There is **enormous potential** for new treatments and new devices to make a profound improvement in the lives of people with epilepsy.

*Epilepsy is a complex disease*
- It has many different physical manifestations.
- It has wide ranging, physical and emotional impacts on patients and their families.
Epilepsy is a hard disease to manage, and many patients are NOT happy with their current treatments, medication and support
• Over 40% of patients report being severely affected by lifestyle restrictions, corporeal affects and emotional impacts.
• Only 55% are happy with their current treatment, 47% with their current AED medication, and 45% with their current support.
**Epilepsy: Executive Summary**

*Messages that people with epilepsy would like to convey*

- **To those newly diagnosed:** Accept you have a scary, complex disease that restricts your lifestyle; get informed and manage your disease by staying connected, accepting help, and staying positive.

- **To friends and family:** Epilepsy doesn’t define me as a person, I don’t want to be treated differently; it is hard work coping with this disease, it is not just about the seizures; after seizures I am exhausted and vulnerable, please help me recover.

- **To HCPs:** There should be more access, better interactions and more information supportively provided to overwhelmed patients and caregivers.

- **To healthcare companies:** There is a need for new medications (with fewer side effects and better seizure control) and for access to new devices.
EPILEPSY:
Disease Demographics and Episodes
### Disease Demographics

**Age, Respondent Type and Gender**

#### Who has epilepsy?
- My child: 47.62%
- Myself: 45.83%
- Other relative/friend: 5.95%
- My parent: 0.60%

#### What is the age of the person with epilepsy?
- Infant (less than 2 years old): 1%
- Childhood (2-12 years old): 24%
- Teenager (13-18 years old): 13%
- Young Adult: 15%
- Adult (26 to 55 years old): 39%
- Elder (greater than 55 years old): 8%

#### What is the gender of the person with epilepsy?
- Male: 68%
- Female: 31%

N=168
Disease: Onset and Types

At what **age** was the patient diagnosed?

- Infant: 18%
- Childhood: 35%
- Teenager: 21%
- Young Adult: 9%
- Adult: 17%
- Elder: 1%

What **type of seizure** does the patient experience?

- Tonic Clonic: 28%
- Absence: 26%
- Focal: 18%
- Myoclonic: 10%
- Atonic: 4%
- Tonic: 4%
- Dissociative: 3%
- Febrile: 1%
- Other: 5%

*Other – FOS fixation of sensitivity, Clusters, Nocturnal, Gellastic, Visual, Todd’s Palsy, Infantile spasms, partial, West Syndrome, Aura, Abdominal
Disease: Impacts

How much of an impact does having Epilepsy have on your day to day life?

38% of respondents said their lives were considerably impacted by Epilepsy

Regular seizures impact on all aspects of my day-to-day life

37% of respondents said their lives were slightly impacted by Epilepsy

It’s not difficult to manage as the seizures normally happen at night and very infrequently

MINIMAL (take daily medicines, stay watchful).

MINOR (careful with food, activities, awareness).

MODERATE (limitations to some activities).

MAJOR (limitations to daily activities).

SEVERE (substantial impacts on education/ job/ social life).

Severe, 22%

Minimal, 28%

Major, 16%

Minor, 9%

Moderate, 25%
Disease: Main Impacts

While lifestyle restrictions were overall the main impact, the most cited individual factor was the impact on the patient and family’s mental health.

Emotional Impacts (66)
- Anxiety/depression/stress (36)
- Limited social relationships (11)
- Uncertainty / constant vigilance (10)
- Isolation (8)
- Others’ poor attitudes (6)
- Embarrassment (3)
- Loss of confidence (2)

Lifestyle Restrictions (117)
- Not being able to drive (33)
- Loss of independence (26)
- Restricted activities (22)
- Work/school restrictions (19)
- Avoiding lights/noise (8)
- Need for sleep (5)
- Timings of medications (4)

Corporeal Impacts (86)
- Exhaustion/tired/sleepy (19)
- Part of severe disability (16)
- Memory problems (15)
- Associated medical issues (14)
- Development/learning difficulties (12)
- Seizure physical injuries (8)
- Medication side effects (6)
- Disrupted sleep (4)
- Incontinence (2)
<table>
<thead>
<tr>
<th>General Impacts</th>
<th>Lifestyle Restrictions</th>
</tr>
</thead>
<tbody>
<tr>
<td>• It is a daily battle of us all trying to live life and fighting a brain that has other ideas.</td>
<td>• I was medically retired when I was 40 because of impact Epilepsy has on my memory. Not being able to drive gets me down – it means losing my independence.</td>
</tr>
<tr>
<td>• We try and keep as positive as possible. For the parent, it’s really worrying that we may not be able to save her one day.</td>
<td>• I am unable to socialise as I would like. I don’t drink at all. I always have someone with me who is aware of my epilepsy and how to help me when I fit.</td>
</tr>
<tr>
<td>• Although my son hasn’t known anything else, he now understands that he is limited and not everyone has this condition.</td>
<td>• He cannot be left unsupervised; we need to have a strict routine at home with things like food, bedtime etc.</td>
</tr>
<tr>
<td>• There are certain things, the little things everyone takes for granted, that she can’t do alone anymore; it’s had a massive impact on the patient, the parents and the siblings due to it being a scary time.</td>
<td>• People seem scared to let me do things. I’m not allowed to play football at school with my friends. I don’t go out with friends. People don’t invite me to parties or to their house.</td>
</tr>
<tr>
<td>• When I am having seizures, I stay home and do very little. I take a long time to recover from seizures and then have to clean up.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Emotional Impacts</th>
<th>Corporeal Impacts</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Epilepsy has left my child very anxious, he is afraid of having seizures.</td>
<td>• The side effects of the medication mean I struggle to walk far.</td>
</tr>
<tr>
<td>• Despite desperately wanting to be independent, I can’t be left alone to enjoy time for myself or with my children.</td>
<td>• Exhaustion from seizures and not knowing when they’re coming restrict my daily activities.</td>
</tr>
<tr>
<td>• I was only diagnosed in August 2017 and I am struggling to accept it. My depression and anxiety is now really bad, I very rarely leave the house unless I have to.</td>
<td>• I can’t drive or watch large screens; sometimes I loose entire days of memory.</td>
</tr>
<tr>
<td>• You definitely need to be referred to mental health specialist after being diagnosed with epilepsy. It’s a very scary illness for the patient and for the carers/parents/friends etc</td>
<td>• Seizures have affected my son’s development and affected his heart. His life has been shortened; he is now in end of life care.</td>
</tr>
<tr>
<td>• I no longer cook as much, instead relying on ready meals; I struggle with being cold.</td>
<td>• I no longer cook as much, instead relying on ready meals; I struggle with being cold.</td>
</tr>
</tbody>
</table>
### Episode: Triggers

**What triggers an episode?**

<table>
<thead>
<tr>
<th>Trigger</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tiredness/ Lack of sleep / Overtiredness</td>
<td>127</td>
</tr>
<tr>
<td>Stress/ Anxiety</td>
<td>108</td>
</tr>
<tr>
<td>Not taking medicine as prescribed</td>
<td>98</td>
</tr>
<tr>
<td>Illness/ High temperature</td>
<td>82</td>
</tr>
<tr>
<td>Flashing/ Flickering lights</td>
<td>40</td>
</tr>
<tr>
<td>Menstrual cycle</td>
<td>25</td>
</tr>
<tr>
<td>Missing meals</td>
<td>24</td>
</tr>
<tr>
<td>Alcohol/ Recreational Drugs</td>
<td>12</td>
</tr>
<tr>
<td>Other</td>
<td>35</td>
</tr>
</tbody>
</table>

*Other:*

- No idea / nothing in particular (11)
- not following recommended diet (3)
- Heat (3), Pain (3), Loud Noises (3), video games, bathrooms, TV, Shock, Startle, Dehydration, Menopause, Humidity, Exercise, Excitement, waking up, certain medications, certain foods

N=168
### Episode: Precursors

If yes, what **type of precursors** warn of an incipient episode?

<table>
<thead>
<tr>
<th>Precursor</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unexplained confusion/sleepiness/weakness</td>
<td>34</td>
</tr>
<tr>
<td>Unusual tastes/smells/feelings/vomiting</td>
<td>32</td>
</tr>
<tr>
<td>Daydreaming/forgetfulness/memory loss</td>
<td>30</td>
</tr>
<tr>
<td>Jerking movements/weakness of limb or body</td>
<td>27</td>
</tr>
<tr>
<td>Tingling</td>
<td>21</td>
</tr>
<tr>
<td>Headaches</td>
<td>18</td>
</tr>
<tr>
<td>Losing control of urine or stool unexpectedly</td>
<td>8</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
</tr>
</tbody>
</table>

*Other* - Unnatural body movements (5), mood swings (2), white vision, lose hearing, chest pain.
Episode: After Effects

What **after effects** occur after an episode?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>129</td>
</tr>
<tr>
<td>Sleeping</td>
<td>127</td>
</tr>
<tr>
<td>Confusion</td>
<td>116</td>
</tr>
<tr>
<td>Headaches</td>
<td>102</td>
</tr>
<tr>
<td>Memory problems</td>
<td>98</td>
</tr>
<tr>
<td>Bitten or sore mouth</td>
<td>84</td>
</tr>
<tr>
<td>Physical injury (bruising, broken...)</td>
<td>60</td>
</tr>
<tr>
<td>Vomiting</td>
<td>46</td>
</tr>
<tr>
<td>Long-term hospitalisation</td>
<td>17</td>
</tr>
<tr>
<td>Other</td>
<td>12</td>
</tr>
</tbody>
</table>

*Other: muscle weakness (4), short term hospitalization (3), loss of speech (3), incontinence (2), loss of hearing, hungry, crying/sad*
**Treatment**: Main Healthcare Professional

~80% of respondents are treated in hospital settings

- Consultant at Tertiary Hospital / Specialist Centre: 27.6%
- Consultant at Local Hospital: 30.0%
- Specialist Nurse at Local Hospital: 21.5%
- Paediatrician: 1.0%

~20% of respondents are treated in community settings

- GP: 15.8%
- Specialist Nurse in Community Clinic: 4.0%

N=168
Treatment: Type of Treatment/Happiness

Please note that patients may be on more than one type of treatment at a time.

How happy are you with your current treatment?

~55% of respondents are happy or very happy with their current treatment.

12.3%
15.3%
20.2%
17.2%
35.0%
Treatment: Issues

It can be difficult to find the right treatment

My son’s medication is always changing. We tried five AED medications, two rescue medications and VNS, and we are still trying to control his seizures.

Have tried all the many different epilepsy drugs; recently started ketogenic diet and now looking into VNS.

We have tried so many different medications and combinations. We looked at ketogenic diet, however now we are considering VNS.

They change my daughter’s medicines around, not in any logical order. They stop them, start a new one and then add the old ones back in. It’s useless!

Even treatments that provide good control are not straightforward

Daily medications are required to be taken twice daily, 12 hours apart at 7am and 7pm. Failing to take these medications at the correct dose, at same time and on time, every day will trigger a seizure.

If the dose has been changed over phone by consultant, school personnel won’t administer the correct dose of medication until the GP changes it and pharmacy dispense new medication with new labels.

We’re still on a 4+ year waitlist to see a neurologist.

We need to provide epilepsy training to each setting school/family/respite/butterfly club before she can attend. If staff are then off she can’t attend.
**Treatment: Issues**

But patients would also like new treatments to be made available…

I’d really like a medication that would make me able to live properly without the fear of having another seizure.

It would be helpful not to experience all the side effects of the medication - they are exhausting!!

Can’t they develop a medication for my daughter that actually stops her seizures?

Please find a better way to monitor a fit when person is alone; not wrist alarms that cost hundreds of pounds!

We’d like some kind of alarm to warn us that he is about to have a seizure at night, I know that they are available to buy, but they are so expensive…

… and new technologies

I’d really like access to an epilepsy monitor and an anti-suffocating pillows for my child!

Can someone develop a device that alerts to all types of seizures?

Please find a better way to monitor a fit when person is alone; not wrist alarms that cost hundreds of pounds!

Please can CBD be made easily available in the UK?

Can we please get a device that reminds my son to take his medication…

Alternative treatments without so many side effects.

Can they develop a device that actually stops her seizures?
AED Medicines: Happiness/Side Effects

How happy are you with your current AED medication?

~47% of respondents are happy or very happy with their current AED.

~60% of respondents have had to change medications, often repeatedly.

What type of side effects have you experienced on your current AED medication?

- Fatigue: 133
- Weight gain: 59
- Depression: 56
- Dizziness: 55
- Rashes: 17
- Loss of bone density: 11
- Inflammation: 10

Please note that patients may have experienced more than one type of side effect.
AED Medications: Issues

It can be difficult to find the right AED medication

I swapped from one AED which gave me bad weight gain and didn’t actually control my seizures to a second, which has been fantastic. No side effects and works really well.

Took 8 years to find medication that worked having tried lots of different kinds.

I have gone through several AED drug changes, several dose changes as the seizures were not being controlled very well. Now in menopause which has offered some relief.

Many patients are still seeking an effective AED medication

For normal AED medicines we have tried so many, we have been told no more left to try. What we are currently on leaves my daughter with tremors and ITP (a blood condition).

We’ve yet to find an AED which fully works.

I have tried six different types of tablets, but still struggle with the side effects.

Gone from taking daily meds that made me feel so unwell and actively suicidal to not taking anything because I hate the side effects.
Rescue Medications: Type / Where Kept

What type of rescue medication are you on?

- Oral suspension: 20
- Buccally tablet: 4
- Swallowable tablet: 2
- Pessary: 2
- Nasal spray: 1

~80% of respondents who are prescribed rescue medicines have used them, from regularly to very occasionally.

Effectiveness of rescue medication is quite varied. Over half of respondents have changed rescue medicines to achieve a better outcome.

Where do you keep your rescue medication?

- At home: 35%
- At school/work: 24%
- On my person/the patient at all times: 41%
**Rescue Medications: Issues**

There are wide-spread difficulties with rescue medications

Tonic clonics are not always fixed with one oral dose and a rectal second medication has to be given. Our most recent episode occurred at home with paramedics, who then transferred her to resus at A&E.

Though my daughter’s last seizure happened at her respite centre, her rescue medicine didn’t work AGAIN and her seizure persisted for 57 minutes. She ended up with a supported airway and IV drugs and fluids being syringed in really quickly. Recovery took 3 days.

The rescue medication usually works, but on occasion when my son has had 2 doses in 24hrs it makes his breathing shallow and blue around the lips, very frightening!

We’ve had to use it many times over the years. It never gets easier to use, recovery times differ each time depending on the seizure, we’ve had to go into hospital for recovery a couple of times also.

The last time we used rescue medications was to stop a cycle of clusters. It worked within a couple of minutes. This was at home with paramedics present, as my daughter always desats on rescue meds and requires oxygen.

It can take a few hours for my heart rate to return to normal after using the rescue medication.

I often worry my son will aspirate the oral rescue medication. Often it is ineffective. We have tried rectal medication but this caused him to stop breathing.

It never gets easier to use rescue medications, recovery times differ each time depending on the seizure; we’ve had to go into hospital for recovery a couple of times.
Epilepsy Medicines: Requirements

There is a wide variations in taking and storing epilepsy medications

**Taking Medications:**

- Most take their medication at regular hours at home
- Some simply carry medications with them
- Others must take the medication at rigid times with careful monitoring of food
- A few also have become socially isolated due to medication needs

**Storing/Administering Medications outside the home environment:**

- Most must keep their medications in locked cupboards at work/school
- Some require care plans in place at work/school
- Others must have specially trained staff available or they may not attend work/school
- A few must sign medications in and out of activities
Main Caregiver

Who is your **main caregiver**?

- Parent: 42%
- Patient: 40%
- Spouse: 13%
- Adult Child: 3%
- Other: 2%

*Other – Grandmother, Friend, Assistance Dog, Employed Caregiver

How happy are you with the **support** you receive?

Only ~45% of respondents are happy with the support they receive.

- Not happy: 14.2%
- Somewhat happy: 18.7%
- Very happy: 31.0%
- Extremely happy: 23.2%
Improvements to Cope

What one thing would make **coping** with epilepsy easier for you?

~35% of respondents cited some type of **increased support** as their main need.

The largest single mention was for **better public awareness and understanding**, followed by **better medicines and treatments**.
Support: Issues

Accepting and providing support can be hard

"I feel guilty that my children have to be my carer at times; guilty that my condition has caused my family upset and stress."

"I may look fine on the outside but I am fragile and have to look after myself more carefully, like go home early on a night out and limit alcohol content. Don’t make me feel like I am somehow lesser for needing to do this."

"It’s hard that I need someone to look out for me even during my seizure free moments."

Others need to realise that support involves more than ensuring medications are taken and coping with episodes...

"Epilepsy isn’t just having a seizure, everything exhausts you even in the prolonged periods without seizures."

"For more understanding in the workplace. I am criticised for not being as quick as every one else."

"More understanding from my employers about needing time out after a seizure."

"I cannot drive and struggle to attend my son’s clinic appointments as public transport to the clinic hospital is non existent."

"Support for caregiver’s mental health, as we often give up work to care; being sent home from hospital saying ‘you are great at this, call us if you need us’ isn’t sufficient.."

"Benefit advice is sporadic. Blue badge is impossible to get even though some days its vital."

"Parents often need financial help as they can’t always work due to needing to go to lots of hospital visits and child having days off school."
Awareness

Who knows or should know about patient’s epilepsy?

- Friends: 134
- Parents: 115
- Siblings: 111
- Spouse: 98
- Children: 94
- First Aider/Occupational Health: 105
- Teachers/Managers/Instructors: 90
- Colleagues: 71
- Others: 7

*Other (7) -
Everyone (2), All family, parents of friends, boyfriend, neighbors, babysitter

"Everybody I know is aware. It’s not fair not to tell people in case something happens."
**Awareness**: Emergency Responders

How do you let **emergency responders** know you have epilepsy?

- **Nothing**: 80
- **Medical bracelet/ necklace/ tag**: 49
- **Epilepsy card**: 49
- **Phone Note**: 6
- **Other**: 7

*Other*: Wearable alarm (3), Assistance Dog, Red Flag with ambulance service, tattoo, home alarm

N=168
Support Groups

Are you a member of an epilepsy support group?

- Yes: As Patient
  - 13%
- Yes: As Caregiver
  - 21%
- NO
  - 66%

What type of support group?

- Online
  - 63%
- National
  - 16%
- Local
  - 12%
- International
  - 9%

N=168
>60% of respondents believe it is helpful to have online access to information on the disease itself and treatments.
Messages: for New Patients

First of all, accept that you have the disease (21) and then ensure you keep living your life (21) to the best of your limitations. Make sure you keep reaching out to others (8), it isn’t contagious, your friends and family won’t catch it (3).

It’s a complex disease, with different types of seizures, different triggers and every seizure is different (18) and is about more than just the seizures (8). So empower yourself (18) with as much information as you can get, from a variety of source. Trust your body and your instincts (4), and keep trying different medications (8) and medication combinations until it works.

It’s a scary disease (12), that will impact your day to day life (12) and leave you feeling vulnerable and embarrassed (6). So do what you can to take control of the disease via adhering to routines (5) and knowing your own triggers and limitations (5). Recognise that you will need assistance in both your day to day tasks and post seizure recovery (5).

Two very useful bit of practical advice: (1) Keep a log of your seizures with descriptions for reference, as your mind will go blank at appointments. (2) Make plans but be aware they may have to be cancelled at the last minute.
Messages: for Friends and Family

First of all, I am not an epileptic, I am a person with epilepsy (18) so see the person behind the disease.

Remember, it’s a complex disease, with different types of seizures, different triggers and every seizure is different (18) and is about more than just the seizures (8).

It is very hard work coping with this disease (13), it impacts my day-to-day activities (12). Even when I don’t have a seizure, I feel vulnerable (6). When I do have a seizure, I am embarrassed (6) and exhausted afterwards (7).

Please be aware of all facets of my individual manifestation of this disease (6) and ready to help me recover afterwards (6), maybe by specific training (3).

One very useful bit of practical advice: Remember that I am not joining in activities not because I don’t want to, but because I would rather be safe.
Messages to Healthcare Professionals and Pharmaceutical Companies

~40% of the messages related to the difficulties of having epilepsy

- 23 Wide range of impacts on the patient
- 19 Difficulty coping with epilepsy
- 15 Impacts on the family
- 11 Impacts on patient’s mental health

~35% of the messages related to HCP interactions

- 18 HCPs should provide better information
- 17 HCPs should be more understanding
- 14 HCPs should be better informed
- 9 Need improved access to HCPs

~25% of the messages related to the medications

- 22 Side effects
- 15 General Medication Issues
- 9 Difficulty with prescription
- 5 CBD access

N=183
## Quotes: Difficulties of Having Epilepsy

<table>
<thead>
<tr>
<th>Wide range of impacts on patient</th>
<th>Difficulty coping with epilepsy</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Episodes aren’t just about seizures and their injuries — they cause changes in mood, tiredness, brain fog, and cognitive processing as well.</td>
<td>• Its mentally and physically draining.</td>
</tr>
<tr>
<td>• It impacts all aspects of my life — driving, work, social, children, confidence, fear.</td>
<td>• It isn’t as easy as taking medications; having epilepsy is exhausting.</td>
</tr>
<tr>
<td>• There is a rollercoaster of emotions trying to get seizures under control and the unpredictability of the disease.</td>
<td>• Epilepsy is horrible and hard to deal with on a daily basis.</td>
</tr>
<tr>
<td></td>
<td>• Please don’t treat it as a lesser illness, even if the medications are working and we haven’t had a seizure in 8 months, it still effects our lives.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Impacts on family</th>
<th>Impacts on patient’s mental health</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Its hard, the family need as much support as the patient.</td>
<td>• There is a rollercoaster of emotions trying to get seizures under control and the unpredictability of the disease.</td>
</tr>
<tr>
<td>• It is very tiring, patients and caregivers never fully relax.</td>
<td>• There is a huge emotional toll, your life is restricted and you are constantly worried about when your next seizure is coming.</td>
</tr>
<tr>
<td>• Epilepsy doesn’t just effect the patient, it effects the caregiver and the entire family.</td>
<td>• Epilepsy and depression tend to go together.</td>
</tr>
</tbody>
</table>
### Quotes: HCP Interactions

<table>
<thead>
<tr>
<th>HCPs should be better informed</th>
<th>HCPs should be more understanding</th>
</tr>
</thead>
<tbody>
<tr>
<td>• We are all different; no two patients, no two seizures are the same.</td>
<td>• HCPs need to believe their patients more.</td>
</tr>
<tr>
<td>• Seizures aren’t the only impacts.</td>
<td>• I wish they would understand on a more personal level, not just medical.</td>
</tr>
<tr>
<td>• Understand that people with epilepsy don’t just have one trigger or one type of seizure.</td>
<td>• Learn to listen more to patients and their caregivers.</td>
</tr>
<tr>
<td>• Not everyone is the same; not all epilepsy seizures are tonic/clonic.</td>
<td>• Be more compassionate.</td>
</tr>
<tr>
<td>• I think there have been advances in or more information regarding AEDs, but I haven’t been made aware of these.</td>
<td>• It can be very delicate managing epilepsy; if a patient complains about side effects they should be listened to and not need to collapse in front of a moving car.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>HCPs should provide better information</th>
<th>Need improved access to HCPs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Breakdown information to a level patients and parent’s can understand.</td>
<td>• Music can be a trigger – get rid of the ‘on hold’ music PLEASE!</td>
</tr>
<tr>
<td>• We don’t get information or answers in a timely manner.</td>
<td>• Please can we have sufficient check-ups to ensure we are okay?</td>
</tr>
<tr>
<td>• Please can explanations be made in a gentle manner? I was unable to take in the information from the nurse when my son was first diagnosed due to being overwhelmed.</td>
<td>• Sometimes things change, but you can’t get onto the doctor’s schedule for 8 months; it can be scary and frustrating for the patient and their family.</td>
</tr>
</tbody>
</table>
Quotes: Medications

Side effects
- The drugs are dreadful; my head is always foggy.
- My daughter says she would rather have seizures than medications sometimes.
- It’s hard to take medication that causes side effects that get in the way of day-to-day life; especially as they don’t work to fully control seizures.
- The impact on my cognitive function is too high a price to pay for the small amount of seizure ‘control’ gained.

General medication issues
- Please can you develop tablets to take once a day, not two or three times?
- I wish there were other options that worked.
- Adding more AEDs is not always the answer.
- The taste of the medicine – it’s hard for a 6 year old to take.
- Please can we have more information on the potential long-term side effects of the medications?
- Children struggle to take the tablets.

Difficulties with prescriptions
- Make it easier to get repeat prescriptions.
- Appreciate that it’s important to consistently take the same brand of medication and not swap between generic and branded versions.
- We need more than one month’s supply of medications at a time.

CBD access
- Please provide better access to CBD.
- Please can CBD be made more easily available in the UK.
- CBD can work, and we need to fight for it to be allowed in the UK.
- Cannabis oil stops my seizures.
Thank You

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Many thanks to our respondents