Medicine Adherence in Paediatric Epilepsy [MAPE]

Final report

A qualitative study commissioned by Health Innovation East and undertaken by the University of Hertfordshire

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Executive Summary

> *"Well, I think it's really important to take it* [medication] *because if I don't take it then I will have a lot of relapse seizures and that would just not be good."* [CYP3]

Epilepsy is a long-term condition that affects approximately 112,000 children and young people in the United Kingdom [UK] (NHS England, 2023). It has been identified as one of the five conditions in the Children and Young People Core20PLUS5 document (NHS England 2023), highlighting its prevalence and need to focus on healthcare in this area. Children and young people who live in areas of deprivation are more likely to receive a diagnosis of epilepsy and those who have the condition are more likely to have neuro-developmental conditions.

Adhering to epilepsy medication regimes is crucial for the child or young person to be able to maximise their overall health and wellbeing as well as fulfil their potential. However, there is evidence that adherence can be poor with parent health literacy being just one factor that could negatively influence it (Paschal et al, 2016); other aspects have a more positive impact, including: Family support, parental relationship, higher socio-economic status, healthcare support (Yang et al, 2018).

Qualitative research that had specifically sought the views of children and young people (who have an epilepsy diagnosis), as well as their parents/carers, about medication adherence had not previously been undertaken within a UK context – this work, commissioned by Health Innovation East, funded by NHS England East and undertaken by the University of Hertfordshire, sought to address that omission.

The aims of the research were to gain insight and understanding of:

- The facilitators and barriers to epilepsy medication adherence in children and young people (aged 0-16 years).
- How the barrier(s) to epilepsy medication adherence in this age group could be addressed.
- The changes required to facilitate good epilepsy medication adherence.

Information in this report is derived from data collected via semi structured interviews with:

- Children and young people (aged 5-16 years) who had a diagnosis of epilepsy (n = 5)
- The parents of children/young people (aged 0-16 years) who had a diagnosis of epilepsy (n = 16)

Key findings

Summary of findings from the interviews with children and young people

The children and young people provided an invaluable insight into their experiences of taking epilepsy medication. The key findings revealed that:

- The children and young people's knowledge of their epilepsy medication and how it works was very limited.
- A change in the normal day-to-day routine had the potential to impact on medication adherence.
- All participants reported that parental support played a substantive role in medication administration and ensuring that the prescribed regime was adhered to.
- The involvement of the child/young person in hospital consultations and appointments was varied indicating an inconsistent approach in this respect.
- None of the children/young people had had any involvement with organisations or charities (they were specifically asked a question about this).

Summary of findings from the interviews with parents

- Parents reported that the diagnosis of epilepsy, and the associated medication, could have a substantive impact on the lives of both the child/young person and parent(s) – both in terms of parental emotions as well as the practical implications and the forward planning that was required to maintain parental vigilance and medication adherence. This impact should not be underestimated.

- Parents wanted their child to have as 'normal' a life as possible and organised everyday activities to try to ensure that medication was given appropriately.

- Parents had a thirst for information that related to their child's epilepsy and their medication regime; however, they were not always aware of how to access appropriate resources, meaning that they frequently turned to charity websites and relevant Facebook pages.

- Parental knowledge of their child's epilepsy drugs, and how they worked, was limited; this had the potential to impact on medication adherence if they did not realise the full implications of missing a dose or not accurately following the recommended timings for the administration.

- Parents wanted responsive advice and information from health professionals when queries about medication arose (for example, if a child was unable to take their drugs for any reason). The availability of such support was variable, a lack of it could lead to feelings of uncertainty and anxiousness about what action to take; whereas when advice was readily available, parents felt reassured. Overall, parents felt very supported by their health professional team (in particular their consultant and epilepsy nurses); it was felt that going directly to the consultant, who was responsible for the care and management of their child, was the best option when possible.

- Involvement in healthcare decision-making processes was important for the participants; the building a trusting and therapeutic relationship with practitioners, in particular, the medical consultant and epilepsy nurses played a key role in medication adherence.

- The majority of parents took responsibility for all aspects of the epilepsy medication (including ordering, collecting and administering it). One of the concerns for parents was running out of drugs, this worry was exacerbated by the *“chasing”* [P11] that they sometimes needed to do.

- Many of the parents reported that their son or daughter took their medication without any problems; others commented on difficulties associated with its form, the taste of the drug as well as their child’s stage of development and their other health needs.

- All participants very much wanted to be involved in their child’s healthcare decisions; most parents reported positive experiences of this and even the small number who did not, were able to give examples of how they had vocalised their views.

- Parents were concerned about the side-effects of medication that their child either did, or could, in the future, experience. However, they were very aware of the need for their son or daughter to take the drugs to control the epilepsy; in the main, there were good relationships with the consultant managing their child’s care, with a proactive approach being reported in terms of trying to minimise any adverse effects of the medication.

- As the child matured, parents were trying to relinquish some responsibility for the medication, allowing their child to take ownership; however, this was not without its challenges and could increase parental anxiety.

- Parents’ full understanding of ‘adherence’ was not wholly demonstrated; in addition, they were not all routinely asked about their child’s medication adherence at health appointments. They reported that they understood the need to administer their child’s drugs at certain times, but had less knowledge about how flexible this was. In addition, they were able to describe examples of when they had forgotten to give drugs and what they did when they had then remembered. However, it was not clear if there were times when medication had been forgotten and parents had not recalled the error and therefore not taken any action. On other occasions, parents reported difficulties with administering medication to their child, but did not link this with non-adherence.

- A range of reminder strategies were employed to help parents to remember to administer medication, these included alarms, visible placement of the drugs and dosette boxes (the latter being the most popular).

Similarities and differences between the parents' and children/young people's findings

There was substantively more data from the parent interviews than the children/young people ones; this was due to the difference in participant numbers, but also the length of the interviews. Understandably, the children/young people spoke for less time, they were still developing cognitively, and their language skills were still being refined; not all of them were able to talk in longer and more complex sentences and this frequently resulted in brief responses to questions. Secondly, their attention span varied and was limited at times. Despite these factors, it was invaluable to hear the voices of children and young people; without their contribution, the research simply would not have been able to encapsulate or appreciate the perspective of the child/young person.

There were a number of similarities in the parent and children/young people findings:

- Parental and child/young person knowledge of the epilepsy medication and how it works was limited.
- It was agreed that a change in the normal day-to-day routine had the potential to impact on medication adherence.
- Children/young people and their parents both reported that parental support played a substantive role in medication administration and ensuring that the prescribed regime was adhered to.
- The parental and children/young people interviews both revealed that involvement of the child/young person in hospital consultations and appointments was varied, thus indicating an inconsistent approach in this respect.

One key difference between the parents and children/young people was, when specifically asked, none of the children/young people had involvement with charities or support organisations – this was in stark contrast to parents who had a 'thirst for knowledge' and had made contact with a range of different groups.

The parent findings identified a range of additional points that were, understandably, more specific to their own perspective (please refer to Section 3.4) that included, for example, the desire for responsive advice.

Recommendations

The findings from this study highlighted key recommendations:

- Families understand the importance of medication adherence and try hard to follow the prescribed regime. However, having timely answers to queries when difficulties arise (such as the child vomiting their medicines), is fundamental to their medication administration decision-making. It is recommended that there is an identified point of contact for parents – perhaps having, for example, an epilepsy nurse ‘on-call’ for a region who can offer a prompt and supportive response. We do not believe that this would be too onerous for the personnel involved as parents mentioned that their need for this advice is only occasional.

- The building of a trusting and therapeutic relationship with practitioners, in particular, the medical consultant and epilepsy nurses is crucial; we suggest that strategies continue to be employed to facilitate this, with both parents and children/young people – thus enabling a shared approach to decision-making that underpins medication adherence.

- A disruption to the family routine can impact on medication adherence; the most used and successful reminder system was a dosette box. It is suggested that this strategy is recommended to families and, if feasible, a suitable and developmentally appropriate box is offered to them.

- A number of parents reported that they were not specifically asked about adherence to epilepsy medication, or associated side effects, during hospital appointments. It is suggested that questions about these are included in all consultations.

- It is recommended that families are provided with support services information that provides details of, for example, relevant charities, support networks, reputable sources of healthcare advice, such as the medicines for children factsheets/webpages. Resources that meet the developmental needs of children and young people should be particularly considered.

- We recommend that parents and children/young people are clearly told what adherence to medication actually means, this includes the degree of acceptable flexibility with the timing of medication administration. Families should be encouraged to report, to the child’s medical team, any challenges associated with medication administration (including the taste, form of the drug and any side effects). Appropriate information and support can then be offered.

Limitations

The research team are aware that this work was not without its limitations, most notably:

- The views of the participants may not be wholly representative of other families across the UK and that experiences may vary.
- Recruitment of children, young people and their families can be challenging; whilst our sample size was commensurate with other qualitative studies, we are aware that all the parents were white, mothers and in a stable partnership. It is acknowledged that the perceptions of other groups may be different.

Future research

This study has provided a valuable insight into the experiences of children and young people (who have epilepsy) and their parents; however, we are aware that whilst our participants were from a breadth of geographical locations and had a wide socio-economic profile, there was not diversity in terms of culture and ethnicity. It is suggested that future research is undertaken to:

- Target specific populations such as single parent families as well as those from ethnically diverse backgrounds.
- Gain insight into the perspectives of fathers as all our parents were mothers.
- Ascertain the views of more children and young people (in particular, boys) as our sample was small, with just one male participant.

The Report

Section 1.0: Introduction and background

1.1 Introduction

This report summarises the research processes as well as the findings of the Medication Adherence in Paediatric Epilepsy [MAPE] study, that was commissioned by Health Innovation East and conducted by the University of Hertfordshire. All aspects of the research, including the writing of this report, were undertaken by the research team: Lisa Whiting [LW] (Principal Investigator), Rosemary Godbold [RG] (Co-Principal Investigator), Saadye Ali [SA] and Adam Ali [AA].

This report initially gives background information before presenting the research aim and explaining each aspect of the research process; Section 3.0 provides a comprehensive overview of the findings with Section 4.0 listing recommendations, limitations of the study as well as suggestions for future research.

1.2 Background

The World Health Organization [WHO] (2023) define epilepsy as:

> *“A chronic noncommunicable disease of the brain that affects around 50 million people worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized) and are sometimes accompanied by loss of consciousness and control of bowel or bladder function.”*

There are several different types of epilepsy seizures, some of which are identified and described by NHS England (2020); WHO (2023) suggest that the epilepsy can be categorized (structural, genetic, infectious, metabolic, immune and unknown) with specific examples including:

- Cerebral damage during the prenatal and perinatal periods (including birth trauma and hypoxia)
- Congenital problems and genetic abnormalities that are associated with cerebral malformation
- Head injuries
- Cerebral infections (such as meningitis or encephalitis)
- Brain tumours
- Genetically linked syndromes

Young Minds (2025) add that approximately 60% of epilepsy seizures in children and young people have an unknown cause.

Epilepsy is a long-term condition that affects approximately 112, 000 children and young people in the United Kingdom [UK] (NHS England 2023), it has been identified as one of the five conditions in the children and young people Core20PLUS5 document (NHS England, 2023) – highlighting its prevalence and the need to focus on health care in this area. Unfortunately, children and young people who live in areas of deprivation are more likely to receive a diagnosis of epilepsy and those who have the condition are more likely to have neurodevelopmental conditions (NHS England 2023).

Adhering to epilepsy medication regimes is crucial for the child or young person to be able to maximise their overall health and wellbeing, minimize the impact of their condition as well as fulfil their potential. However, there is evidence that adherence can be poor with parent health literacy being just one factor that could negatively influence it (Paschal et al, 2016); other aspects have a more positive impact, including: Family support, parental relationship, higher socio-economic status, healthcare support (Yang et al, 2018).

Qualitative research that had specifically sought the views of children and young people (who have an epilepsy diagnosis), as well as their parents/carers, about medication adherence had not previously been undertaken within a UK context – this work sought to address that omission.

1.3 Research aims

The aims of the research were to gain insight and understanding of:

- The facilitators and barriers to epilepsy medication adherence in children and young people (aged 0-16 years).
- How the barrier(s) to epilepsy medication adherence in this age group could be addressed.
- The changes required to facilitate good epilepsy medication adherence.

Information in this report is derived from data collected via semi structured interviews with:

- Children and young people (aged 5-16 years) who had a diagnosis of epilepsy (n = 5)
- The parents of children/young people (aged 0-16 years) who had a diagnosis of epilepsy (n = 16)

Section 2.0: Undertaking the research: Methodological approach and data collection methods

2.1 Introduction

This section will provide an overview of each aspect of the research process that was undertaken within the study. The qualitative nature of this research guided the approach used with data being collected via 21 semi structured interviews (five with children and young people; 16 with parents).

2.2 Methodological approach: Qualitative research

Qualitative research involves asking *“open questions about phenomena as they occur in context rather than setting out to test predetermined hypotheses”* (Carter and Little, 2007: 1316). This approach enables in-depth and rich data to be collected and aims to gain a greater insight into participants experiences (Grove and Gray, 2018). As such, qualitative research was well suited to the aims of the study, allowing participants the flexibility to share their perceptions.

2.3 Consultation strategies

2.3.1 Consulting with children/young people and parents

One of the recognised methods of consulting with children/young people, and of involving them in decision making processes is via an advisory group – this enables key documentation, terminology, and data collection approaches to be developmentally appropriate and user-friendly. The University of Hertfordshire has an established YPAG (https://www.herts.ac.uk/research/centres/cripacc/public-involvement-in-research-group-pirg/public-involvement-research-group). We consulted with this group on 9th July 2024 to ascertain their thoughts about the proposed research process and the associated documentation (such as the consent form and Participant Information Sheets); we met again with the YPAG on 5th November 2024 to obtain their thoughts about our progress to date and the potential use of pseudonyms for participants; their feedback informed the decision to use ‘CYP’ and ‘P’ rather than names (Sections 3.3 and 3.4). The YPAG members received a ‘thank you’ gift voucher as an acknowledgement of their time.

We had recently consulted with a Parent Advisory Group [PAG], comprising of three parents, in relation to another initiative. The PAG commented extensively on a range of paperwork (including consent form, Participant Information Sheet and Support Services Information Sheet); this advice was used to inform the development of our documentation for this research.

2.3.2 Steering group

Each aspect of the study was informed by a monthly online steering group meeting that included Health Innovation East staff, the research team as well as a consultant paediatrician, a children’s epilepsy clinical nurse specialist and a pharmacist. In addition, smaller weekly ‘Operations’ discussions were held with the research team and Health Innovation East. These meetings were not only invaluable in terms of providing guidance and the sharing of thoughts, but also gave a clear audit trail of decision making with detailed notes subsequently being made.

2.4 Data collection procedures

2.4.1 Demographic pro forma

In addition to the interview, the parent participants were asked to complete a short demographic pro forma; this was read out to them for ease of completion with the process being recorded and transcribed verbatim. The pro forma asked for details about the participant’s age, gender, postcode, the number of children they had, how many of their children had a diagnosis of epilepsy, how long the diagnosis had taken to be made and details of their child’s current epilepsy medication.

2.4.2 Semi structured interviews

Interviews are now one of the most used methods of collecting data (DiCicco-Bloom and Crabtree, 2006) with a number of texts (such as Lahman, 2025) differentiating between their types (structured; semi-structured and unstructured). It was the semi-structured approach that was felt to be most appropriate for this study as it provided both the parents and children/young people the opportunity to talk about their experiences, whilst also allowing the use of a set of ‘prompt’ questions to optimise the data collection.

Two members of the research team conducted the interviews (n = 2 by RG and n = 19 by SA). The data collection took place between September 2024 – November 2024; interviews with the children and young people lasted between 11 to 18 minutes; those with the parents were 25 to 56 minutes.

Parents were interviewed alone and in a private area of their home; however, children and young people had a parent with them in case they should need any support. All interviews were conducted via Microsoft Teams Teams and were digitally recorded, with all participants (both children/young people and parents) consenting to this. The recordings were sent securely to an established transcription agency who produced word for word transcripts.

2.5 Recruiting the participants

Sample sizes in qualitative work can be difficult to establish in advance; however, it is acknowledged that the number of participants involved is normally small, due to the depth of data that can be obtained (Parahoo, 2014). Qualitative research often draws on purposive sampling as this facilitates the recruitment of appropriate participants (Polit and Beck, 2006) who are *“selected because of their personal experience or knowledge of the topic under study”* (Cleary et al, 2015: 473). This approach was congruent with the aims of the research.

We sought to recruit both parents and children/young people to the study. Children/young people have different experiences and perceptions to adults; their contribution to research is invaluable in terms of gaining insight about what is important to them and what health care strategies work best for them. In addition, they appreciate opportunities to participate in research and share their opinions, particularly when personally relevant (Whiting, 2015).

Prior to the recruitment of participants, clear inclusion and exclusion criteria were drawn up:

Inclusion criteria (parents):
- Fluent in the English language
- Resident in the UK with their child who was receiving prescribed epilepsy medication via a UK organisation such as the NHS
- The parent's child had had a diagnosis of epilepsy for a minimum of two months

Inclusion criteria (child/young person):
- Aged between 5-16 years[1]
- Fluent in the English language
- Resident in the UK and receiving prescribed epilepsy medication from a UK organisation such as the NHS.
- Had had a diagnosis of epilepsy for a minimum of two months.

The participants were recruited via Epilepsy Action and Young Epilepsy who kindly agreed to disseminate details of the study via their sites and networks; the contacts in both organisations were sent a flyer, developed by the research team, inviting parents to contact us, via a bespoke email address, if they were interested in participating in an interview. On receipt of their email, parents were sent a Participant Information Sheet and, if they agreed, an interview was subsequently arranged with them. Some parents were happy to approach their son or daughter about being involved in an interview; if this was the case, an age-appropriate children and young person's Participant Information Sheet was sent and, if they agreed to be involved, an interview date was later confirmed.

2.6 Ethical Considerations

Ethical approval to conduct the study was sought and gained from the Health, Science, Engineering & Technology Ethics Committee with Delegated Authority at the University of Hertfordshire [protocol number: aHSK/SF/UH/05776].

It was recognised that there was a possibility that the research could cause some distress as participants were being asked to recall personal, and sometimes,

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[1] Interviews were not undertaken with children aged between 0-5 years – instead, we drew on the perspective of the parent/carer for this age group This is not to devalue the voice of the younger child – rather, it is that their control over their medication is more limited and more likely to be under the auspices of the parent.

challenging situations. In case a participant wanted to debrief, time was allocated at the end of each interview for this purpose; in addition, a Support Service Information Sheet was provided, detailing sources of advice (for both children/young people and parents), should they need it. No participant exhibited signs of undue distress; in fact, the parents were particularly grateful of the opportunity to talk about their experiences.

The maintenance of confidentiality is fundamental to research with human subjects; to protect this, the following actions were taken:

- All participants' names were removed from the focus group/interview transcripts. When presenting the findings, children and young people are referred to as 'CYP' followed by an individually allocated number; a similar approach has been followed in respect of the parent data with 'P' being used with an assigned digit.
- Care has been taken when reporting all the findings to protect participant identity. For example, some of the children/young people had extremely rare and complex forms of epilepsy which, if revealed, could potentially lead to a breach of confidentiality; where this is the case, the condition has been replaced by the phrase: 'Medically confirmed complex epilepsy diagnosis.'
- All data was stored securely on the University of Hertfordshire OneDrive.

Participants were assured that their participation was voluntary, that they could withdraw at any time, and that their involvement in the study would remain confidential. Informed consent was provided by the parents; the consent form was read to the parent who consented to each aspect in turn; this process was recorded and then transcribed verbatim. In terms of the children and young people's interviews, both their consent, and that of a parent, was obtained using the same verbal and recording process.

2.7 Data analysis

Descriptive statistics were used to analyse the demographic questionnaires, this was undertaken by two members of the team [AA and RG].

The analysis of qualitative data:

> *"Involves organizing, accounting for and explaining the data; in short, making sense of data in terms of the participants' definitions of the situation, noting patterns, themes, categories and regularities."* (Cohen et al, 2007: 461)

The interviews were transcribed by a professional service and treated as two data sets (children and young people, n = 5; parents, n = 16). The thematic approach offered by Braun and Clarke (2022) was drawn on to independently analyse both data sets:

1. Familiarising yourself with the data set:
2. Coding:
3. Generating initial themes:
4. Developing and reviewing themes;
5. Refining, defining and naming themes
6. Write up

On completion of data collection, and prior to the qualitative data analysis, the research team held an extraordinary meeting on 28th November 2024 - the specific aim of this was to reflect on the study and to plan the analysis strategy. Each member of the team independently read and attributed initial basic codes to a child/young person transcript and a parent one (all members of the team had the same transcripts). This process facilitated a discussion and review of the basic coding; as there was commonality in this respect, it was agreed that LW would undertake the qualitative data analysis as she had not been involved in the interviews – thus facilitating objectivity. LW's analysis was initially reviewed by RG and then the remainder of the team. All were in agreement with both the analytical approach and the findings.

The transcripts for each data set were initially read several times by LW before initial coding was undertaken; comprehensive notes were made, enabling the identification of rudimentary themes, which were reviewed and 'collapsed' before being named. The participants' actual words are used to illustrate the themes (Section 3.0), as advocated by Chiovitti and Piran (2003), to ensure accurate reporting of the findings.

Section 3.0: Findings

3.1 Introduction

This section presents the findings that resulted from the analysis of the demographic pro forma data (Section 3.2) and the semi structured interviews (Sections 3.3 and 3.4). The qualitative commentary is supported by participant quotations. In order to maintain confidentiality, names have been replaced by CYP (for children and young people) and P (for parent), followed by a number.

Our sample of participants comprised of:

- Children, who had a diagnosis of epilepsy, who were aged 5-11 years [n = 3].
- Young people, who had a diagnosis of epilepsy, who are aged 11-16 years [n = 2].
- Parents/carers who had a child (aged 0-16 years) with a diagnosis of epilepsy [n = 16].

3.2 Demographic pro forma data

The data from the demographic pro forma was collated and subjected to descriptive statistics, the summaries of this are provided in Figures 3.1 – 3.3; the remaining demographic pro forma information is incorporated into Tables 3.1 and 3.3. Participants were from a broad range of locations across the UK (Tables 3.1 and 3.2), with the majority being from a White British background (n = 13), Figure 3.1.

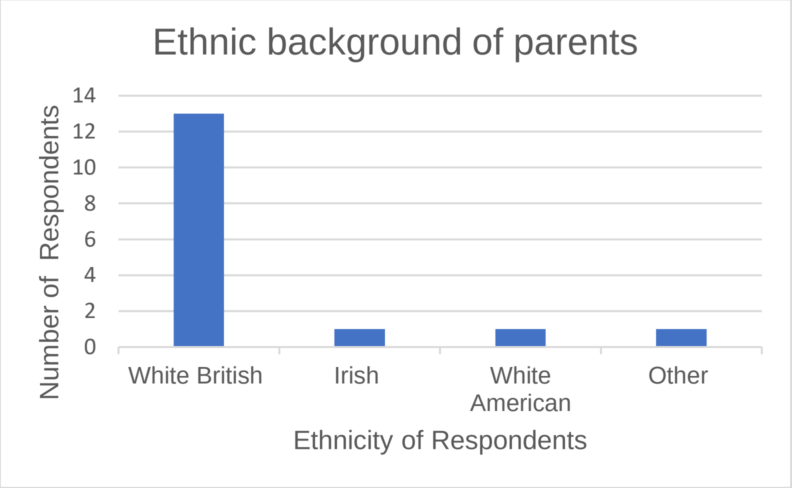

Figure 3.1: Ethnic background of the parents

The age of the parents' children ranged from under 1 year to 16 years old, with most being aged 6 years and above (n = 7). The ages of the children and young people at the point of diagnosis are depicted in Figure 3.2.

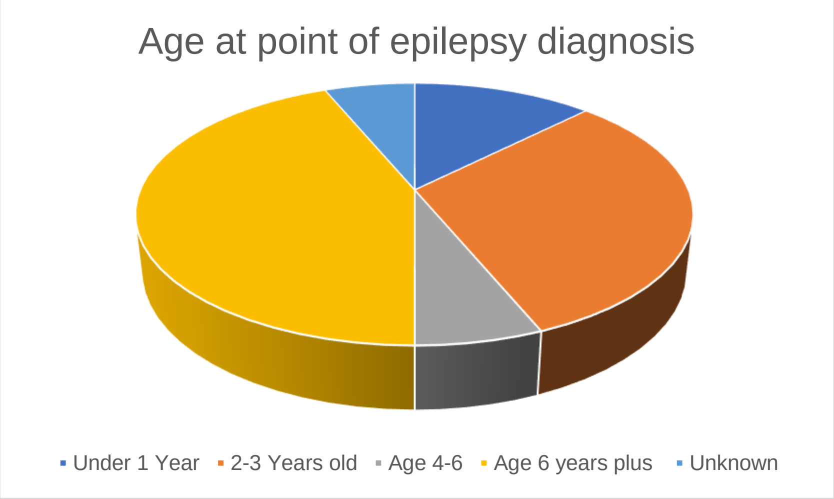

Figure 3.2: Age at point of epilepsy diagnosis

The parents identified their child's epilepsy diagnosis on the demographic pro forma – further specific details about this, together with the prescribed medication, are provided in Table 3.1. Parents were asked how long it had taken for their child to receive a confirmed diagnosis of epilepsy. This ranged from under 2 months (n = 4) to over 1 year (n = 1) with most having been diagnosed within 2 – 6 months of having initial symptoms (n = 6).

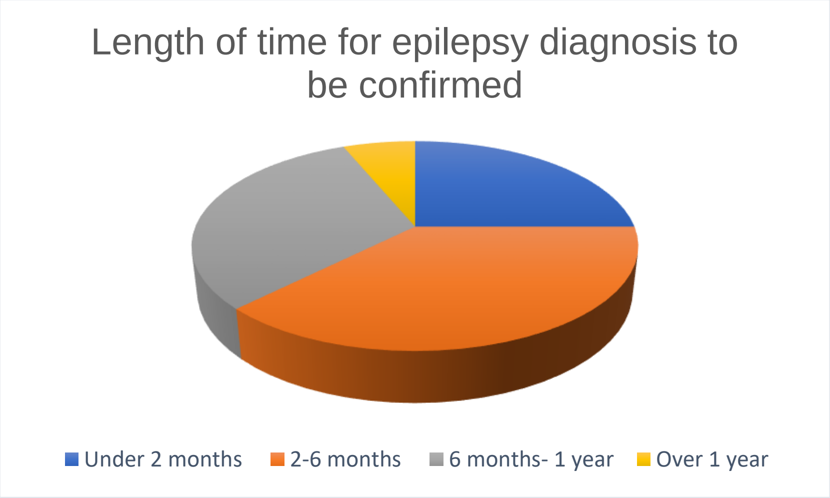

Figure 3.3: Length of time taken for the child's epilepsy diagnosis to be confirmed

3.3 Findings from the interviews with children and young people

Section 3.3 presents the three themes from the interviews that were conducted with the five children and young people; the title of each theme identifies its focus, but a quote from one of the participants is also drawn on to encapsulate the theme from their perspective. The theme relating to medication (Epilepsy medication**:** *"It's like a checklist in my head"* [CYP3]) has four subthemes that facilitate further insight into this key area:

- **Theme 1:**
  Everyday life: *"Sometimes I do get a bit annoyed"* [CYP4]
- **Theme 2:**
  Involvement in healthcare: *"How do you feel about this?"* [CYP2]
- **Theme 3:**
  Epilepsy medication: *"It's like a checklist in my head"* [CYP3]
    - **Subtheme 1:**
      Knowledge of epilepsy medication: *I think it's really important to take it* [CYP3]
    - **Subtheme 2:**
      Taking medication as prescribed: *"Sometimes I forget"* [CYP1]
    - **Subtheme 3:**
      Medication reminders: *"I have, a pillbox type thing"* [CYP4]
    - **Subtheme 4:**
      The medication: *"It tastes like rotten old eggs"* [CYP1]

Each of the themes are presented in the following Sections. Table 3.1 provides further details about the children and young people who were interviewed.

CYP Identifier	Gender	Ethnicity	Age	Geographical location	Child’s type of epilepsy and associated medication (as identified by the parent)
1 [Child of P1]	Male	White [British]	7 years	Essex [England]	*Childhood absence epilepsy* Ethosuximide, BD [bis in die (twice per day)] (liquid)
2 [Child of P2]	Female	White [Other]	14 years	North Lanarkshire [Scotland]	*Partial frontal lobe* Temporary pause in epilepsy medication; Iron supplements
3 [Child of P3]	Female	White [British]	15 years	Derbyshire	*No diagnosis (possible temporal lobe)* Levetiracetam, BD (tablet)
4 [Child of P4]	Female	White [Irish]	9 years	West Midlands [England]	*Temporal lobe* Clobazam, OD [omni die (every day – once)] (tablet); Oxcarbazepine, BD (tablet)
5 [Child of P5]	Female	White [British]	7 years	West Midlands [England]	*Medically confirmed complex epilepsy diagnosis* Levetiracetam, BD (liquid); Buccal midazolam (rescue medication)

Table 3.1: Demographic data of the children and young people who were interviewed

3.3.1 Theme 1:
Everyday life: *“Sometimes I do get a bit annoyed”* [CYP4]

Whilst the taking of the epilepsy medication needed to be ‘fitted’ into everyday life, there was no suggestion from the younger participants that this impacted on their lives. They described the day-to-day activities that they were involved in with the zest and fun that would be expected from a child of this age, for example CYP1 excitedly described one of the recent games that he’d played at Beavers:

> *“We played toilet tag…So when somebody tags you they have to sit…like a toilet….Then somebody has to come and flush you.”* [CYP1]

The older participants were developing other social activities, and it was then that the medication could effect their lives:

> *“Yeah, sometimes I do get a bit annoyed because it’s just scary, it’s just like people saying that you need to have your medicine, it’s like make me feel upset because sometimes I feel like I don’t need medicine, because…yeah, it’s not my fault is it? Yeah, like say if I’ve gone to a party I’m like can I have my medicine before so we don’t have to leave…earlier… Because if I don’t take my medicine I have seizures… Because like it just gets on my nerves sometimes. If I don’t have it something will go wrong, I’ll have a seizure and that type of stuff.”* [CYP4]

> *"When I'm out places at clubs or like with my friends I always have to like…if it's time for me to take my medication my parents are quite paranoid so I always have to like text them to say that I've taken it and things like that… Sometimes just like when I'm out with friends I find a lot…like if I'm at a sleepover then I'll wake up really early because I'll be worried about like remembering to take it, but then I'll wake up like an hour too early to take it so I'm just like waiting."* [CYP3]

Another participant explained that if she was going to be out late, she would need to take her medication with her: *"So, like if I took it at eight o'clock in the morning, I'd have to take it at like eight o'clock at night."* [CYP2].

Three children/young people [CYP2; CYP3; CYP4] reported an impact on their school-life on occasions – this related to their epilepsy, rather than the medication. For example:

> *"Well sometimes say if I'm at school I feel dizzy and I have to come home. If it's just starting a little bit* [the convulsion] *I'm fine but if it gets worse then my dad has to pick me up."* [CYP4]
>
> *"So sometimes I kind of zone out and that can also be a sign of an absence seizure. So when I zone out you can't really tell if it's an absence or me just zoning out. So sometimes that can affect my learning because I'm obviously not paying the most attention."* [CYP2]
>
> *"Yes, so I'm in Year 11 and it can be quite stressful like thinking what if I'm in an exam and the medication doesn't work or something and I have a seizure. And then like if I have a seizure when I'm at home which happened I think like two weeks ago, I couldn't go into school the next day, so I missed a lot of work and that was quite stressful as well."* [CYP3]

3.3.2 Theme 2: Involvement in healthcare: *"How do you feel about this?"* [CYP2]

The children and young people reported that they normally met with a health professional approximately every six months (this was affirmed if a parent was present in the interview), but the period between appointments could be up to a year.

The perceptions of the children and young people about their health appointments varied; however, all the participants reported some involvement to a lesser or greater extent. Although the children young people said that the health professional (normally a doctor) asked them about their epilepsy, it was more usual for questions to be directed at the parent who was accompanying them:

> *"I don't know really how to explain it. They just really just ask me a couple of things and then they just mainly ask my mum things… Like what medicine I'm on and how I'm doing, any seizures I've had, how the medicine is working. That's really all they ask me… Yeah, they don't really say do you take it properly, they just say what medicine you are on, that's all they say."* [CYP4]
>
> *"Yeah. Like how often do you have them?* [Convulsions?] *Sometimes he's like* [name removed] *how tall are you?" Or* [name removed], *are you eating? Stuff like that."* [CYP1]

Interestingly, one participant initially reported that:

> *"Yeah, they kind of just discussed it amongst like my parents as well and then at the end they'd ask me like how do you feel about this, like if it was to happen would you be okay with it? That's what they asked me."* [CYP2]

However, on after further discussion, she said that:

> *"Yeah, I did, I felt quite involved. Too involved!... Yeah, my doctor asked me if I'd kind of like ever forgot it* [the medication]." [CYP2]

CYP3 was very positive about her contact with medical staff; she felt involved in decision-making and thought that it was because of her direct discussion with her doctor that her medication was recently revised:

> *"So I had one* [an appointment] *the other day where we discussed changing the medication and that's why I'm now on the new one as well as the one I was on before."* [CYP3]

3.3.3 Theme 3: Epilepsy medication: *"It's like a checklist in my head"* [CYP3]

All of the children and young people spoke in detail about their medication and how it impacted on their lives. As a result, this theme contains four subthemes, each of which will be discussed in turn:

- **Subtheme 1:**
  Knowledge of epilepsy medication: *I think it's really important to take it* [CYP3]
- **Subtheme 2:**
  Taking medication as prescribed: *"Sometimes I forget"* [CYP1]
- **Subtheme 3:**
  Medication reminders: *"I have, a pillbox type thing"* [CYP4]
- **Subtheme 4:**
  The medication: *"It tastes like rotten old eggs"* [CYP1]

3.3.3.1 Subtheme 1: Knowledge of epilepsy medication: *I think it's really important to take it* [CYP3]

All of the children and young people were aware of the importance of taking their medicines, with the younger ones using words such as *"very"* [CYP5] and explaining that they took it "*to help* [them] *get better"* [CYP1]. The older participants elaborated further, for example:

> *"Well I think it's really important to take it because if I don't take it then I will have a lot of relapse seizures and that would just not be good."* [CYP3]

Although they did not demonstrate insight into the specific nature of their medicines, such as the names or dosage, the children and young people were able to explain the 'best' way of taking it, when it was due and the amount that they needed:

> *"Seven o'clock in the morning and seven o'clock in the evening."* [CYP1]
>
> *"It's like before I go to school, just to make sure, and like maybe around eight o'clock in the evening."* [CYP4]
>
> "*Syringe to go in* [the bottle of medicine]…*And then daddy does the syringe to 2.6…Then he takes the bottle back down and takes it out."* [CYP5]
>
> *"10ml out of the bottle… She* [Mother] *does it, then I just put it in my mouth."* [CYP1]
>
> *"Yeah, so at the start I had the big tablet which was 200 mg and plus the little small one that was 100 mg and started taking tablets I had to switch it down to just three of the 100 mg because they were too big to take and then I just continued with that until I got my suspension… When I was young obviously I got prescribed the liquid, so I didn't really know what it meant then. Then like tablet form, I just figured it did the same thing, so I didn't really ask much*

> *questions on it, so I'm not really too sure on how it helps me, but I guess it does... I take 300 mg in the morning, 300 mg at night."* [CYP2]

Knowledge of their epilepsy was limited in the younger children, CYP1 referred to his convulsions as *"funny bunnies"* – this was because he felt funny and bunny rhymes with funny. The older participants had a little more insight about their diagnosis with one of them mentioning the literature that had been provided by Epilepsy Scotland [CYP2]. However, this did not include information about medication. This lack of information meant that she had a perception that:

> *"I think it was pretty important* [medication] *but I feel like it wouldn't have been as important for me as for other people, as mine* [epilepsy] *was quite like calmed down, like under control. I didn't have seizures as frequent as other people may, so it was important but then if I missed a dose it didn't have any effect."* [CYP2]

Another participant of a similar age [CYP3] also commented on *"not really"* understanding how her medication worked, but she said that she knew that the dosage prescribed was dependent on *"if you are taller or things like that"*; she had recently started on a new drug but was unable to recall its name.

3.3.3.2 Subtheme 2: Taking medication as prescribed: *"Sometimes I forget"* [CYP1]

Although there were instances when the younger children (CYP1, CYP4 and CYP5) reported that their medication had not been taken, this was reported as an infrequent occurrence as their parents assumed the main responsibility for administering it. When a dose was missed, it was normally due to a change in the daily routine, such as going out for the day or being in a rush:

> "*Sometimes I forget, sometimes…Yeah, we was like "All get in the car!"* [the family were going to catch a flight] *Get in the car, this hire car and then they were like "Did you have your medicine?" and then mum was like "No! No!" Then she run and got water, chug it down, chug, chug…. Actually I think we forgot it twice… twice, which is annoying."* [CYP1]
>
> *"Well if like we're in a rush to go to school sometimes it's my mum's fault or sometimes…because when it's my dad brings me to school and it's his fault. So it's not just my fault… Or she hasn't put my pills in the pillbox, that's her fault."* [CYP4]

The children explained that the situation was remedied as soon as the error was realised:

> *"But like say if I forgot, but it doesn't affect me if I have one bit of medicine a day. Say if I forgot in the morning, I would have it in the afternoon and I would still be fine…, I have my medicine like the other day and I had it and I thought, 'Oh my God, I didn't have my medicine yesterday', when it was actually today when I had it… If I have it in the morning or evening, I'll feel fine."* [CYP4]

Although it was more unusual for the younger children to miss their medication, they were aware of when it was due, commenting on the need to sometimes prompt those around them, especially if they were in a different environment, for example:

> *"At beaver camp I had to remind them"* [CYP1]

The two older participants (CYP2; CYP3) reported more frequent forgetfulness in terms of missing medication, CYP2 said that she was still reliant on her Dad to remind her. She commented that she could miss her medication approximately twice a month:

> *"Yeah I did forget to take the medication. It was sometimes quite frequently but then it didn't happen so often like after that, because obviously my dad had to continue to remind me and it was the same as the tablets I was on, like my iron, he had to remind me. Because I'd just wake up, I was tired, I was in a rush to get to school, I had to get ready, I was already out the door, so my brain didn't have really that much time to like think about what…I need to get this done, this done, because I didn't have time. So I'd just forget it out of like rush."* [CYP2]

Forgetting the medication meant that she needed to ask pupil support to contact her parents; this resulted in one of them either having to drive to the school, or if the call was later in the day, saying to her: *"Okay, that's fine, just take it at night"* [CYP2], this decision was based on the prescribed medication times (08.00 hours and 20.00 hours) and the feeling that taking the missed morning dose at, for example, 14.00 hours, would mean that the next one was due at 02.00 hours the following day.

Another participant of a similar age (CYP3) stated that:

> *"I do forget to take it sometimes, yeah. So, I usually take it at eight o'clock in the morning and the evening, because then there's 12 hours in between and it's quite easy to remember. But then like in the holidays we might move it to nine o'clock, so I get a bit more sleep in the morning, but then when I like go*

> *out or maybe we've changed it a little bit, the timings, I find it quite hard to remember when to take it."* [CYP3]

The parents of CYP3 would remind her to take the medication or, if necessary, they would drive to school with it. She added that when alone, or at an activity such as Scouts, there was no-one to jog her memory so she was more focussed on remembering to take the drugs; whereas at home, with others around her, she knew that someone would prompt her, if needs be.

There was no indication from any of the participants that they deliberately missed their medication or changed the dosage in any way; not taking the drugs was more associated with a busy lifestyle and simply 'forgetting':

> *"No, nothing would make me stop the medication if I wasn't told to not take it. No, because it was quite important to me to take the medication to make sure I was under control, so yeah, nothing would make me stop that."* [CYP2]

Despite this, CYP3 gave an example of when she had been undertaking the Duke of Edinburgh award; she was not allowed to carry her own medication, so whilst out on a hike she was unable to access it as the group leaders were holding it and were not in the immediate vicinity. This resulted her needing to contact the leaders and ask them to bring the medication to her; after this incident, CYP3 was able to keep her medication with her.

There was a concern expressed, even by those in the younger age range, about what might happen if the medicines were not taken:

> "*I normally feel a little bit worried…Because if I don't take it then...something bad is going to happen."* [CYP5]
>
> *"Yeah, I think it will make me feel better. But sometimes…sometimes I feel like it won't work because of what's happening. Like I say if I had a very big one* [convulsion] *and I've already had it, it won't help would it, kind of thing. If I have like…sometimes I have seizures, like I come from school but after I feel sick and I can't eat anything and sometimes I throw up. I have to have Calpol and that don't work either."* [CYP4]
>
> *"It's fine taking the medication, it's just like a bit stressful maybe if it doesn't work and things like that."* [CYP3]

3.3.3.3 Subtheme 3: **Medication reminders:** *"I have, a pillbox type thing"* [CYP4]

As a result of the worries that were vocalised, the children and young people described the strategies that they and their families used to ensure that they remembered to take their medicines – these included *"a diary"* [CYP5], *"mummy"* [CYP1], *"My Mum"* [CYP4], *"My Dad"* [CYP2]; *"routine…like a checklist in my head"* [CYP3].

Although the older children and young people were developing some independence with their medicines management, it was parents who played the most prominent, consistent and important role in relation to this. Three participants [CYP4; CYP2; CYP3] explained that they took their medication themselves, however, the interview later revealed that it was their parents who organised the drugs to facilitate this:

> *"So I have this little daily box that has little sections of my medicine and it's a pillbox. I open my pillbox for the morning, I have one big tablet, I have it with some water and I do the same thing, but I've got two tablets in the evening."* [CYP4]
>
> *"Usually me, I would take myself… Yeah, sometimes I would need my dad to remind me to give me the medication because I would forget."* [CYP2]
>
> *"Yeah I take it myself but my mum usually puts it in like labelled pots so I know which day and whether it's for the morning or the night."* [CYP3]

In addition, all the participants were asked if they had any advice that they could give to others of their age who were taking epilepsy medication, these are summarised in Table 3.2.

Child/young person	Advice
CYP1	• Take the medication with a drink: *"Maybe just do it with a glass of milk, pink milk…Or some water."*
CYP2	• Follow medical advice: *"I would just say keep following what your doctor says, listen to them."* • Use a reminder/alarm system: *"Set reminders to remind you so you don't forget it"* • Use a dosette box: *"I had this box that had the days of the week, so like if…I take it in between, like at lunchtime or stuff like that, in the afternoon, I would have a box and it said Monday, Tuesday, Wednesday, Thursday and the days of the week and it was all organised, so you could just look at the day of the week and take it which was easier."*
CYP3	• Labelling and use of medication pots: *"Maybe have like labelled pots as well because then you know what you need to take and you don't end up taking stuff you should take in the afternoon in the morning."* • Remembering yourself and having a routine: *"I've got into the routine now..it's like a checklist in my head…I just think like sometimes I don't…like I know a lot of people set alarms but I don't like setting alarms because I think it can be quite embarrassing if you are just out somewhere and then all of a sudden an alarm goes off and you have to get a drink and take your tablets, instead of just remembering it by yourself. And I know it's hard to remember it for some people but I just would find it quite embarrassing if I had to set an alarm."* • Support from parents: *"Definitely at the start my parents checking if I had taken it and things like that, but I think as you get more used to taking it they should maybe stop asking you so much, because then you learn how to be independent in taking your medicine."*
CYP4	• Ask parents to help with the medication administration: *"Tell their mum to give their medicine."* • Use a dosette box: *"Or maybe have like what I have, a pillbox type thing… And it has like the days of the week, so Monday, Tuesday, etc, all that type of stuff."* • Place medication in visible areas as an aide memoire: *"If they take a liquid just like put it out on the side where they usually go and then they could have it, like remember."*
CYP5	• Document the taking of the medication: "*You can write on a piece of paper"*

Table 3.2: Medication adherence advice

3.3.3.4 Subtheme 4:
The medication: *"It tastes like rotten old eggs"* [CYP1]

The children and young people talked about their medication, the main focus of the discussion was the taste and the physicality of taking it:

> *"It tastes funny…It tastes like rotten old eggs…Like somebody's cracked one open and then just went plop…Different medication…has tasted better. Even my vitamin tastes better than that. I mean who makes a medicine that tastes of rotten eggs? Please tell me. I don't know… So milk before I take it and after I take it."* [CYP1]

> *"Just when I swallow the pill, sometimes it gets stuck... Just get more water… it just tastes weird… I have tablets…. the one's big and the little one tastes a bit more weird… When I was first having my tablet because of how big they are we had to like snap them in half, the big ones, so I could have it and then it actually did work. And then I got the courage to keep on having the big ones and I got braver and then I had it."* [CYP4]

To help with the taste, the children and young people explained how they, for example, had a drink before and afterwards. For others, the taking of the medication did not present any problems: *I don't mind the taste of it or anything like that and it's fine to swallow* [CYP3].

Only one of the children and young people reported any side effects from the medication; the other participants' concerns were more related to the form that the drug came in and the taste. However, CYP3 said that she had encountered sleep problems, feeling tired as well as mood changes. These symptoms had been discussed with her doctor and had resulted in a revision of her prescribed medication as well as a drug to help combat some of the problems (this was all very recent, so the outcome was yet to be determined).

The younger children said that they did not mind taking the medication, but CYP5 had also been diagnosed with autism so this condition could impact on her anxiety levels as well as her emotions, meaning that she then resisted taking the drugs. One of the other children [CYP4] said that the convulsions themselves could mean that she was unable to take her medication, for example:

> *"The other day…no, not the other day. Like a couple of times when I've had a seizure and I've had to go in bed…I can't walk type of thing. So I don't want it and I'm just scared to take it because of having a seizure, that would stop me from having my medicine… And, yeah, when I've been vomiting."* [CYP4]

3.3.4 Summary of findings from the interviews with children and young people

In summary, the children and young people provided an invaluable insight into their experiences of taking epilepsy medication. The key findings revealed that:

- The children and young people's knowledge of their epilepsy medication and how it works was very limited.
- A change in the normal day-to-day routine had the potential to impact on medication adherence.
- All participants reported that parental support played a substantive role in medication administration and ensuring that the prescribed regime was adhered to.
- The involvement of the child/young person in hospital consultations and appointments was varied indicating an inconsistent approach in this respect.
- None of the children/young people had had any involvement with organisations or charities (they were specifically asked a question about this).

3.4 Findings from the interviews with parents

Section 3.4 presents the findings from the interviews that were conducted with the 16 parents (all of whom had a son or daughter with a diagnosis of epilepsy; no parent had more than one child with the condition). As with the themes from the interviews with the children and young people, the title of each identifies its central tenet, but a quote from one of the participants is used to capture each of the 5 themes from their viewpoint. The themes are listed below, Epilepsy medication regimes: *"We've got our routines"* [P16] generated the most data and therefore led to the development of five subthemes. The first four themes will initially be presented to provide context to the lives of parents who have a child with epilepsy; the focus will then move more specifically to medication:

- **Theme 1:**
  Feeling anxious: *"It definitely has an emotional impact"* [P15]
- **Theme 2:**
  Gaining information: *"When it's your child, you'll become an expert"* [P7]
- **Theme 3:**
  Parental involvement in healthcare decisions: *"A hundred per cent involved"* [P4]
- **Theme 4:**
  Everyday life: *"We want him to have exactly the same opportunities"* [P1]
- **Theme 5:**
  Epilepsy medication regimes: *"We've got our routines"* [P16]
    - **Subtheme 1:**
      Gaining advice, information and support: *"We can email or phone"* [P12]
    - **Subtheme 2:**
      Acquiring the medication: *"Make sure that I don't run out"* [P8]
    - **Subtheme 3:**
      Administration of medication: *"It's always down to me"* [P3]
    - **Subtheme 4:**
      Side-effects: *"We have had some issues"* [P5]
    - **Subtheme 5:**
      Sometimes mistakes happen: *"We have forgot a few times"* [P6]

Table 3.3 provides further details about the parents, whose children were aged between 1-16 years. The participants' postcodes were used to identify the English Index of Multiple Deprivation Decile [EIMDD] or the Scottish Index of Multiple Deprivation Decile [SIMDD]; however, it should be noted that these figures are calculated differently for each nation, therefore it is not possible to do a formal comparison between them (for further details, please see: Ministry of Housing, Communities and Local Government, 2019 [English data]; National Services Scotland, 2022 [Scottish data]). Please note that a decile of 1 = most deprived areas and a decile of 10 = least deprived areas. Participant representation was from a wide geographical area and encompassed socioeconomic diversity (Table 3.3).

P Identifier	Gender	Ethnicity	Geographical location	EIMDD/ SIMDD	Age of child	Child's type of epilepsy and associated medication (as identified by the parent)
1 [Parent of CYP1]	Female	White [British]	Essex [England]	10 [EIMDD]	7 years	*Childhood absence epilepsy* Ethosuximide, BD [bis in die (twice per day)] (liquid)
2 [Parent of CYP2]	Female	White [Other]	North Lanarkshire [Scotland]	5 [SIMDD]	14 years	*Partial frontal lobe* Temporary pause in epilepsy medication; Iron supplements
3 [Parent of CYP3]	Female	White [British]	Derbyshire	9 [EIMDD]	15 years	*No diagnosis (possible temporal lobe)* Levetiracetam, BD (tablet)
4 [Parent of CYP4]	Female	White [Irish]	West Midlands [England]	1 [EIMDD]	9 years	*Temporal lobe* Clobazam, OD [omni die (every day – once)] (tablet); Oxcarbazepine, BD (tablet)
5 [Parent of CYP5]	Female	White [British]	West Midlands [England]	4 [EIMDD]	7 years	*Medically confirmed complex epilepsy diagnosis* Levetiracetam, BD (liquid); Buccal midazolam (rescue medication)
6	Female	White [British]	South Yorkshire [England]	9 [EIMDD]	1 year	*Tonic* Tetrazepam, BD (liquid); Topiramate, BD (liquid)
7	Female	White [British]	Oxfordshire [England]	10 [EIMDD]	33 months	*Generalised prolonged seizure, suggestion of focal onset* Sodium valproate, BD (liquid)
8	Female	White [British]	Kent [England]	7 [EIMDD]	3 years	*Medically confirmed complex epilepsy diagnosis* Clobazam, BD (liquid); Lamotrigine, BD (tablet); Fenabalb, BD (liquid)
9	Female	White [British]	Buckinghamshire [England]	10 [EIMDD]	14 years	*Medically confirmed complex epilepsy diagnosis* Sodium valproate, BD (tablet); Brivaracetam, 75mgs BD; Melatonin, OD
10	Female	White [Other]	Manchester [England]	1 [EIMDD]	15 years	*Absence and tonic clonic seizures* Lamotrigine, BD (tablet)
11	Female	White [British]	Exeter [England]	9 [EIMDD]	10 years	*Medically confirmed complex epilepsy diagnosis* Rufinamide, BD (tablet); Clobazam, BD (liquid); Topiramate, BD (granules); Cannabidiol, BD (liquid); Buccal midazolam (rescue)
12	Female	White [British]	Yorkshire [England]	10 [EIMDD]	16 years	*Focal with secondary generalised seizures* [Initially diagnosed at 10 years, weaned off mediation and then re-diagnosed at 16 years] Lamotrigine, BD (tablet); Levetiracetam, BD (tablet)
13	Female	White [British]	Sussex [England]	6 [EIMDD]	12 years	*Focal; absence seizures* Sodium valproate, BD (liquid)
14	Female	White [British]	Cambridgeshire [England]	7 [EIMDD]	13 years	*Focal, tonic clonic, atonic and absence seizures* Topiramate, BD (tablet); Lamotrigine, OD (tablet); Clobazam, OD (liquid)
15	Female	White [British]	Hertfordshire [England]	6 [EIMDD]	11 years	*Focal; absence seizures* Lamotrigine, BD (tablet); Levetiracetam, BD (tablet)
16	Female	White [British]	Norfolk [England]	7 [EIMDD]	11 years	*Macrocephaly-capillary malformation; atypical, myoclonic with other types of seizures, including grand mal* Sodium valproate, BD (sprinkles); Topiramate, BD (sprinkles); Clonazepam, BD and PRN [PRN = pro re nata (as required)] (liquid); Diazepam, PRN (rectal)

Table 3.3: Parent's demographic data

3.4.1 Theme 1: Feeling anxious: *“It definitely has an emotional impact”* [P15]

As can be seen from Table 3.3, the participants’ children had a range of epilepsy diagnoses as well as a breadth of prescribed drugs; the complexity of parental experiences varied, but there were many commonalities, especially in terms of medication administration and adherence. As a result of their experiences, and perhaps not surprisingly, all the participants reported that they had felt anxious at some point on their child’s epilepsy journey.

The initial diagnosis of epilepsy had a substantive impact on parents, and this had resulted in increased anxiety levels as well as a need to have a constant vigilance in terms of their child’s health and wellbeing; example quotes that illustrate this are provided in Table 3.4.

“When she was first diagnosed, I found that ridiculously hard and my GP referred me for talking therapy.” [P3]

“It [the diagnosis] *was just so overwhelming…I don’t mind telling people, I had to go on anxiety medication, it’s really affected my mental health…I actually had time out of the NHS because I couldn’t go to work.”* [P4]

“At the time when she was prescribed it [and epilepsy diagnosed]…*I have like undiagnosed PTSD from that time because it was so horrendous.”* [P7]

“I do feel quite anxious and stressed. Obviously, we’ve only recently got the diagnosis of the gene PCHD19, so it’s kind of getting my head around that” [P8]

“I had a pre-existing anxiety condition and that has definitely impacted on that and I’ve been on and off antidepressants virtually for anxiety since…My husband is also on sertraline, so he has a diagnosed mental health condition.” [P11]

“I thought I was going to go mad when he first got diagnosed.” [P13]

“It definitely has an emotional impact on me and my husband” [P15]

The son of P16 had a number of complex needs, but she commented that: *“The only thing we would want to change is the epilepsy that’s the only thing we would kind of want to take away, everything else makes him who he is… But I think for us the biggest impact that epilepsy has on our homelife is that constant fight or flight is up here, that anxiety.”* [P16]

Table 3.4: Parents’ comments about the impact of an epilepsy diagnosis

P9 was the only parent who mentioned the impact of their child's diagnosis on their personal finances, this being because her son had a complex epilepsy profile with night seizures that resulted in frequent bedding changes and disposable pants.

Many of the children had been diagnosed with epilepsy at a very young age, but for others, it was later in childhood (as in the case of the daughter of P15 who nine years was old). In this instance, parents reported the impact on their child as well as themselves; it appeared to be more substantive with the child not fully understanding why this had happened, or the subsequent consequences for their life (such as medication and day-to-day activities). P3 reiterated this point saying that her 15 year-old daughter asked *"Why me?"*; she did not feel that her daughter had *"come to terms with the fact that she's got epilepsy"* and felt that she would benefit from some support, but was struggling to locate something appropriate (for example, Young Epilepsy had offered online sessions, but her daughter wanted face-to-face options).

Parents had seen their children have seizures and needed to manage these on a day-to-day basis, *"I think we feel like nobody really quite understands what you have to go through"* [P14]. Some of these experiences had been very distressing and had left their mark: *"So I'm traumatised for ever"* [P2]. These situations also impacted on, for example, medication reviews and not always fully appreciating why a drug regime was being changed when there was still a fear of more seizures. As the epilepsy journey progressed other issues arose so in essence, *"you worry all of the time"* [P9]. P10 spoke of when her daughter was undertaking her Duke of Edinburgh award and she had her first tonic-clonic seizure, describing this as a *"really hideous experience."*

Apart from the epilepsy diagnosis, parents described anxiety in relation to two other key areas: Medication and what the future might hold. In relation to the future [P3; P4; P6; P7; P8; P9; P12; P14; P15; P16], concerns were particularly expressed about the possible impact of epilepsy on their child's prognosis and their development (physical, cognitive and emotional). All the participants expressed some anxiety (to a lesser or greater extent) about their child's medication. This included: Either potential or actual side-effects;

missing the medication; administration of medication within a school environment and/or the school's support with it, and whether the child would continue to take the medication as they became older.

Epilepsy, and the associated anxiety could impact on all aspects of the family's lives. For example, P2 had become more worried about her teenage daughter's health and wellbeing when her medication had been stopped by the consultant. This had meant that her daughter had lost some of her independence and the parents had become more anxious and vigilant, ensuring that they were nearby during activities such as when their daughter was shopping or in her drama class: *"one of us is sat in the car park….there's not many places she goes when we're not far away"* [P2]. P9 explained the long and complex journey that the family had had with her son's epilepsy, from the age of three to 14 years; this included managing his seizures as well as a range of associated medication with the result that it had all *"made a big impact on us"* [P9].

Many of the parents felt that the implications, and associated anxiety of the epilepsy diagnosis, were on-going with little light at the end of the tunnel, for example:

> *"The tonic-clonics, he has them maybe two to three times a week, often as he is waking in the morning which means that he then can't go to school on time. It's basically it's meant really that I have to give up work so that I can be around for him…also if he has a seizure at school I have to be available to go and pick him up as well….He's had atonics at school where he falls and he smashes his face in, he's lost teeth. So, I just need to be around for him, but also I think more than that…You can struggle quite a lot psychologically in that it affects your emotions…just it's quite stressful… But one of the first things the doctor says to you when your child starts having these seizures is to talk to you about like SUDEP* [Sudden unexpected death in epilepsy] *and things like that, which is so scary."* [P14]

Although anxiety always seemed to be prevalent in parents' lives, living with epilepsy over a number of years could help them to adjust to the situation:

> *"There is obviously a sense of anxiety because of the dangerous nature of the seizures really and the fact that they cause her to stop breathing and the fact that*

> *they require the administration of emergency medication and mouth to mouth….but I feel like it's been a number of years now, it's just something that at the moment at least, is factored into our daily routine. Touch wood the meds are doing their job… but actually it's manageable and it doesn't stop her doing anything that she wants to do."* [P5]
>
> *"It has had almost no effect now for the last year…there was a few months where…it was in the forefront of our minds but she didn't have any seizures, so she is totally seizure free for the last year-ish."* [P10]
>
> *"When he first got diagnosed, I was panicking because I don't know how we're going to do this twice a day forever… But actually, like with everything with him, it becomes a routine and as long as that routine doesn't change it's fine."* [P13]

Feeling anxious also had an impact on some of their child's activities. For example, two parents [P2; P4] mentioned sleepovers - this was not something that their child would normally participate in as they had concern for their wellbeing, but, in addition, they did not want to pass responsibility to another parent. If their children did have sleepovers, they were few and far between or with people who the parents knew fully understood their child's situation.

Despite the impact that epilepsy could have on both the child and their family's lives, in the main, parents expressed positivity:

> *"Both of our children are completely amazing and joyful, and she brings us so much joy, she's absolutely hilarious. And there are many…for all of the horrific moments, there are times where we are so joyful to an extent that I don't believe perhaps other families would be, because we appreciate just the smallest things; if she says the right word or if she's just giggling, it's amazing, it brings us a lot of joy."* [P11]

P11 went on to explain that despite the challenges that they had faced, they were very grateful for the support that they had received and for having the skills to be able *"to advocate"* and *"navigate a very complex system"*. P11 spoke of the strategies that her and her husband employed to enhance their own physical and mental wellbeing (such as exercise and counselling), being appreciative of the infrastructure as well as their financial situation that facilitated some of this.

The support that participants received from their family (in particular, their partners), friends, carers and school was pivotal to the lowering of anxiety levels and the maintenance of day-to-day life, especially when a child had complex health needs:

> *"My mum comes every Tuesday and Monday evening. The short breaks package we get from* [name of area removed] *County Council, it took a long time to get there but it's actually a really good package, so we get a personal assistant on every other Sunday and a Tuesday afternoon as well which takes that pressure off a little bit…it's that family network that makes it seem a lot less stressful than it could potentially be."* [P16]

To summarise, parents reported that having a child with an epilepsy diagnosis could be challenging and anxiety-provoking; however, participants were wholly committed to their child's health and wellbeing, feeling that with the appropriate support, life could be very positive.

3.4.2 Theme 2: Gaining information: *"When it's your child, you'll become an expert"* [P7]

Parents had a thirst for knowledge that was related to the needs of their own child and/or their specific diagnosis. Several participants had drawn on the information provided by charities (sometimes these were specific to the type of epilepsy, such as in the case of P5 whose child had a medically confirmed complex epilepsy diagnosis), in other instances they were more generic and included Epilepsy Action [P1; P2; P4; P10; P11; P12; P14; P16]; Epilepsy Society [P13; P14]; Young Epilepsy [P3; P9; P13; P15]; Epilepsy Scotland [P2]; Parents and Carers of Children with Epilepsy UK [P7]. Overall, parents commented extremely positively on the support offered by charities – this could be in the form of telephone conversations, web resources or literature that was physically sent to them. A typical comment was made by P15:

> *"Young Epilepsy…were really supportive and they have like a specialist nurse and they have people that you can talk to and they can give you their experiences and what they've tried and they were probably more valuable in that support and advice than her actual hospital team."* [P15]

Some parents, whose children had particularly rare or complex diagnoses, sought advice from very specific charities and/or organisations; for example, P6 and P16 had both contacted Daisy Garland and P6 had also been in touch with Matthew's Friends via Facebook; both parents had done so in reference to their sons' ketogenic diets:

> *"As soon as the hospital tells them that you're about to go on it they* [Daisy Garland] *send you this massive pack with keto to try, tea towels, they do all these badges and stickers that say I can only food from home and all of it was free, just this huge welcome pack. It had information in there on SUDEP* [Sudden Unexpected Death in Epilepsy] *as well, that was the first time I'd heard of SUDEP but I thought actually my child is 11, why is this the first time I've kind of heard of that as well?... And they were the first charity that do stuff for parents so they do free well-being training courses, they do well-being events away that you can sign up to and you can go away with other mums or dads to like a well-being retreat."* [P16]

P16 had also contacted the macrocephaly-capillary malformation charity who had provided support via both online and face-to-face events.

More commonly, parents had joined relevant Facebook groups, these primarily being used for peer support; Table 3.5 provides some example comments.

"I'm in a Facebook group for parents of children with epilepsy and I'd found out through that group I think it was first about this newer version that worked the same way as levetiracetam and I'd mentioned that to the clinician." [P3]
"I'm like on a few parent groups on Facebook, one is like an international one and one is a UK-based one. I would never ask for medical advice or dosage or anything from a parent. I have asked in the past but it's more like how did your child do side-effects wise on this medication and how did it affect their seizures?...If like 10 people said, "Oh it gave my kid a rash on their back", then I know to keep an eye on a rash on the back." [P4]
"The charity has a Facebook group of parents with children and so I certainly…Keppra [levetiracetam] *is quite well-known for causing mood swings and we had some concern at the outset about that, although I have to say that settled down very quickly. But certainly, around things like that, side-effects, whether there was anything to mitigate those side-effects, whether it had been a successful medication for other people, whether their children also struggled with the taste of it."* [P5]
"I did get chatting to a mum on there through messenger which was kind of nice because it was like we both related to the same type of epilepsy...The Facebook pages have been the biggest help for me because it's people that relate to the same things as you and it's parents as well, it's not like it's the children that's got epilepsy. Because on a Facebook page I found out that the charity HOPE does the anti-suffocation pillows, I've applied for one and they're sending one, but if it weren't for someone on the page, I wouldn't have known anything about it." [P8]
"I've looked on like the Facebook groups and what people are saying about ethosuximide…they were like, 'Oh yeah, it is quite common that they have a lot of nausea'…So I think if I was worried about side-effects or other things with medication, I would probably also be interested in what those…epilepsy parents' groups have to say. And I know you take those things with a grain of salt but often there is a lot of information around that isn't necessarily part of the evidence-based stuff that they can tell you…sometimes it's useful to have your eye out just for something." [P10]
"There is a lot of discussion that goes on on Facebook forums for this. There's a big one called Parents and Carers of Children with Epilepsy UK, I think there's about 20,000 people in that. And I regularly see people post saying, "We've just been given this medication, what are people's experiences?" [P11]
"I think sometimes they can be helpful to some extent I think on some kind of knowledge. But I think it's still important to remember to sort of speak to the professionals really to get the right information." [P14]

Table 3.5: Parents' comments about their usage of Facebook

Parents could find the Facebook groups useful, but there was a general agreement that it could also lead to feeling *"a* little *bit misled"* [P10] and *"that I was actually scaring myself about the medications"* [P11] as different families had a range of experiences that were based on individual circumstances.

P13 mentioned that she spoke to parents at her son's school, this was a similar strategy to those participants who accessed Facebook groups:

> *"I speak to a few parents at school whose children have got some form of epilepsy or are having seizures just as part of their rare genetic condition or that kind of thing. Yeah, I found that much more helpful and reassuring in a way than speaking to a professional about it, because… but they just haven't got the time to explain it in great detail and actually sometimes explaining it really quickly makes it even more confusing."* [P13]

The use of "Google" was commented on by several parents, P7 explained that:

> *"Dr Google can be a* blessing *and a curse at the same time… I read so much the neurologist asked me if I was a neurologist, I got that bad"* [P7]
>
> *"I'm constantly Googling things but also, I try to be very careful because I don't want to see obviously bad stories and stuff like that. So, yeah, I suppose it's kind of knowing where to go for the right support and who to reach out to."* [P8]

Parents such as P7 and P8 also spoke of *"research that I've done myself on the medication"* [P8], the location and accuracy of this was not altogether clear. Participants did not generally feel that they had been directed to particular sources of information, although they sometimes mentioned (for example, P5) that they had been given a wealth of resources when their child received an initial epilepsy diagnosis, but that they had had little since.

One parent [P9], who was a health professional, specifically mentioned seeking information from the *"*BNF [British National Formulary]…*just to look up medication or NICE* [National Institute for Health and Care Excellence] *guidance as well"*; P3 was a researcher and was "*always doing PubMed searches…that I think might be relevant"* and P11 had looked to see if there was any NICE guidance in relation to cannabidiol – however, the use of these type of resources was not commonplace.

The parents echoed the information provided by the children and young people in their interviews insomuch as the appointments with the consultant were normally every six months although, of course, this could vary if, for example, there was a change in medication, the control of the epilepsy was more complicated or further investigations were required. P6 mentioned that her son had started a ketogenic diet, so this necessitated a *“bit more monitoring”* [P6]. Although parents used some of the ‘jargon’ and abbreviations associated with epilepsy such as AEDs (anti-epileptic drugs) [P6]; ‘phenobarb’ (phenobarbitone) [P8]; VNS (vagal nerve stimulator) [P9], their specific knowledge of these was limited.

Overall, it was felt that going directly to the consultant who was responsible for the care and management of their child was the best option, where possible: *“I’m not on any forums or anything like that, I just go straight to Dr* [Consultant’s name removed]” [P1].

3.4.3 Theme3: Parental involvement in healthcare decisions: *“A hundred per cent involved”* [P4]

Parents described how they had been involved in their child’s healthcare and the associated decisions; whilst there were a small number of exceptions, most participants were very positive about their experiences, with the quotes in Table 3.6 epitomising the overall comments.

“A hundred per cent involved.” [P4]
“I think they are being led by what we say as well, or we have said before.” [P9]
“Definitely, yeah.” [P14]
“Absolutely. We have a brilliant team.” [P11]
“We definitely feel supported by the consultant, and he makes it clear his plan of action, so yeah, I think we’re really lucky with that.” [P12]

Table 3.6: Parents’ comments about their involvement in healthcare decisions

Many parents had built a good rapport with both the consultant who was responsible for their child’s care (two being on first name terms) and the epilepsy nurses; they gave specific examples of discussions that had taken place about their child’s overall management and medication (Table 3.7).

"'Are you happy to leave the medication in place, given that she's been seizure-free for two years, three years, whatever', and we say, 'Yes', and she says, 'that's absolutely fine.'" [P5] *"So like we had a meeting the other week, his keto meeting and she* [consultant] *was like, 'Oh we can up his medication', but she didn't really say much about it and then we got the clinic letter and she was like, 'I advise we up it to this', to which at that point we were like he was like kind of comfortable and he was sleeping. So, I rang the epilepsy nurse, I was like, 'Actually can we hold off a bit? We don't want to do it.' So we didn't at that time, but then a few weeks later we got his EEG results back and it has worsened a little bit, so then we did up it based on those results"* [P6] *"I said 'I want to go up on this one and I want to add that one and I go up on that one and if that doesn't work then we'll change.' At least we know, because she's tolerating these ones with no side-effects, I would rather optimise these ones than change on to something where she might have side-effects. And they were very…very happy to accept my proposal."* [P15]

Table 3.7: Parent examples of discussions about their child's care and management

The majority of participants reported that they felt comfortable to contact professionals via, for example, email or WhatsApp (the latter being in relation to the epilepsy nurse[s]):

> *"I can send a message, or it will get passed back to* [consultant's name removed] *and he will call me himself, it will never be a secretary, and he will apologise, he will tell me the next steps that they're going to do… I can call his secretary and within 24 hours I will have* [consultant's name removed] *on the phone going, 'We've got option A, we've got option B, you know him best and you are there, which one do you think we should go with?'"* [P16]

P14 and P6 also referred to the uploading of videos of their son's seizures, this facilitated a virtual dialogue about the child's situation:

> *"So when I'd uploaded the video it was…it was probably a couple of days later the consultant gave me a ring and went through it with me and we had a discussion and at those points we always just look at what medication he is on and if she* [the consultant] *thinks that there's something else that could be added."* [P14]

In the main, there was a negotiation between the consultant and the parent in terms of healthcare decisions; however, sometimes, a parent felt very differently to the consultant and wanted to go against their suggestion:

> *"I'm fighting to keep my daughter on the medication because they* [the consultant] *want to do the wean in April…I don't think that's a good idea…I don't have any concerns because she's been on it 20 months and her development has been on track...All of her seizures have been to do with illness and a child starts to regulate*

> *their own body temperature at the age of six, so I feel it would be beneficial to keep her on the medication until she can regulate her own body temperature….Since she's been on the medication she hasn't had any more seizures, so it's like a no-brainer in my head"* [P7].

P7 went on to explain that the consultant neurologist had told her that children do not regulate their body temperatures until they're six years of age so, based on this, she felt that her daughter should remain on the epilepsy drugs until at least then. As another illustration, P16 explained:

> *"She* [the consultant] *wanted to up a medication that affected* [child's name removed] *behaviour, I didn't want her to up it. So, she told me it makes no difference to behaviour whatsoever, I said, 'I've read the studies, and it does, so I would really like it if we could look at something else other than raising it.' She said, 'You either put it up or we discharge you', and bear in mind I've got a severely epileptic child. So, I said, 'Discharge me then and then we will see how that goes, that you've randomly discharged a child with really high needs.'"* [P16]

Following her experience, the son of P16 was admitted to hospital and had then come under the care of another consultant, since then: *"his* [son of P16] *neurology care since then has been absolutely top notch"*. P2 was one of a small number of parents who felt that their child's care and management was being influenced by finances (please also refer to Section 3.4.5.2); she felt that her daughter's medication had been stopped as a money saving strategy:

> *"Save money prescribing…but the reality is we weren't wasting any medication, she was taking it."* [P2]

P2 felt that she had seen the impact of the lack of medication on her daughter's school attendance which she said had dropped from 94% to 80%. P2 thought that her discussions with the consultant about her daughter's epilepsy drugs had not been listened to and that he had taken her daughter's views [CYP2 agreed about ceasing the medication] into account above her own: *"I'm like oh my goodness, that's not helpful when you're a parent"* [P2].

P7 and P2 both felt that they had had experience of not being fully involved in healthcare decision-making processes. The interview transcripts indicated that there could be a fine line for the health professional to tread (in particular the consultant) in order to support involvement in decision-making processes whilst also maintaining the best interests of the child or young person in their care.

Some parents vocalised that they were very aware that their child was growing and developing and needed to participate in the decisions surrounding their epilepsy management; P9 said that she wanted her son to *“feel empowered and take ownership as well as they grow and develop…*he’s *got to take maybe control of that at some point.”* [P9]; P3 said that she was *“trying to work on that, because I do want her…obviously she’s going to be 16 next month, she needs to start speaking for herself a bit more.”* [P3]

Whilst most parents felt that health professionals did try to include (when possible) their child in decision-making conversations, occasionally, there were comments such as: *“The clinician unfortunately doesn’t often talk to her, she shuts down in the appointments because she doesn’t want to acknowledge it, when I say to her ‘Have you got any questions?’ but they often quite talk to me, they don’t…they talk to us together.”* [P15]

In essence, it was evident that all participants very much wanted to be involved in their child’s healthcare decisions; most parents reported positive experiences of this and even the small number who did not, were able to give examples of how they had vocalised their views.

3.4.4 Theme 4:
Everyday life: *“We want him to have exactly the same opportunities”* [P1]

There was no doubt that the everyday lives of parents and their families was impacted by their child’s epilepsy:

> *"There's some contemporaries that* [child's name removed]*…went to pre-school with and what a different life them and their families are having to what we have."* [P14]
>
> *"She should be going out and about with her friends but because of her safety, I constantly feel like I'm saying no to things that she should be doing at her age but isn't because she can't go out and cross roads because of her safety… She just started senior school so she's having a little bit more…freedom which she is enjoying, but it's definitely more restricted than I think it would be if I had another child this age without epilepsy. I constantly feel like I'm just worrying about her safety all the time… I don't think I've ever seen a day where she's not had a seizure."* [P15]
>
> *"Our entire life revolves around our child's epilepsy. She has a really severe form of epilepsy* [medically confirmed complex epilepsy diagnosis removed]*….Over the years we've tried about 10 different medications, none of them have controlled her seizures. She is currently 10 years old, had her first seizure at 18 months, she has a vagus nerve stimulator and is on the ketogenic diet…at one point she was having about 700 absence and drop seizures a day."* [P11]

Despite the impact on their lives, participants spoke about wanting their child to have as normal as life as possible and did not want the diagnosis of epilepsy to interfere with their child's lifestyle or the opportunities offered to them, Table 3.8 provides some typical and illustrative quotes.

"All you want is your child to be normal." [P15]
"She does go out and she still does lots of activities, she does karate once a week, she goes to a Scout group, she does some after-school clubs." [P3]
"We don't let it impact us in terms of we want him to have exactly the same opportunities as all his friends… he takes part in everything and we make sure that he does everything." [P1]
"We are very keen that she does everything and has exactly the same opportunities that her brothers do. And so she has swimming lessons like the boys did, but she just has one-to-one swimming lessons just in case. She will go horse riding like the boys went horse riding… but again she will do that in a one-to-one environment rather than in a group. So it's just those kind of very small adaptations that they probably aren't very aware of." [P5]
"She's currently not controlled but we manage as a family, she is our only child as well, so we do manage and she's involved in football and she does all her school activities, she does gymnastics, so we very much try to keep her life as normal as possible." [P4]
"She loves open water swimming; she loves climbing up very high things." [P10]
"So our eldest is the one who has epilepsy, so he loves kind of caving and climbing, mountain biking and that kind of thing, he regularly does that every Tuesday evening and he plays tennis on other evenings and I would say the way it impacts…and paper round in the mornings, every morning." [P12]

Table 3.8: Parents' comments about how they strive to maintain a 'normal' life for their child

As a result of the effect that their child's epilepsy could have on their lives, careful planning of day-to-day activities was required so that parents could be readily available, should their son or daughter need them; P2 gave the example of paying *"£18 quid to park* [near to work] *because it's close so that if I need to leave in a hurry"*. There was a feeling that the children/young people were not aware of this and the fact that "*everything is planned around it* [the epilepsy]" [P2].

Parents described how they organised everyday life to try to ensure that the epilepsy medication was still given appropriately; this could be taking medication with them or returning home early from an event. in addition, there was a fear that they could run out of drugs, so this required them to think ahead. Participants explained the logistics of, for example, of going out for the day or on holiday and the associated medication arrangements. P10 said that their recent holiday (of a few weeks duration) had involved considerable forward planning including *"several phone calls and like begging the GP to give us extra meds which felt really upsetting."* P1 explained how they collated everything before travelling so that they had the consultant's letter with the medication always at their side; in the hotel, the drugs were locked in the safe as it's *“almost more important than our passports”* [P1]. The travel also meant that the family chose to go to areas where they knew there was good healthcare and where they could access appropriate services. P10 spoke about her teenage daughter and the need to be prepared in case “s*he spontaneously wanted to stay overnight somewhere, but I think she's always got a packet* [medication] *in her bag”* [P10]. Table 3.9 provides further quotes from parents to illustrate the planning and organisation that they undertook on an everyday basis.

“Well back in February that we had to take it on a plane and…you have to give all the information don't you…and you've got a worry that what happens if it goes missing…we take it in the hand luggage… what happens if you're in another country and you can't get hold of that or different languages.” [P1]
“We would sit and carefully plan how we would nudge it [the epilepsy medication] *forward with the time difference, so we'd nudge it forward an hour, an hour, an hour, an hour. We became dab hands at that.”* [P2]
“So if we're booking a holiday are we within an hour's drive of a hospital, just in case. It's those sorts of things.” [P5]
“We've been fortunate we've been able to fly three times this year so we have to take a cool bag, take it through customs, etc, and there's always that anxiety that it might not stay cold, so we have to have like ice packs, etc. And then when you get to the hotel or wherever you're going you have to kind of make sure there's a fridge.” [P6]
“Like what if I forget to take it with me or if the car breaks down, but also the medication, if it's a really hot day you don't want to leave it in a hot car…. I've always got a couple of spare bottles…better safe than sorry.” [P7]
“We went to Spain in July and there was a time difference so I made sure we done it at the time that it would be in England….…the epilepsy nurse done a letter for us listing her medications, the dosage and everything, that we took for security and then obviously the bottles just got checked and stuff… we made sure we was at quite a tourist area, there was a local hospital and luckily we didn't need it, but just preparing for if anything was to happen.” [P8]
“We can't go abroad…when we go on holiday now…we have it in a big tub, like an Ikea tub, I used to take it all out and put it in a bag. Now so we don't forget anything I get cling film and wrap it around the tub so the whole entire medication cabby comes away with us. And it's things like as well remembering to bring syringes.” [P11]

Table 3.9: Parents' comments about how they plan everyday activities

It was clear that the everyday management of their child's epilepsy and associated medication was not without its challenges, but it was acknowledged that it helped children to live the best quality of life possible: *“So he* still *had the best time in both holidays but the difference is he could really, truly join in and do everything he wanted and it's the medication that enabled him to do that.”* [P1]

A big part of everyday life for the participants' children was school; however, parents reported very different experiences in terms of the support provided, some felt that the school was lacking in knowledge and did not really understand the child's epilepsy diagnosis, thus meaning that decisions about what the child could and could not participate in were not fully informed:

> *"*[The school] *wanted to stop him climbing and to stop him doing bits and pieces and we put a stop to that, for want of a better word. We were like actually there is no reason that he can't join in all of these elements"* [P1]
>
> *"The school didn't seem to have a clue if I'm really honest with you about it. I've written his care plan in school because there is no one else to write it. Being that it's quite common, they say childhood absence epilepsy, the school hadn't seen it before, hadn't heard of it before and were quite unprepared"* [P1]
>
> *"It's a constant battle with the school and I do hope that the day will come when actually schools understand"* [P2]

Whilst school could be a *"constant worry for parents"* [P8], many (including P8) felt that the staff had been very supportive, in terms of managing their child's epilepsy and in contacting parents if they felt it was necessary:

> *"If they are a little bit unsure, like say she's acting a bit out of character they phone straightaway and say, "What do you think of this?"* [P8]
>
> *"The school are really great, really supportive and are confident to deal with seizures and I'm confident they can"* [P4]

P5 explained that not only were the school very helpful, but the *"paediatric nurses in our local community…have every year gone into school to give them training on administering the buccal midazolam and CPR"* [P5].

It is important to reiterate that the participants' children had a breadth of epilepsy diagnoses, meaning that some of the children attended mainstream schools whilst others went to schools that provided educational provision for children with epilepsy and/or more complex health needs. It is therefore not surprising that parents reported varied experiences in terms of school support as well as the associated epilepsy knowledge and understanding.

3.4.5 Theme 5: Epilepsy medication regimes: *"We've got our routines"* [P16]

Understandably, there was considerable commentary by all the parents about their child's medication and its associated regime; as a result, this theme is comprised of five subthemes, each of which will be discussed in turn:

- **Subtheme 1:**
  Gaining advice, information and support: *"We can email or phone"* [P12]
- **Subtheme 2:**
  Acquiring the medication: *"Make sure that I don't run out"* [P8]
- **Subtheme 3:**
  Administration of medication: *"It's always down to me"* [P3]
- **Subtheme 4:**
  Side-effects: *"We have had some issues"* [P5]
- **Subtheme 5:**
  Sometimes mistakes happen: *"We have forgot a few times"* [P6]

3.4.5.1 Subtheme 1: Gaining advice, information and support: *"We can email or phone"* [P12]

Parents gained their information about their child's epilepsy medication in several ways; in the main, they spoke very highly of the medical consultants and the epilepsy nurses who they encountered – these being a key source of information. P1 explained that the consultant had said: *"Get your phone out", and he typed it in on my phone and then got the medicines for children factsheet on my phone….I thought that was a really good way of doing it and it's so clever"* [P1]. Whilst parents stated that they were not normally offered specific written information about medication, many felt that they had received verbal details and could have asked for more if they wanted it.

When asked, most of the parents said that they had little or no understanding of their child's medication and how it worked (Table 3.10 identifies phrases that were typically used).

"I suppose." [P1]

"I did right at the start look at how it worked but honestly I can't remember." [P3]

"No, not really." [P4]

"Nobody ever explained to us how it works." [P5]

"I have no idea how it works. That's never been explained to me." [P7]

"A basic understanding." [P8]

"I don't always understand how it works." [P9]

"I have no idea how it works." [P10]

"I do not understand how the medication works… it's just too complicated and overwhelming and my brain just goes 'Ohh!'" [P11]

"I don't necessarily know how it works… But I understand what the consultant is aiming to do with the course." [P12]

"I understand as much as I can about it." [P13]

Table 3.10: Parents' comments about their understanding of their child's medication

P16 said she did *"understand how it works because I've researched it myself, it's never been explained to me, so if I wasn't so proactive the answer to that would probably be no"*; a similar comment was made by P15: *"Not by the hospital. Through my own exploration and researching."* When parents did feel that had an understanding, this was rudimentary in its nature: *"I probably had a pretty good understanding of that, you know, the fact that it stopped the misfire of the signals in the brain and gave it a bit of a rest"* [P2].

Despite the lack of more in-depth knowledge of the epilepsy drugs, many of the parents commented that they knew that it was based on weight, for example:

> *“I know it goes on weight, so they do keep an eye on her weight, because obviously she’s growing, and then they do change it if needed. But yeah, I do understand about the dosage.”* [P8]

> *“So, the dosage increases due to weight… so obviously he weighs more as a baby, they do…a lot of his medication was based on weight, but also it’s been increased due to like epilepsy worsening.”* [P6]

> *“I understand it in the way that the dosage is prescribed per kilogram of weight, I understand it to that extent, and yeah, I understand why we would have titrated up through certain medications and then perhaps come down a bit. Yeah, so I suppose I roughly understand the dosing theory.”* [P11]

> *“Every time we went when they were upping the dose they were weighing her every time, so it was clear that whatever dose…it was linked to how heavy she was. And then, yeah, she knew that it was gradually being increased so that hopefully she didn’t get loads of side-effects or breakthrough seizures as she was starting it.”* [P3]

> *“We know that obviously it is based on a weight and we know at certain times she will outgrow that dose, but nobody has ever explained to us when that is and what if any other considerations are taken into account.”* [P5]

This level of information was sufficient for parents, there was no desire to understand the intricacies of how a drug specifically worked or how it helped to manage their child’s epilepsy. In the main, the parents were happy to trust the medical staff in terms of the prescription and what was the most appropriate drug(s) for their child; in fact, P8 commented that:

> *“I don’t want to like try and take too much control, because obviously I don’t know what’s best and what medications there are out there.”* [P8]

Several parents spoke about *“titrating the doses up to the full amount”* [P1]; *“we were titrating up the carbamazepine and lowering down the Epilem”* [P4]; *“we might have been going down or up, every week it was changing so it was all over the place”* [P9]. This titration might need to be done over quite a significant period, especially if medication needed to be changed, P8 said that *“it’s kind of like trial and error at the minute and we’ve kind of waited till she gets poorly to see what her seizures are like.”* Whilst the parents needed to understand how to do this, no substantive problems were reported in relation to it. In fact, some exhibited a confident approach in this respect; P1 explained that she had increased the dose and *“emailed the consultant and said this is what we’re doing because this, this and this and he was absolutely in agreement with it and he did say we could”*. P14 also spoke of the *“good service”* that the family had received; her son had been on several medications, none of which had fully controlled his seizures, nevertheless, she said that *“letters…from the consultant…always detailed exactly what we need to do.”*

One of the key issues that parents faced was the gaining of information and advice when they had an unforeseen query. This could arise, for example, when they went home from hospital or if their child became unexpectantly ill and was unable to take the medication or vomited it:

> *“We have our appointments and stuff and then we come home and then you’re just kind of left. If I’ve got like questions I do speak to the epilepsy nurse and I’ve got her on WhatsApp which is useful, but she is on holiday a lot and she only works I think three or four days a week and then she won’t answer at a weekend….she’s handy when she’s there… so if I do have a question there and then like who do I phone or who can I ask this to? I normally have to wait till Monday or something like that.”* [P8]

Some parents had direct (or indirect, via the secretary) email contact with their consultant. One parent [P4] not only said how responsive the consultant was, but that she had provided her with her telephone number explaining that she could contact her should she need some immediate advice. P4 had never used the number because *“I* [would] *never use that, only if it was a dire, dire emergency, I respect those boundaries and I’m not going to abuse the fact we have her mobile number”* [P4]. Other parents echoed the views of P4 in terms of being able to get in touch with the consultant, for example:

> *“We feel like if we have questions the consultant is available, it’s quite amazing in that we can email or phone and leave a message and they will usually phone back the same day, or the epilepsy nurse will, so we’ve got a dedicated epilepsy nurse, so we feel the support is there…*[child’s name removed] *is about to transition to adult care so there’s big question marks and unknowns there.”* [P12]

There was general agreement that the consultant was contactable via email (although there were exceptions to this such as *P13* who said: *"I don't have his email….like actually trying to get in touch with him by telephone or email is really difficult"*).

Several other parents *mentioned* the epilepsy nurses who were available in some geographical areas, but not others. Table 3.11 provides some illustrative quotes that explained how advice, support and information was gained from nurses.

"Nurse team there, the epilepsy nurse team were really great, and they'd get back to you, if it was urgent they'd get back to you within the day and if not within two days." [P3]

"Also the epilepsy nurses, they're lovely….If I can't get in touch with the consultant then I'll try the epilepsy nurses…But I have that and I feel supported." [P4]

"Catch-ups with the epilepsy nurse…The only bad thing is obviously they are not on an emergency line, so you get a response usually…usually it's the same day but it's not like instant." [P6]

"I just send messages and I get information back from them [epilepsy nurses] *and they've sent through leaflets on medications or proposed medications, so I've got the leaflets."* [P9]

"I think I would ask the epilepsy nurses in the first instance… the epilepsy nurses are the ones whose like phone number we have and if I ring them and leave a message they will ring me back and they've been really good at doing that… at one point I had to email them because we were in [name of country removed]*…when she had one of her seizures, but then they were very responsive… I think they've come out to the house maybe a couple of times as well."* [P10]

"We're really lucky, we have had the same nurse and actually consultant since she was 18 months and she is super responsive on phone, super responsive on email." [P11]

"We have like the medication information leaflets but also the epilepsy nurse has provided information too." [P12]

"We have a very good epilepsy nurse who is very, very approachable, we can contact her all the time and she always gets back and reassures and gets help where needed for us. Yeah, I never feel alone with it, I do feel like we have great support… If not I think out of hours it would be 111 I would contact." [P14]

Table 3.11: Parental quotes illustrating their support from epilepsy nurses

Some of the nurses were immediately responsive and this was very much appreciated, especially when advice was needed within a tight timeframe; however, a few parents reported a different experience:

> *"I emailed them a couple of times….it's normally two weeks to two months when I get a reply…In terms of trying to contact someone to talk about medication it's*

> *hard, there's not a lot of people around and it takes a long time to get a response."* [P7]

> *"We do have an epilepsy nurse but the epilepsy nurse service here I've got to admit is not great…If you call them there is no emergency line to call them, so if you call them you have to go on to an answer machine and you can be waiting up to five days before they call you back, which really isn't particularly helpful when you're talking about such a changeable illness…. When you meet them they're lovely but I've never benefited from having an epilepsy nurse at all really."* [P16]

Many parents also mentioned the support and advice provided by their School Nurse (*there's a really amazing school nurse* [P13], GP and local pharmacist *("there is one of the pharmacists at Tesco who is really good"* [P12]); they felt that these professionals were more immediately accessible, especially the pharmacist as they were just able to 'pop' into their chemist to speak to them.

Knowing that they were able to get in touch with someone, if needed, was a great source of comfort and reassurance for parents. Those who had limited contact with health professionals were desperate for further advice and support:

> *"I think signposting to the charities. I guess any sort of peer-to-peer group support, parent-to-parent support that might be local, yeah, patient and carer as parent kind of information…. They're* [health professionals] *not just there to diagnose and prescribe medication, they're there to look after you holistically and that includes your emotional wellbeing."* [P15]

In summary, parents reported that accessing advice, information and support, especially once they were in their home environment, varied and were perceived as being non-existent by a small number of participants.

3.4.5.2 Subtheme 2: Acquiring the medication: "*Make sure that I don't run out"* [P8]

Parents spoke about a range of issues relating to the prescribing, ordering and collection of their child's epilepsy medication. Only one [P12, whose son was the oldest child at 16 years of age] mentioned that their child was involved in this aspect of their care:

> *"So* [child's name removed] *is responsible, so he has access online to order the medication, but because at the moment we're adjusting the medication all the time it's really complicated to work out how much we need for the next X amount.* [Child's name removed] *is really switched on, he's aced his GCSEs, so he's really switched on and likes maths and that kind of thing, but with the medication he could probably sort it out himself, it's my husband who will work through for the next X amount of weeks how much we need… if I go to the shop I'll pick it up, if my husband goes to the shop he'll pick it up. So that's purely practical reasons."* [P12]

P9 said that her son had started at a residential school for children/young people with epilepsy, so the staff were now responsible for the ordering, collection and administration of medication, which was *"a bit of a weight off the mind"* [P9]. For all the other participants, they felt that it was their responsibility and role to oversee the acquisition of their child's medicines. Some parents mentioned that the GP had not been willing to either prescribe the relevant drug(s) or to support the discontinuation of medication; in these instances, the GP had directed the family back to the hospital. Parents perceived that these situations arose because the GP did not want to take the responsibility for these actions:

> *"Some GPs are very reluctant…they want it under specialist care…we're going backwards and forwards."* [P9]
>
> *"The GP…said, 'it's come up to his medication review, you can't have any more until the paediatrician has seen him.'"* [P13]
>
> *"If it wasn't on the formulary."* [P1].

In addition, sometimes medication was prescribed in an incorrect format (such as liquid instead of tablets); in the case of P9, she said that this impacted on her son taking the drug as he did not like the taste.

There were also occasions when the sourcing of medication by the local pharmacist, had been challenging, especially when these were first prescribed (P1 described this as having been a *"nightmare the first six months"*); this was anxiety-provoking and spurred parents to plan ahead as much as possible, for example:

> *"He gets given three bottles at a time and we usually do it when the first bottle is empty, we'll just do it straightaway, but actually now I'm like I don't know, I can't really take the risk because it seems to take quite a few days to…just to get in touch to tell us it's out of stock."* [P13]
>
> *"I put the prescription in three weeks early. So, I've been told before I haven't put it in in time… I know things like the clobazam can be hard for them to get more than is actually needed, because I think it's the grade of the drug or something…And sometimes that we've gone in the brand changes…which was not a problem when he was not on keto diet, but now he is on the keto diet…we then have to sit there and I literally won't take the medication until they've googled the carbohydrate content. Then the pharmacists tend to get a bit flustered because they don't know what is or they can't find it and that makes it quite challenging…I have a few times had to get really cross because I've gone in several times and the medication is still not there."* [P16]

There was a consistent fear from parents about potentially running out of medication so there was a tendency from some to *"over order now… so I've constantly got that kind of stash going"* [P16]; *"We haven't run out as yet but it's been very close to the vein on occasions, but you know… I've had to run up there before they close because I've forgotten to collect it. Yeah, we've not run out yet"* [P15]. P10 mentioned that she also tried to think about if her daughter had an upcoming school trip, in which case she asked for *"an extra week in case she loses it"* and was frustrated when this was questioned. A similar situation arose when the family were away for four weeks and P10 received a message to say *"we've refused the request"* for the additional medication; whilst this matter was eventually sorted out, it highlighted the stress and anxiety that could be caused in terms of securing the drugs when a process that was outside of the more normal routine was being sought.

Despite some of the issues raised, in the main, once the medication ordering and collection system was in place, it was normally a straightforward process. Parents referred to the use of Apps to facilitate this as well as the physical collection; once again, it tended to be both parents who were involved with the mother taking the prime responsibility. However, when the child had particularly complex epilepsy, specific roles might be assigned: *"So fairly early on we named him head of medical and me head of* *social and education…. So I deal with all the school, enablers, paying people on the payroll that look after my child and he deals with all of the medical appointments, medication.”* [P11]

A few parents spoke of the cost of their child’s medicine, saying that this had been pointed out to them by a health *professional* such as a pharmacist, which participants found upsetting and frustrating:

> *“Like they write it in the chemist on the top of the form ‘expensive’, yeah, you’re like ‘Yeah?’”* [P1]
>
> *“I know it costs like £300 a bottle, so they told me kind of thing, it could be something else…I was like, ‘I don’t really care how much it costs, the doctor is giving it’…the pharmacist at the GP rang me multiple times to say, ‘your consultant needs to fill this form out, it’s not a medication we give out usually, the liquid,’ I think it was because of the liquid was the issue.”* [P4]
>
> *“I do know there’s a more recent version of the drug…I had asked them* [the consultant] *about that drug because I’d heard…it works in the same way as the one my daughter is on but because it’s newer it’s meant to have fewer side-effects….he* [consultant] *just said because it was so expensive they don’t use it.”* [P3]

Overall, parents wanted to make sure that they were able to access their child’s medication in a timely manner, any obstacles to this could be challenging to address leading to an increase in anxiety.

3.4.5.3 Subtheme 3: Administration of medication: *“It’s always down to me”* [P3]

Parents agreed that the administration of the medication was incredibly important and that it was *“a massive help”* [P13] in terms of the management of their child’s epilepsy. The parents echoed the children and young people’s perspectives saying that it was themselves who were primarily responsible for medication administration (in the main, this was reported to be mothers rather than fathers). Even if the young person was a little older and the parents were trying to foster a degree of independence, there was still an overarching parental responsibility (Table 3.12).

“It’s always down to me to remind my daughter to take her tablets which I find quite stressful, especially because she is now 15 and obviously in my mind, I’m thinking she’ll be doing her A-levels in the next couple of years and if she’s going to uni she really needs to start taking responsibility for taking her own tablets… I have to put her tablets on her packed lunch bag, otherwise she’d forget… And for some reason, who knows why, two years down the line she still will not set an alarm on her phone, so it’s me that has the alarm on my phone and then if I’m not with her I’m always messaging her saying, ‘Will you take it?’… So I go into her room at eight o’clock in the morning [at the weekend], tell her it’s time for her tablet, she doesn’t even open her eyes, she just opens her mouth, I put the tablet on her tongue and give her a sip of water and she just swallows it and then goes back to sleep. Ridiculous!” [P3]

“It’s joint between me and her dad. Her dad works from home so if I’m at work he’ll give it to her in the morning and then we’re trying to give her a bit more responsibility, so because she is on the tablets now we have a pillbox and it’s got morning and night and we’ll say to her at night time, not so much the morning but at night time we’ll go, “Go and have your medicine”, and she does.” [P4]

“I think on the weekends when I know she’s having a lie in I will stick my head in and just like give her a little nudge. But she’s very good at taking it and I completely basically leave it with her to make sure that she takes it. I think at first I probably was sort of like, “Oh have you remembered? Have you remembered?” [P10]

“We are always aware that has he/hasn’t he taken the medication and so we are always on alert for that I guess…. We just have a look at the box to see whether he has taken it…. The things that the pills are in, they label them up like for each day, so because he’s taking a mixture at the moment it’s not always clear, yeah but like Monday AM/PM and then AM/PM for Tuesday, that kind of thing, so it’s clear.” [P12]

“So she can go and get the medication out of her little dosette box herself, because she knows what day it is and whether it’s morning or afternoon, and she will oftentimes do that, so she can go and access it. But she wouldn’t know to get them out of the packets, which one is which and which one should be…how many tablets and what dose that makes it up to, so she does definitely need that part done by us.” [P15]

Table 3.12: Parent quotes illustrating their medication administration responsibilities

The teenage daughter of P10 was one of the few who took more responsibility for her own administration of her medicines. She was prescribed tablets and took these without water; this had prompted P10 to express concern about the potential effect on her daughter’s oesophagus and the need to raise it with the nurse at their next appointment; she felt that specific guidance about how to take the tablets had not been provided.

In the main, the preparation of the medication itself did not cause issues, except if, for example, a tablet needed to be broken in half and crushed – this could leave the parent (as in the case of P6) wondering if their child had received the correct amount.

There were mixed views in terms of the ease with which parents felt they child took their drugs, with some indicating that it could be a challenge for younger children, especially if they did not like the taste - a change in the brand of the drug could further influence this situation. In addition, children who had more complex health problems may not be able to take the medication because of having a seizure. Examples of parental quotes illustrating some of the difficulties associated with medication administration are provided in Table 3.13.

"So he doesn't like the taste. He's also said to me sometimes, 'I don't like having it mummy, I don't like it.'" [P1]
"Epilim we had the red syrup…then the generic brand is white…and you'd get things like, "Oh I'm not having that, I don't like the taste of it." [P4]
"She really struggled with the taste of it, but now it's just so ingrained that it doesn't bother her" [P5]
"She does sometimes kick off…and doesn't want to take it…I just think that she's a toddler, she's strong willed." [P7]
"He didn't like the taste…and then he refused to take it." [P9]
"When she has a seizure cluster she will not eat or drink for one to two days, on those days it's really, really hard to get the medication into her… she just will not have any food or drink pass her lips but we still have to get it [the medication] in, so on those days we…liquid isn't too bad because we can sort of push that in through her lips, but we need to get her to take these off a spoon. So we use a squirty cream… But we do need to follow her around and we just have to keep trying until she opens her mouth and then we just put it in… she refuses that medication [potassium citrate] *completely."* [P11]
"We've got Epilim, the pink one, and that's the one we generally do get prescribed, but then quite often that doesn't seem to be in stock so they'll prescribe…there's another sodium valproate, but because my son's got autism…and the other one is clear and he doesn't understand suddenly this clear stuff and…then he'll really actively not want it at all, doesn't want to put it in his mouth, it takes ages…but you know it's kind of stuff that we could really do without when it's quite a stressful situation… my heart sinks when we get the clear medicine." [P13]
"In the beginning it was difficult, she didn't want to take it, she didn't like the taste, didn't like the texture, we tried different tablets. We have been to pharmacists and asked for a particular brand over another because she preferred taking it. And then we've obviously changed tablets and then they've gotten bigger and we used to have to put them into yoghurt so that she would be able to take it easier… Sometimes I've had to split the tablets in half, so I guess she doesn't like that because you can taste it a bit more…. but it's definitely been a gradual process." [P15]
"If he's had really bad seizures he is unconscious sometimes for a couple of days, so trying to get any food into him is a) dangerous, and b) nearly impossible." [P16]

Table 3.13: Parental quotes illustrating medication administration difficulties

If there was an issue with the taste, the family had adopted strategies to ameliorate this, for example, having a drink or adding medication to food (such as mayonnaise [P11]). Some parents had developed techniques to help with the administration (particularly with the younger age range), for instance, P6 explained that not only had her husband tasted each of their son's drugs so that he knew what he was experiencing, but she also said that:

> *"We find we have to do it* [give the medication] *when he just wakes up, just to kind of get it in him when he's laid down, so that's kind of like when we do it and then at nighttime we do it while he's laid down just before he has a bath….if he's teething he's not going to want it, but we just have to hold him down and kind of get him to swallow. I know like very much at the beginning when it used to spit out, we were how much has gone out of his mouth to give him extra."* [P6]

Other factors could influence the taking of medication, P13 described how she and her husband needed to wake their son *"really, really early so that he is awake enough to actually have the medicine. One of his triggers for epilepsy is sleep... we need him to have his epilepsy medicine in good time before he catches his school bus to school."* These examples illustrated the commitment that parents had on a day-to-day basis to ensure that the medication was appropriately taken.

Despite the difficulties mentioned, others reported much more positive experiences saying that their child took their medication without any difficulty:

> *"She's never refused to take it. I think she just accepts that she has to take it and it probably…because she's so good at taking tablets actual taking the tablets probably doesn't bother her at all."* [P3]
>
> *"Tablets wise, she's fine."* [P4]
>
> *"He has been very, very, very good actually in taking all of his medications, he takes them generally with no problem"* [P9]
>
> *Luckily on the whole he's always been pretty good with his meds. And we can normally bribe him, like he loves the dogs going out the back door so it's kind of, 'If you open your mouth we'll let the dogs out, that's the deal', it's that kind of…we've got all the tricks."* [P16]

One of the points that several parents commented on was the need for the form of medication to be appropriate for the child:

> *“Making sure that children are able to access medication in the best form for them.”* [P11]
>
> *“Some of the medication is…not user-friendly. You know they are quite big tablets.”* [P14]
>
> *“Like each medication having different ways to administer I think is really important. I think particularly when we keep being told that topiramate is sprinkles or nothing, or tablets or nothing, it’s actually if you’re going to give it to a child particularly with complex needs, or even a child that doesn’t have complex needs, if they have big seizures they are going to struggle to eat. It’s just always I think having that option of that medication to be administered in a different way so that they don’t miss a dose.”* [P16]

Younger children tended to be given their liquid drugs via a syringe; however, P7 did say that the medication (sodium valproate) did not come with a syringe which meant that she had needed to buy a bottle of Ibuprofen to get one (even then, the numbers rubbed off, necessitating further purchases).

On occasions, parents had to trust others to give the medication – this could be nursery, school, carer or a family member.

> *“Which is us like training them and trusting them to provide the correct amount and also it’s very specific, that amount”* [P6]
>
> *“Occasionally a carer will give it but we always prepare it, they don’t measure it out. … When carers and enablers come in on shift they would check the rescue medication is in date, it’s a part of the routine which helps us because it is hard to remember to check all the time.”* [P11]
>
> *“It’s me, my partner, my ex-husband and my mum are really the only five people that we would let administer any of the pill medication to him, we wouldn’t let anyone else do it really.”* [P16]

The issue of parents trusting others to give their child's medication was paramount; P16 explained that she still wanted to be the one to give her son's medication when he was hospitalised:

> *"'The medication isn't going anywhere, if you give me a key for the box next to it, I'll keep it in there.' And I know now they can give you the parental form, so I'm always like, 'Just give me the form and I'll sign it and we'll do it ourselves.' But I get really anxious about handing any of that over to medical staff because it's never gone well."* [P16]

P16 commented that she *"had about a two year fight with the bus to carry his* [her son's] *medication on the bus"*; P16 felt that her son should have his rescue medication with him in case of a seizure, but because the bus driver would be unable to administer this, the request was initially refused – it was later granted when P16 explained that whoever came to give the drug needed to know that it was already with her son.

In summary, many of the parents reported that their child took their medication without any problems, others experienced difficulties with the form and taste of the drugs as well as their child's stage of development and their health needs.

3.4.5.4 Subtheme 4:
Side-effects: *"We have had some issues"* [P5]

Parents were aware that some of their child's medication had side-effects that could potentially be very substantive: "*You read the side-effects…and they are absolutely petrifying"* [P4]. As a result of this, P4 and her partner had delayed starting their child's medication for a month; it was not until they chatted with both an epilepsy charity and the consultant (*"she's a lovely very responsive doctor"*) that they were willing to start the regime.

Many parents described the *challenges* that their child had encountered because of the prescribed medication, sometimes, these were quite severe:

> *"So she was on Keppra, had like the really bad side-effects to the point she was like trying to headbutt the walls…it was really like aggressive."* [P8]
>
> *"Big concerns I've had around medication are cognition…We definitely saw cognitive decline during the time she was on clobazam on higher doses, and I would also say on topiramate. What again, because this is quite a sort of muddy picture, it's hard to say whether that decline was due to the medication itself or the sheer amount of seizures that she was having. I suspect it's a bit of both."* [P11]

A very common medication side-effect was a change to the child's mood:

> *"It really does affect her mood…and that overwhelming feeling of sadness."* [P4]
>
> *"We have had some issues previously with one particular type of non-branded alternative that contained an E number which seemed to give headaches, gave her very suppressed mood, it just didn't seem to suit her."* [P5]
>
> *"When she first started taking the levetiracetam she has got really low mood, worse than she's ever been before. There was one night, and she was just uncontrollable, sobbing for about three hours saying she doesn't feel as though she's…ever going to feel happy again."* [P3]

Many of the children had been prescribed different medication to ascertain the most appropriate regime for them; sometimes, the epilepsy was difficult to control and one of the side-effects from a medication change could be a reduction in the number of seizures, but an increase in their severity, accompanied by vomiting (as in the case of P4's daughter). In other instances, the side-effects were milder, but impacted on both the child and the parents:

> *"When you up the medication we do have side-effects affecting his sleep and his mood."* [P6]
>
> *"She's gained a massive amount of weight."* [P4]
>
> *"She's always really tired since she's had epilepsy, but it's difficult to know whether it's due to having epilepsy or due to the medication, a side-effect of the medication… she could go to bed at half nine and she could still be lying there awake at one o'clock in the morning, she finds it really hard to get to sleep. Then she wakes up in the morning and the first thing she says is, 'I'm so tired'… also memory loss, she says she struggles to remember things as well."* [P3]

Whatever the nature of the side-effects, all of them needed to be addressed and a decision made about whether they were acceptable.

P9, whose son had had epilepsy for 11 years, mentioned the potential longer term and future side-effects of the medication that she thought he could have, these particularly related to his development (physical and cognitive), bone density as well as his nutritional status. This was a view echoed by others, such as P13:

> "*I'd read before about the concerns around fertility in girls and now there's a new message on it about men too about that in some cases it can cause some kind of developmental disorders or silly worrying things like that, and it obviously does make me worry about what else might come out about….It sounds awful but in our case* [child's name removed] *is not going to be in that position, he's got severe developmental delay, he's not going to have a family of his own."* [P13]
>
> *"*[The medical team] *tell me that he is on medication that they know will cause him liver and kidney failure at some point."* [P16]

On a positive note, other parents, such as P10, said that her daughter had initially had some challenging nauseous related side-effects, but once the medication had been revised and stabilised, *"the side-effects have been so low it's been amazing".*

Overall, parents were undoubtedly concerned about the side-effects that their child either did, or could, in the future, experience. However, they were very aware of the need for their son or daughter to take the drugs to control the epilepsy; in the main, there were good relationships with the consultant managing their child's care, with a proactive approach being reported in terms of trying to minimise any adverse effects of the medication.

3.4.5.5 Subtheme 5: Sometimes mistakes happen: *"We have forgot a few times"* [P6]

All parents reported that they were usually extremely vigilant about medication adherence, realising the importance of both the medication itself as well as the regime. A small number of parents, such as P13 said that *“we’d never forget to give it”* and *“we’ve dealt with loads of medications over the years, and I can’t think of a time when we’ve ever forgotten”* [P11]. However, this was unusual as for most participants, there were times when a genuine mistake had been made (Table 3.14).

“I think both of us are a little bit confused about when, because we got told that if you forget to take it you’ve got a two-hour window and so as long as you take it within those two hours it’s fine, although it’s more effective if you stick to 12 hours apart, but neither of us really understand why… Even if it was four hours later, I sort of think surely it’s better to take it than not, but yeah, I don’t know the answer to that…for her it’s a lifestyle, she’s a teenager, she wants to be like everyone else, she doesn’t want to be having to think ‘Oh when am I taking my tablets or make sure I’ve got some water with me when I need to take my tablets’, or anything like that, she just wants to go and be as free as everyone else without having to think about that.” [P3]
“Yes, we have forgotten to give her medication, I’m not going to lie… there’s some times when I forget to give it in the morning…some of the days when I’m off and I take her to school I forget the medication because it’s not in my forefront of my mind, because I’m not usually the one that gives it in the morning, her dad is, so that can happen… I just chalk it up to a missed dose and then she gets a regular dose at the next time.” [P4]
“It’s just remembering to kind of give it at the same time every day is kind of like what you are told with epilepsy medication, it’s kind of got to be the same times, obviously that means no more lie ins and making sure you kind of stick to the same routine… I think we have forgot a few times to do the afternoon dose because it was kind of like only started a month ago. We kept telling our parents like, “You’ve got to give it him”, and then I realised on a Wednesday I’d forgot to give it him...So I gave it as soon as I remembered and then did the night dose as normal. But yeah, I understand the instructions, it's like if it’s within four hours still give it them but if it’s over four hours you then just wait till your next dose. But there’s always that if the timings aren’t quite right, I’m always like oh he’s going to have a seizure today or something and more than likely he does. So yeah, I do feel bad.” [P6]
“I think she told me she forgot like once or twice maybe, I think maybe once ages ago. Anyway, she was like, ‘I didn’t tell you’… She does say sometimes she forgets how many she’s had because it’s just…it’s really late at night or really early in the morning…when it’s school time, certainly five days a week, that’s pretty easy to do. When it’s the weekend, you know, she’s not up at seven, I’m not waking her up at seven, but I will wake her up about 10 and be like, ‘Take your drugs’, and so that’s probably two or three hours later on the weekend…the evening one is always a little bit late…. So I think we’re pretty loose, the timing isn’t super exact and that’s just been okay and I haven’t sort of worried about it, so I guess the way it’s meant to be taken is exactly 12 hours apart.” [P10]
“He’s got into a habit of snoozing the alarm and especially in an evening if he’s out doing something it’s remembering whether he’s taken the medication with him or he quite often doesn’t… So in our seizure diary we’ve also started logging if he’s been a bit late taking medication, to see whether there is a pattern in the seizures he’s having, but haven’t got enough information yet to determine yes or no.” [P12]
“Unfortunately, I think about a week or so ago I did forget to give it to him and the problem was that he woke up in the morning and he had a seizure… I think it was because it was out of the routine in the morning that I completely forgot that I hadn’t given it to him… I went back off to school and gave it to him then. So it was probably about two hours after it would usually be taken.” [P14]
“In the beginning it was saying…me and my husband would be like “Have you given her her medication? Have you given her? Has she had it?” or not handing that over to each other, so we got a pillbox and then that meant that we knew if she’d had it or not, because it was in the box or not in the box for that particular same time.” [P15]

Table 3.14: Examples of medication errors reported by parents

It was clear that parents were less worried about changes to their child’s medication times if they did not feel that there was a substantive impact:

> *"I think I asked fairly recently* [about absence episodes] *and in the last six months and so she was like, "Maybe once or twice." So if she is missing the timing it doesn't feel like it's having a massive impact because she's not having breakthrough absences or any bad effects that we can tell."* [P10]

> *"Twice probably* [that *medication* was forgotten] *but he didn't have any seizures then. He's having fairly frequent seizures, but yeah, that time it didn't have any effect."* [P12]

It was hard for parents of children/young people with more complex epilepsy to know whether missing a dose of medication had had an effect or not:

> *"It's difficult to pinpoint and say that he had more seizures because he missed a dose or was he just going to have more seizures there anyway."* [P9]

> *"Again, none of us know that any of that* [the medication] *is doing anything."* [P11]

> *"I think it's very difficult to* measure *whether it* [missing medication] *affects him… he can still have a bad run on them* [the seizures] *and for no real reason."* [P14]

The biggest cause of a disruption to medication adherence was a change of routine, this could be, for example, going on holiday:

> *"We have forgotten and it is possibly twice a year max. It's usually where there has been a very significant change to the routine and so the last time it happened we were caught out, we were stuck in traffic coming home from holiday…We were jetlagged, we completely lost track of all time."* [P5]

> *"Sometimes if we are out and about I guess, like she plays netball, so we've had times where she's played netball, then I've played netball after her so we've not remembered to give it to her before we've gone out and then she's having it later than she should do and I think that that sometimes has an impact on the regularity of having it…we find it a bit better as well that we will take a dose out with us, we've got a little travel pot that we just take a dose with us and so we know that we are covered, even if we think we're going to be home we'll just take one with us in case."* [P15]

The busyness of a family lifestyle also had an influence. P7 remembered a specific time when she had forgotten to give her daughter her medication, it had simply been a busy morning and she and her husband had thought that the other had administered it. This omission caused panic and distress (that was echoed by other participants); in this situation, P7 had contacted Parents and Carers of Children with Epilepsy UK as well as the NHS website and the epilepsy nurses. Unfortunately, P7 reported that the website was not *"clear and precise",* and the epilepsy nurse did not reply. P7 managed to establish (from Parents and Carers of Children with Epilepsy UK) that the dose should not be given *"more than six hours to the next one"* so the medication was omitted. The *"shock of forgetting"* was then *"etched"* into her brain with the result that she did not feel that a morning medication alarm was required (she was so affected by the incident that she now always remembered). Like other parents, this mistake meant that they had revised their medication reminder strategies, P7 assumed responsibility, but if she was not available, she texted her husband to remind him. P4 reported a similar confusion with her husband so they bought a dosette box to remedy the situation: *"it's just a case of if the pillbox is empty I know my husband has given it"* [P4]. P9 mentioned that although they used a dosette box, they still messaged each other to check that the medication had been given.

Parents reported that the older children/young people were developing a degree of independence with their medication, but, as previously mentioned in Section 3.4.5.2, the parents still oversaw this as *"she wasn't great at doing it on her own"* [P2] and *"she went to get her own medication, and she nearly took the wrong tablet and oh my God!"* [P4].

Parents reported that they tried to be discreet when administering their child's medication, especially if they were outside of the family home: *"We don't make a big thing of it"* [P1]. Parents of older children commented about how their son or daughter may feel (Table 3.15) in terms of taking their medication when others were around.

"I think she was a bit embarrassed about it." [P2]
"In the evening if she is at activities she's normally with people she knows well so she'll just take herself off to the toilet or the kitchen area or something and take it….I don't think she really talks about it with any of them, so some of them probably still don't even know that she's got epilepsy…she didn't want to set an alarm on her phone because she didn't want to be embarrassed by her phoning going off, because obviously on a big school group there are people she doesn't really like… I have always checked with the teacher or whatever that she's taken it." [P3]
"*A little bit anxious about it or embarrassed about it with other people around… he might be reluctant there to take it."* [P9]
"She has strops and so the impact of even just getting her to take her medication, she'll then have kind of an outburst of 'Why have I got to have this? Why have I got epilepsy? I don't want to have this.'…'Why do I have to take all these medications because they don't work.' And it's just really trying to reassure her, even though we don't have really the answers… if she has friends round when her medication is due she definitely doesn't like us to kind of say out loud, "Can you take your medication?", it has to be quiet." [P15]

Table 3.15: Parental comments about their older child's reaction to taking medication

Other participants commented on other challenges that their child faced in day-to-day life (such as autism) which could mean that they were sometimes reluctant to take the medication, adherence was therefore dependent on the time and strategies that the parent employed to ensure that the drugs were taken. For example, P14 commented that her son might find it quite amusing to spit the medication out; the family could be quite firm with him at home, but it was more difficult in the school environment and this behaviour (at home or school) meant that the dose was then missed.

To help the family to remember to administer the medication, a number of strategies were reported (Table 3.16).

Getting *“it out of the cupboard and put it on the side, so that’s my reminder.”* [P1]
“The medication box.” [P2]
“We’ve got one of those tablet packs with the dates, Monday, Tuesday, Wednesday, blah, blah… every Sunday night I put everything in there… Mum, mum reminder!” [P3]
“We have a pillbox…definitely been a game changer.” [P4]
“We write in that book…Predominantly so we don’t either miss it or accidentally double dose between us.” [P5]
“I now set an alarm for like one o’clock.” [P6]
“We set alarms on our phones to remind us and there has been one occasion where we both forgot to give it to her in the morning and three days after I was still crying and thinking ‘Oh no, here comes a seizure’, because you worry about it.” [P7]
“I have an alarm on my ‘phone.” [P8]
“We did have a dosette box…there’s so much going on and when you’re sleep deprived…you don’t want to give a double dose.” [P9]
“She leaves it in a particular place…where the light switch is, at the doorway on a side that’s almost at eye level…when she goes into bed and out for the morning it’s right there and it’s by her…” (in addition, P10 would ‘reorder’ the tablets so that they were in one box). [P10]
“What we do do is set an alarm on our oven for an hour after we’ve given the epidiolex to remind us to give the clobazam.” [P11]
“He has an alarm on his phone… like a little plastic Lock & Lock box that’s just a standard box with the pill packets inside.” [P12]
“It’s out in the kitchen, as a big reminder.” [P13]
“It goes off on my phone.” [P14]
“We have a pillbox.” [P15]

Table 3.16: Medication reminders

Some of the children and young people themselves also played a part in reminding parents about their medicines *(“On a few* occasions *he’s actually said to us, ‘I haven’t had my medication yet’”* [P9]; *“she will very often remind us”* [P5]).

When specifically questioned, most of the parents said that when they attended medical appointments, they were not asked about their child’s adherence to the medication regime; they felt that it was rather assumed that there were not problems in this respect:

> *"No. I suppose they just assume she does… I suppose it would be nice to be asked, because you know they're like keeping on top of things and everything. But I suppose even just by like a phone call or an email, text message or even if we're at an appointment or something like that."* [P8]
>
> *"They've never asked me that, ever, not once."* [P7]
>
> *"I think they just assume that he is taking it and there's no problems because they haven't heard from us, but no, they don't really ask."* [P9]
>
> *"There's just an assumption that if they're prescribing it she must be taking it."* [P5]
>
> *"They all assume I think that we're responsible and we give the medication which obviously we do"* [P13]

However, other parents (such as P11, P12, P14, P15 and P16) commented that:

> *"They* [health professionals] *would ask what medication she's on and what she's taking."* [P11]
>
> *"It's part of the conversations at the consultant appointments."* [P12]
>
> *"They ask at every appointment how he's taking it and whether there's any problems."* [P14]
>
> *"They do ask every time. It's done with me and her there and it's answered by me."* [P15]
>
> *"I would tell them if he wasn't, but I think they would definitely ask if I hadn't already told them, I think that would always be a question, is he taking it okay, is he responding well?"* [P16]

Interestingly, the above quotes came from parents who had children with epilepsy that was difficult to control (necessitating a range of medication) and/or complex health needs. The only exception to this was the comment from P15 whose 16 year-old son was taking responsibility for his medication as well as approaching transition to adult services. In essence, at health appointments, there was a varied approach to ascertaining information about the adherence to medication.

With older children/young people, sometimes, the child's school would notice that they were not their usual selves and would ring the parent who then discovered that the medication had not been taken that morning – thus further reinforcing the need for parental vigilance.

Finally, in this section, parents primarily focused on discussing the administration of medication on time, only two participants [P11; P12] mentioned giving more than was required:

> *"Early days he did actually manage to give six times the dose of the medication she should have had, that was actually I believe levetiracetam. Then we took her to A&E but there were no ill effects at all and it was absolutely fine, but we informed the epilepsy nurse."* [P11]
>
> *"There was one time he took a double dose accidentally… He did have more seizures around that point afterwards…whether those seizures were due to that double dose…we don't know, or whether it was just he would have had those anyway, not sure."* [P12]

P9 spoke about her son who attended a residential school for children and young people who have epilepsy; whilst this was an environment where staff were familiar with different types of epilepsy and the associated medication, P9 reported that:

> *"He was given double of the medication…they came back to me and said they're investigating it and they've put things then in place with a staff member."* [P9]

The only other mention of a different type of non-adherence to medication was by P4 who described how she had not given her daughter her *"rescue medication"*, despite her focal epilepsy seizures lasting more than an hour, as *"it's really heavy medication"*. This had resulted in her being *"told off"* by the consultant who explained that she *"should be giving it".* P4 spoke of the *"ownership as parents"* and not being *"very quick to medicate"* as well as the child's happiness being "v*ery much at the forefront of what we want for her".*

Overall, for this section, parents displayed a strong commitment to the maintenance of their child's epilepsy medication regime; however, their full understanding of the implications of fully adhering to what could be a challenging protocol was not wholly demonstrated. It was clear that mistakes did happen, and medication could be missed – to remedy this, parents employed a range of reminder strategies. In their interviews, participants primarily focused on the timing of the drug administration and/or missing doses, giving examples of how they dealt with these situations. However, a question remains in terms of whether parents forgot to administer medication on occasions but did not always realise? Several participants reported that they were not asked about adherence to medication at medical appointments.

3.4.6 Summary of findings from the interviews with parents

- Parents reported that the diagnosis of epilepsy, and the associated medication, could have a substantive impact on the lives of both the child/young person and parent(s) – both in terms of parental emotions as well as the practical implications and the forward planning that was required to maintain parental vigilance and medication adherence. This impact should not be underestimated.

- Parents wanted their child to have as ‘normal’ a life as possible and organised everyday activities to try to ensure that medication was given appropriately.

- Parents had a thirst for information that related to their child’s epilepsy and their medication regime; however, they were not always aware of how to access appropriate resources, meaning that they frequently turned to charity websites and relevant Facebook pages.

- Parental knowledge of their child’s epilepsy drugs, and how they worked, was limited; this had the potential to impact on medication adherence if they did not realise the full implications of missing a dose or not accurately following the recommended timings for the administration.

- Parents wanted responsive advice and information from health professionals when queries about medication arose (for example, if a child was unable to take their drugs for any reason). The availability of such support was variable, a lack of it could lead to feelings of uncertainty and anxiousness about what action to take; whereas when advice was readily available, parents felt reassured. Overall, parents felt very supported by their health professional team (in particular their consultant and epilepsy nurses); it was felt that going directly to the consultant, who was responsible for the care and management of their child, was the best option when possible.

- Involvement in healthcare decision-making processes was important for the participants; the building a trusting and therapeutic relationship with practitioners, in particular, the medical consultant and epilepsy nurses played a key role in medication adherence.

- The majority of parents took responsibility for all aspects of the epilepsy medication (including ordering, collecting and administering it). One of the concerns for parents was running out of drugs, this worry was exacerbated by the *“chasing”* [P11] that they sometimes needed to do.

- Many of the parents reported that their son or daughter took their medication without any problems; others commented on difficulties associated with its form, the taste of the drug as well as their child’s stage of development and their other health needs.

- All participants very much wanted to be involved in their child’s healthcare decisions; most parents reported positive experiences of this and even the small number who did not, were able to give examples of how they had vocalised their views.

- Parents were concerned about the side-effects of medication that their child either did, or could, in the future, experience. However, they were very aware of the need for their son or daughter to take the drugs to control the epilepsy; in the main, there were good relationships with the consultant managing their child’s care, with a proactive approach being reported in terms of trying to minimise any adverse effects of the medication.

- As the child matured, parents were trying to relinquish some responsibility for the medication, allowing their child to take ownership; however, this was not without its challenges and could increase parental anxiety.

- Parents’ full understanding of ‘adherence’ was not wholly demonstrated; in addition, they were not all routinely asked about their child’s medication adherence at health appointments. They reported that they understood the need to administer their child’s drugs at certain times, but had less knowledge about how flexible this was. In addition, they were able to describe examples of when they had forgotten to give drugs and what they did when they had then remembered. However, it was not clear if there were times when medication had been forgotten and parents had not recalled the error and therefore not taken any action. On other occasions, parents reported difficulties with administering medication to their child, but did not link this with non-adherence.

- A range of reminder strategies were employed to help parents to remember to administer medication, these included alarms, visible placement of the drugs and dosette boxes (the latter being the most popular).

Section 4.0: Summary, recommendations, limitations and future research

4.1 Introduction

Using qualitative data collection approaches, this research study sought to gain insight into epilepsy medication adherence from the perspectives of children and young people and their parents. This concluding section highlights the similarities and differences between the parents' and children/young people's findings, provides recommendations for the enhancement of medication adherence, identifies limitations of the study and makes suggestions for future research.

4.2 Similarities and differences between the parents' and children/young people's findings

There was substantively more data from the parent interviews than the children/young people ones; this was due to the difference in participant numbers, but also the length of the interviews. Understandably, the children/young people spoke for less time, they were still developing cognitively, and their language skills were still being refined; not all of them were able to talk in longer and more complex sentences and this frequently resulted in brief responses to questions. Secondly, their attention span varied and was limited at times. Despite these factors, it was invaluable to hear the voices of children and young people; without their contribution, the research simply would not have been able to encapsulate or appreciate the perspective of the child/young person.

There were several similarities in the parent and children/young people findings:

- Parental and child/young person knowledge of the epilepsy medication and how it works was limited.
- It was agreed that a change in the normal day-to-day routine had the potential to impact on medication adherence.
- Children/young people and their parents both reported that parental support played a substantive role in medication administration and ensuring that the prescribed regime was adhered to.
- The parental and children/young people interviews both revealed that involvement of the child/young person in hospital consultations and appointments was varied, thus indicating an inconsistent approach in this respect.

One key difference between the parents and children/young people was, when specifically asked, none of the children/young people had involvement with charities or support organisations – this was in stark contrast to parents who had a 'thirst for knowledge' and had made contact with a range of different groups.

The parent findings identified a range of additional points that were, understandably, more specific to their own perspective (please refer to Section 3.4) that included, for example, the desire for responsive advice.

4.3 Recommendations

The findings from this study highlighted key recommendations:

- Families understand the importance of medication adherence and try hard to follow the prescribed regime. However, having timely answers to queries when difficulties arise (such as the child vomiting their medicines), is fundamental to their medication administration decision-making. It is recommended that there is an identified point of contact for parents – perhaps having, for example, an epilepsy nurse 'on-call' for a region who can offer a prompt and supportive response. We do not believe that this would be too onerous for the personnel involved as parents mentioned that their need for this advice is only occasional.

- The building of a trusting and therapeutic relationship with practitioners, in particular, the medical consultant and epilepsy nurses is crucial; we suggest that strategies continue to be employed to facilitate this, with both parents and children/young people – thus enabling a shared approach to decision-making that underpins medication adherence.

- A disruption to the family routine can impact on medication adherence; the most used and successful reminder system was a dosette box. It is suggested that this strategy is recommended to families and, if feasible, a suitable and developmentally appropriate box is offered to them.

- A number of parents reported that they were not specifically asked about adherence to epilepsy medication, or associated side effects, during hospital appointments. It is suggested that questions about these are included in all consultations.

- It is recommended that families are provided with support services information that provides details of, for example, relevant charities, support networks, reputable sources of healthcare advice, such as the medicines for children factsheets/webpages. Resources that meet the developmental needs of children and young people should be particularly considered.

- We recommend that parents and children/young people are clearly told what adherence to medication actually means, this includes the degree of acceptable flexibility with the timing of medication administration. Families should be encouraged to report, to the child’s medical team, any challenges associated with medication administration (including the taste, form of the drug and any side effects). Appropriate information and support can then be offered.

4.4 Limitations

The research team are aware that this work was not without its limitations, most notably:

- The views of the participants may not be wholly representative of other families across the UK and that experiences may vary.

- Recruitment of children, young people and their families can be challenging; whilst our sample size was commensurate with other qualitative studies, we are aware that all the parents were white, mothers and in a stable partnership. It is acknowledged that the perceptions of other groups may be different.

4.5 Future research

This study has provided a valuable insight into the experiences of children and young people (who have epilepsy) and their parents; however, we are aware that whilst our participants were from a breadth of geographical locations and had a wide socio-economic profile, there was not diversity in terms of culture and ethnicity. It is suggested that future research is undertaken to:

- Target specific populations such as single parent families as well as those from ethnically diverse backgrounds.

- Gain insight into the perspectives of fathers as all our parents were mothers.

- Ascertain the views of more children and young people (in particular, boys) as this aspect of our sample was small, with just one male participant.

Section 5.0: Conclusion

5.0 Conclusion

Childhood epilepsy knows no boundaries in terms of socioeconomic status or geographical location. The importance of adhering to medicines regimes has been well recognised, but achieving this is not without its challenges. This study aimed to identify some of the facilitators and barriers to epilepsy medication adherence in children and young people as well as how they could potentially be addressed.

Some our findings reflect the work of others; for example, NHS England (2023) suggest that families should have increased access to epilepsy nurses and the Association for Young People's Health (2023) recommend that there should be an improved range of developmentally and culturally appropriate information that is readily accessible for children and young people who have epilepsy.

However, our study revealed several other important issues that were specific to medication adherence; we highlighted that a disruption to the medicine regime can be due to a number of factors, such as the child's ability/refusal to take their drugs, illness (such as vomiting), a busy lifestyle and just simply forgetting. Families need a multi-faceted approach to facilitate adherence, this includes reminder strategies (such as dosette boxes) as well as good relationships with healthcare practitioners who are able to provide responsive advice when the needed.

The children and young people interviewed did not report any deliberate omissions to taking their medication – quite the contrary, with phrases such as "*nothing would make me stop the medication if I wasn't told to"* [CYP2] being used. In addition, parents were totally committed to the promotion of the health and wellbeing of their child, even in the most complex of situations. However, several participants displayed a lack of knowledge in terms of what 'adherence' actually meant and were not always specifically asked about this in consultations. It is essential, therefore, that strategies are employed to address these points so that we are all working together to give each child/young person (who has epilepsy), the best possible start in life.

It is hoped that the findings from this study have provided data that has the potential to inform the future planning of some aspects of epilepsy medication management so that health service provision for children and young people can continue to be enhanced.

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