish this sentence.
    In five years time I hope...
Dear parent/carer

We are writing to let you know about a project that we are doing at the University of Birmingham which is looking at children and young people’s understandings of epilepsy, within a broader context of health and illness.

Part of this work involves meeting, and talking with, young people and their teachers at school, this will include children with and without epilepsy. Your son/daughter’s school has very kindly allowed us to contact you to see if you would be willing for your son/daughter to take part in this research.

We include some further information about the project which will help you and your son/daughter to make a decision about whether to be involved. Please do not hesitate to contact us if you have any queries about the project (see information sheet for details).

If you have read the information and are happy to take part in the research, please complete the following slip and return it to the school as soon as possible. We want you to know that we shall not include named comments from yourself or your child in any reports about the project.

We hope that you and your child will take part in this exciting project.

Best wishes

Professor Ann Lewis
Project Director
Consent Form for Project with the University of Birmingham

School name:  

Name of student:  

Name of parent/carer:  

I have read the information provided about the research project with the University of Birmingham and agree that my son/daughter can take part. My son/daughter has also agreed that they would like to take part. I understand we can withdraw at any time and that any information provided will be made anonymous in project reports.

Signed:  

Date:  

[please return this slip to your son/daughter’s school]
8.3 Information sheets

Understanding of epilepsy by children and young people with, or without, epilepsy

Background

To date, there has been little written about the views of children with epilepsy, and their classmates about their condition. We have been asked by the charity Epilepsy Action to find out more about this. Specifically, we aim to:

- explore the understanding of children and young people in mainstream schools of the nature, causes and prognosis of epilepsy.
- use the information to produce guidelines for the most effective ways for teachers and other professionals to support and integrate children with epilepsy in school.

Who is involved and what will happen?

Approximately 40 children and young people from different schools and local authorities will be invited to take part in the research between April 2006 and April 2007.

This will involve a member of the research team visiting the school to talk to children and young people about their understanding and experiences of epilepsy.

How will we do it?

We have already piloted several methods to make sure that children and young people can communicate their views effectively and feel comfortable taking part; for example, we may use individual, paired or small group interviews, games involving
ranking preferences, drawings and posters and. These short sessions will take up to 30 minutes and will take place in school.

In order to accurately represent all views in any reports we will need to tape-record conversations. Please be assured that the tapes will remain confidential to the project and will be stored in locked cupboards at the University. We will not use individual or school names in any of our reports (unless the school specifically requests this) and so any comments will remain anonymous.

**Important information**

- All information is kept at the University of Birmingham in accordance with the Data Protection Act.
- Your son/daughter can withdraw from the project at any time without giving a reason.
- Your participation is confidential to the project and your son/daughter will not be named in any of our reports.
- All members of the research team have up-to-date clearance from the Criminal Records Bureau to work with children and young people.

**Research team**

We are based at the School of Education, University of Birmingham. The project team is: Ann Lewis and Sarah Parsons.

Our contact details are as follows:

<table>
<thead>
<tr>
<th>Name</th>
<th>Telephone</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ann Lewis</td>
<td>0121 414 4822</td>
<td><a href="mailto:A.Lewis@bham.ac.uk">A.Lewis@bham.ac.uk</a></td>
</tr>
<tr>
<td>Sarah Parsons</td>
<td>0121 414 4819</td>
<td><a href="mailto:s.j.parsons@bham.ac.uk">s.j.parsons@bham.ac.uk</a></td>
</tr>
</tbody>
</table>

Please do not hesitate to get in touch if you have any queries about this project.
Project about children’s health and illness: Information sheet

Who’s doing the project?
Ann and Sarah from the University of Birmingham.

To contact Sarah Parsons:

0121 414 4819
s.j.parsons@bham.ac.uk

To contact Ann Lewis:

0121 414 4822
A.Lewis@bham.ac.uk

What is the project about?
The project is looking at what children and young people feel about health and illness and experiences of this in and out of school.

There are a number of ways we can ask young people what they think, for example talking in groups or in pairs or by writing or drawing.

Who will be asked to take part?
There will be a number of schools taking part and children and young people will be aged between 7 and 18 years old. If you would like to take part, Ann will visit your school and meet you there.

The project started in April 2006 and will finish by April 2007.

Doing the project the right way
There are good ways of doing projects and this includes things like making sure people understand why they are doing the project and that they can stop at any time. It also means that we will tell people about what we found out in the project when it is finished, although people’s names are never used when we do this. No-one else will know who has taken part in the project.
### 8.4 Schools approached re interviews

Case study samples in relation to total numbers of pupils in schools approached for involvement

<table>
<thead>
<tr>
<th>SCHOOL</th>
<th>TOTAL PUPIL NOS</th>
<th>NUMBER WITH EPILEPSY according to headteacher</th>
<th>% of pupils known to have epilepsy *</th>
<th>Pupils involved in project?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary A, LEA 1</td>
<td>254</td>
<td>1</td>
<td>0.39</td>
<td>Yes</td>
</tr>
<tr>
<td>Primary B; LEA 1</td>
<td>644</td>
<td>0</td>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>Primary C; LEA 1</td>
<td>324</td>
<td>0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary D; LEA 2</td>
<td>639</td>
<td>1</td>
<td>0.16</td>
<td>No (child not known to have had seizures for many years; SENCO did not think child would be suitable)</td>
</tr>
<tr>
<td>Primary E; LEA 2</td>
<td>200</td>
<td>0</td>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>Primary F; LEA 2</td>
<td>427</td>
<td>2</td>
<td>0.47</td>
<td>Yes</td>
</tr>
<tr>
<td>Primary G; LEA 2</td>
<td>353</td>
<td>2</td>
<td>0.57</td>
<td>Yes</td>
</tr>
<tr>
<td>Secondary A; LEA 2</td>
<td>658</td>
<td>2</td>
<td>0.30</td>
<td>Yes</td>
</tr>
<tr>
<td>Secondary B; LEA 3</td>
<td>1226</td>
<td>6</td>
<td>0.49</td>
<td>Yes</td>
</tr>
<tr>
<td>Primary H; LEA 3</td>
<td>236</td>
<td>0</td>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>Secondary C; LEA 3</td>
<td>730</td>
<td>1</td>
<td>0.14</td>
<td>No (teenage male with mental health and behavioural diffs; Mum did not want him to take part)</td>
</tr>
<tr>
<td>Primary I; LEA 4</td>
<td>72</td>
<td>0</td>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>Primary J; LEA 4</td>
<td>181</td>
<td>0</td>
<td>0</td>
<td>No</td>
</tr>
<tr>
<td>Secondary D; LEA 4</td>
<td>443</td>
<td>2</td>
<td>0.45</td>
<td>Yes</td>
</tr>
<tr>
<td>FE College A, LEA 5</td>
<td>1400</td>
<td>9</td>
<td>0.64</td>
<td>Yes</td>
</tr>
</tbody>
</table>

* Although prevalence rates vary, and despite differences in populations and methodology, most estimates are in the order of 4 or 5 per 1000 children, or about 0.5%. Prevalence rates increase with age, ranging from approx 2-3/1000 through age 7 years to 4-6/1000 in 11-15 year olds (Cowan, L. (2002) The Epidemiology of the epilepsies in children. *Mental Retardation and Developmental Disabilities Research Reviews*, 8, 171-181)
### 8.5 Interviews

#### (a) Participants with epilepsy

<table>
<thead>
<tr>
<th>School stage</th>
<th>Sex</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Epilepsy Medication</th>
<th>Type of epilepsy</th>
<th>Age of onset</th>
<th>Last seizure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>Male</td>
<td>9</td>
<td>White British</td>
<td>Not sure</td>
<td>'Jaw goes funny'</td>
<td>8</td>
<td>About every week</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>8</td>
<td>White British</td>
<td>Yes</td>
<td>Tonic clonic</td>
<td>6</td>
<td>6 months (at school); not known re home</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>9</td>
<td>White British</td>
<td>Yes – although could be for ADHD rather than epilepsy</td>
<td>'Eyes go watery'</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>6</td>
<td>White British</td>
<td>Yes, every day</td>
<td>Petit mal, only at home and night times / mornings</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>6</td>
<td>White British</td>
<td>Yes 2x daily 'Red', 'tastes like strawberry'</td>
<td>Night time only: 'legs don’t move'</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>8</td>
<td>White British</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>9</td>
<td>British Asian</td>
<td>Yes Medazolam</td>
<td>'unstable epilepsy; generalised tonic clonic, partial and absence seizures at home and school</td>
<td>Has underlying condition that causes his epilepsy (and associated learning diffs)</td>
<td>Occurs frequently</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>8</td>
<td>British Asian</td>
<td>Yes; 'makes hair fall out'</td>
<td>Night time only; 'my mouth feels a bit wobbly and I can't talk; Sometimes my hand moves and my leg moves when</td>
<td>Recently diagnosed – aged 7 or 8</td>
<td>-</td>
</tr>
<tr>
<td>Age</td>
<td>Gender</td>
<td>Ethnicity</td>
<td>Type</td>
<td>Medicine</td>
<td>Dosage</td>
<td>Time of Day</td>
<td>Seizure Description</td>
</tr>
<tr>
<td>-----</td>
<td>--------</td>
<td>-----------</td>
<td>------</td>
<td>----------</td>
<td>--------</td>
<td>-------------</td>
<td>---------------------</td>
</tr>
<tr>
<td>10</td>
<td>Male</td>
<td>British</td>
<td>White</td>
<td>No - 'I've got the type that they can't control with medicine'</td>
<td>Mostly at night; occasionally in the day; 'mum says I shake'</td>
<td>Infancy</td>
<td>2 months</td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Yes</td>
<td>Tegretol Lamotrigine</td>
<td>Night time</td>
<td>2</td>
</tr>
<tr>
<td>11</td>
<td>Female</td>
<td>British Asian</td>
<td>Yes</td>
<td>Tegretol</td>
<td>Night time</td>
<td>10</td>
<td>-</td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Has recently stopped after 7 years of medication</td>
<td>Seizure at 18 months and not since</td>
<td>18 months</td>
<td>13 years ago</td>
</tr>
<tr>
<td>14</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Epilim Tegretol</td>
<td>Start at night and sometimes occur during the day</td>
<td>6 months</td>
<td>Grand mal 'not for a long time'; absence seizures and eye twitching still occur</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>Mixed heritage</td>
<td>Used to but now stopped</td>
<td>Night time only</td>
<td>7</td>
<td>4 years</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Used to but now stopped</td>
<td>Night time only</td>
<td>Not sure ('very young')</td>
<td>-</td>
</tr>
<tr>
<td>11</td>
<td>Male</td>
<td>White</td>
<td>British</td>
<td>Yes 2x daily</td>
<td>only happens at home</td>
<td>At primary school</td>
<td>4 years</td>
</tr>
<tr>
<td>17</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Yes 2x daily</td>
<td>Not known</td>
<td>10 or 11</td>
<td>9 months ago</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Yes Small dose</td>
<td>Petit mal Partial</td>
<td>13 or 14</td>
<td>Petit mal: 3 years Partial: 12 months</td>
</tr>
<tr>
<td>16</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>Epilim 2x daily</td>
<td>Absence</td>
<td>13</td>
<td>2 years</td>
</tr>
<tr>
<td>16</td>
<td>Male</td>
<td>White</td>
<td>British</td>
<td>Yes</td>
<td>Temporal lobe</td>
<td>7</td>
<td>3 weeks</td>
</tr>
<tr>
<td>17</td>
<td>Male</td>
<td>White</td>
<td>British</td>
<td>Yes</td>
<td>Grand mal</td>
<td>12 or 13</td>
<td>22 months</td>
</tr>
<tr>
<td>17</td>
<td>Female</td>
<td>White</td>
<td>British</td>
<td>No</td>
<td>In process of diagnosis; fainting and blackouts</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
(b) Participants without epilepsy

<table>
<thead>
<tr>
<th>School stage</th>
<th>Sex</th>
<th>Age</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary</td>
<td>Male</td>
<td>9</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>8</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>7 ½</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>6 ½</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>6</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>8</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>8</td>
<td>White British</td>
</tr>
<tr>
<td>Primary</td>
<td>Male</td>
<td>9</td>
<td>British Asian</td>
</tr>
<tr>
<td>Primary</td>
<td>Female</td>
<td>8</td>
<td>British Asian</td>
</tr>
<tr>
<td>Secondary</td>
<td>Female</td>
<td>13</td>
<td>White British</td>
</tr>
<tr>
<td>Secondary</td>
<td>Female</td>
<td>12</td>
<td>British Asian</td>
</tr>
<tr>
<td>Secondary</td>
<td>Female</td>
<td>14</td>
<td>White British</td>
</tr>
<tr>
<td>Secondary</td>
<td>Female</td>
<td>15</td>
<td>White British</td>
</tr>
<tr>
<td>Secondary</td>
<td>Female</td>
<td>15</td>
<td>White British</td>
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</tbody>
</table>

* additional participants interviewed but data not included because no epilepsy 'match' available
8.6 Interview schedules and procedures

Interview: Primary aged children

To ease participants into a conversation, they were first asked their likes and dislikes about school. Next, children were told they would be shown some cards with the names of different illnesses or conditions that might make children feel poorly. Children could say whether they had heard of the illnesses or not by placing the cards into one of three brightly coloured plastic boxes labelled ‘yes’, ‘no’ and ‘not sure’. From the cards placed in the ‘yes’ box, children were then asked to say whether they had had the illness or condition themselves or knew anyone else who had (they could place the cards in boxes again at this point or just go through each one in turn without placing in boxes).

Next, children were told that the researcher wanted to find out more about what they thought about epilepsy, again using some sort cards to help with this. Children were encouraged to place the statement sort cards (e.g. ‘Makes people/me go to bed at a certain time’) in one of the plastic boxes according to whether they thought the statement was true about epilepsy (or for them), not true, or whether they were not sure.

In addition to the statement cards, there were sort cards that showed different parts of the body in order to explore which parts of the body children thought were affected by epilepsy. There were ‘feelings’ cards also (such as lonely, sad, happy, worried) that children could use to say how they, or someone else, felt about having epilepsy. For children with epilepsy only, there were three additional cards (‘My teacher/family/friends know how to help me’) that asked about support from others. [Note that these cards were not shown to all of the younger children if it appeared they were starting to get tired during the session].

If appropriate, and the child seemed willing and comfortable to chat, some of the child’s answers to previous statements were explored in more detail. The session usually ended after a more general discussion about experiences at school including how teachers help children and whether they think things like epilepsy and other illnesses/conditions should be talked about at school (and in what ways).

Interview: Secondary school and FE age groups

For the young people at secondary school, different methodological approaches were taken depending on the willingness of each participant to talk about their views and experiences of epilepsy as well pragmatic factors such as time available with each student. For some students, only a limited amount of time was available (due to curriculum demands and concerns over missing important lessons) and a ‘short form’ version of the online survey was used to elicit information in a clear and concise way (see below). Where more time, and willingness of the participant, allowed further questioning and discussion about some of the main themes provided more detailed comments. The exact questions asked at these points varied between participants in order to authentically reflect individual experiences although followed, where appropriate and feasible, the general framework of questions developed for the post-16 students.
The short survey form was not used with one of the students in this group as they were very willing to talk about their epilepsy from the outset and there was a longer period of time available for discussion; two additional students were included in the pilot study and so used a pilot version of the interview schedule also based on the online survey.
Prompt sheet /general framework for FE (and some secondary) students

(a) Young people with epilepsy

Active or inactive epilepsy?
Any stigma felt?
Any impact on educational attainment?
Do the teachers know?
Do friends know?
What were the reactions of others like?
What did you do to help or take control of it? How did you handle it?
Any need for greater awareness /understanding from teachers?
Was/is treatment different compared to other children?

How can schools/colleges/teachers help to support children and young people with epilepsy?

How can teachers and schools more generally support children with epilepsy?

How can children with epilepsy help themselves?

How could information/awareness be improved in a way that makes it accessible for children and young people?

Your feelings about the future – impact of epilepsy on that?

(b) Young people without epilepsy

Know anyone with epilepsy?
If yes, experiences of this. If no, what is perception?
Any worries/concerns?
Do people get treated differently?
Any awareness/experience in school of being told/knowing about any other chronic health conditions or disabilities?

Where else heard about/seen anything about epilepsy?
Is this something that children and young people should be taught in schools?

How could friends be involved or help to support people?

**How can schools/colleges/teachers help to support children and young people with epilepsy and other chronic health conditions?**

How could information/awareness be improved in a way that makes it accessible for children and young people?

How could teachers do this better/differently? Any need for greater awareness/understanding from teachers?
### 8.7 Codes used for analysing interview data in Nvivo

<table>
<thead>
<tr>
<th>Peer acceptance</th>
<th>Independence &amp; autonomy</th>
<th>School related issues</th>
<th>Identity</th>
<th>Ambition &amp; aspirations</th>
<th>Epilepsy specific factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do friends know?</td>
<td>Impact on school-related activities</td>
<td>School attitude to condition</td>
<td>Own attitude towards the condition</td>
<td>Aspirations/ future plans</td>
<td>Experience /awareness of seizures</td>
</tr>
<tr>
<td>Do other classmates know?</td>
<td>Impact on other activities (sports, after school)</td>
<td>Teacher attitudes /awareness</td>
<td>Feelings of sadness /frustration</td>
<td>Worries /concerns re future</td>
<td>Immediate physical effects</td>
</tr>
<tr>
<td>Experiences of bullying /teasing</td>
<td>Impact on socialising with friends</td>
<td>Student awareness generally</td>
<td>Feelings of shame/ stigma</td>
<td>Hopes for the future</td>
<td>Taking medication</td>
</tr>
<tr>
<td>Experiences of helpful/ supportive attitudes</td>
<td>Impact on choice</td>
<td>Other people's awareness generally</td>
<td></td>
<td></td>
<td>Side effects of medication</td>
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<tr>
<td>How do friends help?</td>
<td></td>
<td>Is epilepsy taught / discussed in school?</td>
<td></td>
<td></td>
<td>Social impact of medication</td>
</tr>
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<td>How could friends help more?</td>
<td></td>
<td>Should epilepsy be taught in schools?</td>
<td></td>
<td></td>
<td>Feelings re Dr's/hospital</td>
</tr>
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<td>Feelings about disclosure</td>
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<td></td>
<td>How explain epilepsy</td>
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<td>Friends’ feeling about condition</td>
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<td></td>
<td></td>
<td></td>
<td>Seen/heard/ read anything about epilepsy</td>
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<td>Sources of support</td>
<td></td>
<td>What can info be presented / made available?</td>
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<td>Age of onset</td>
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<tr>
<td>Comorbidity</td>
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<td></td>
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</tr>
<tr>
<td>Know anyone with epilepsy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Last seizure</td>
</tr>
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</table>
| Sense of uncertainty | | | | |%
| What helps you to cope? | | | | | |
8.8 Extracts from tables (2)

e survey –Primary

<table>
<thead>
<tr>
<th>Epilepsy means that writing is hard</th>
<th>Having epilepsy stops me doing things with my friends</th>
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<tr>
<td>No! Not at all</td>
<td>No! Not at all</td>
</tr>
<tr>
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</tr>
<tr>
<td>Quite a lot</td>
<td>Quite a lot</td>
</tr>
<tr>
<td>Yes! A great deal</td>
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<th>Having epilepsy stops me learning at school</th>
<th>Having epilepsy stops me from playing certain sports</th>
</tr>
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<th>Having epilepsy stops me from going swimming</th>
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e survey- secondary

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<tr>
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</tr>
<tr>
<td>No response</td>
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Understanding of epilepsy by children with, or without, epilepsy

This one year project was set up to find out what children understand about epilepsy. We were interested in the views of children and young people, in mainstream schools, who had been diagnosed with epilepsy. But we also wanted to know what their classmates, who did not have epilepsy, thought about the condition.

If children with epilepsy in mainstream schools are to make the most of school then it will help if their classmates understand epilepsy. We also wanted to help schools to know what to say to all children about epilepsy.

We set about discovering children’s views in two ways:

- we used a survey on the internet to ask children and young people with epilepsy about their views. Epilepsy Action helped us to reach these children and young people and 44 people responded. We did not ask them to tell us their names so their comments were anonymous.

- we also went to several mainstream schools and talked with 22 children with epilepsy and 22 children without epilepsy. We ’matched’ the children so that in each pair one child with epilepsy was similar to a child without epilepsy from the same school class. In some cases, children with epilepsy asked their friends to speak to us. We talked to each of the children on their own so that they could say what they really felt.

What we found out is important in helping children and young people with epilepsy to be part of their communities through raising awareness about how they think and feel about having epilepsy.
What did children and young people with epilepsy think about having epilepsy?

We found that children and young people with epilepsy, from 7 years old right up to 18 years old, understood what it meant to have epilepsy. Even the younger children had a fairly clear idea about what happened to them when they had a fit or a seizure.

But even so, these younger children were often confused about what caused these seizures. As children got older they became more accepting about having epilepsy and were less troubled by it.

Most of the children and young people were taking medication for their epilepsy. The youngest children sometimes got muddled about why they were taking medication. Nearly all the children and young people who talked with us or sent us survey replies said that their epilepsy made them very tired. We think this is very important because teachers may not realise that epilepsy is making the pupil tired. The tiredness might be because of the medication, not epilepsy, but it will still affect the pupil’s work.

Another thing which we found among lots of these children and young people was that they kept their epilepsy a secret. Often their friends did not know about it and sometimes they felt that even at home, they could not really talk about their epilepsy.

We tried to think of famous people who have epilepsy but we could not think of many people. It would help epilepsy to be accepted if famous people with epilepsy did not keep it a secret.
Many children and young people felt worried and uncomfortable about their epilepsy in school. They wanted teachers to be better at understanding epilepsy and not to feel scared about it.

Some children felt that epilepsy had a big impact on their lives and affected everything they did. However, mostly, epilepsy did not have a big impact on what children did in school or when they were out of school. This might have been because the children were on medication so their epilepsy was well controlled. Some of the things that made them sad were not going on sleepovers with friends or not going to discos.

Young people wanted more information about epilepsy to be available for everyone. They wanted that information to be – not just in booklets or posters- but in all kinds of ways. So this might also include having people with epilepsies in television programmes and stories as well as having lots of different material on the internet about epilepsy. Children especially wanted to hear the views and experiences of other young people with epilepsy.

What did children and young people without epilepsy think about epilepsy?

Children and young people without epilepsy varied a lot in terms of what they knew about epilepsy. They all had classmates with epilepsy but sometimes they did not realise that this was so. On the whole, these children and young people did not know very much about epilepsy. They said it was not discussed at school. Even so they were positive and understanding, although they were not too sure about what to do, for example, if someone with epilepsy had a seizure. It was a big help if they had a friend with epilepsy.

These children and young people had many good ideas about how all children and young people could be helped to know more about epilepsy. They suggested having a ‘buddy’ system to support younger students, and providing information about epilepsy in a range of ways which suited the age group of the pupils.

We learn about respect and responsibilities and all those kinds of things. I think it would fit within that category of learning and I think it should be part of the curriculum to learn about how people are affected and be taught that it shouldn’t affect their future, and to have more respect for people with difficulties

This project was carried out between 2006 and 2007. It was funded by Epilepsy Action. The work was done by Ann Lewis, Sarah Parsons and Penny Smith from the School of Education at the University of Birmingham. If you want to know more about this work then you can contact us through Dee Fellows, secretary to the project, by phoning Dee on 0121 414 4834 or by emailing her at D.R.Fellows@bham.ac.uk.