



EXPLORING EPILEPSY AND THE FAMILY

A report from the Global Youth Team of the International Bureau for Epilepsy [IBE] on International Day of Families 2023.

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ACKNOWLEDGEMENTS

Firstly, we would like to give a big thank you to our families. To our parents, siblings, grandparents and our wider family. We have become the people we are now, thanks to you. And we would like to dedicate this article to you.

We would also like to acknowledge and sincerely thank the family members who shared their experiences with us. We hope the article reflects and does justice to your experiences. Thank you to the wider Youth Team, who have guided the development of this article.

Finally, thank you to IBE staff members, Claire, Marie and Donna, who have supported this project.

Thank you 

ABOUT THE IBE GLOBAL YOUTH TEAM

The IBE Youth Team connects young people with epilepsy around the world, develops young epilepsy advocates and enables them to partner with those working across epilepsy research, healthcare and policy making. The Youth Team meets monthly to discuss and shape the IBE Youth Programme.

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INTRODUCTION

Family is a fundamental part of our lives. We need it to grow and develop. It is the family that instills our values, and within it, we receive the support we need to become independent individuals.

Family becomes even more important when we suffer from a health condition. Whilst it is impossible, due to the informality of the caregiving role, to estimate how many caregivers there are in the world, a recent study showed that there are approximately 100 million carers across Europe [1], that's 20% of the population.



Specifically, for people living with epilepsy, the role of family and the support it offers is crucial for them to move forward and develop fully.

Epilepsy is a common neurological condition and has been described as the most frequent chronic neurological condition in childhood [2]. Around 50% of cases of epilepsy are diagnosed in childhood [3]. This means that caring often predominantly falls on parents and other family members. This can involve dealing with medicines and medical equipment, post seizure care, first aid, tracking and recording seizures and triggers as well as providing emotional support. It requires substantial time, patience and flexibility. This can create a significant mental load for the family member who may also need to balance their caregiving duties with demands from their home, work and social life.

For young people with epilepsy, the role of family is crucial to support their development and allow them to reach their true potential. In many cases, people who live with epilepsy express that it is thanks to their family (and often specifically their parents), that they have achieved what they have. Whilst the impact of managing seizures on parents has previously been described [4], we further explore the experiences and perspectives of how epilepsy impacts family members, including parents, siblings, and the wider family.

APPROACH

Youth Team members worked with IBE to design a short questionnaire to be shared with their own family members. Questions were mostly open text and explored the experiences their family members in relation to the epilepsy diagnosis of their loved one, and the impact of epilepsy on:

- family dynamics and life
- them as a caregiver
- their loved one with epilepsy
- the wider family.

Eight family members responded, representing the perspectives of parents and siblings, and reflecting on the role of the wider family.

IMPACT ON PARENTS AND FAMILY LIFE

Parents shared feelings of devastation, pain and anguish after receiving an epilepsy diagnosis for their loved one, specifically writing about the uncertainty around seizures, and helplessness they felt.

It was almost three very difficult years, full of anguish, pain, and without knowing how her seizures would evolve.

Family members also wrote about the uncertainty of how their loved one's life would turn out. Fears were expressed about life struggles and missing out on opportunities including school, marriage or having children. The social impact and stigmatisation of the condition were often their biggest concern.

Each seizure attack was new to me and I never knew how to deal with it... the fear was that I might lose my child..

An epilepsy diagnosis for a child and the life that ensues is a heavy weight to bear. Parents of Youth Team members described the constant fear and worry for their loved one.

Constant fear and worry are a daily struggle for me... there is no way to explain to friends and sometimes family the true impact... it's lonely and difficult.

They shared that they need to always be ready, always being there for their child, never being able to fully relax – watching, from a distance, "just in case". Parents wrote about their determination to live a normal life, to not let epilepsy impact their life, but "it's always there".

“ We start to live, start to forget and then a seizure happens, bruises show up blood and bitten tongue and we have the rug ripped out from us again and we have to start over, we have to learn to breathe and live again without the fear and it is a cycle. ”

With this comes the struggle of finding the right balance between protecting and caring for their loved one, whilst ensuring they were able to live life to the fullest.

“ We wanted to protect her, shelter her but also didn't want to hold her back, how do we balance both worlds? ”

“ I have learned to follow her lead and work hard to try and not let my fears, our fears, impact what she does or hold her back ”

IMPACT ON SIBLINGS

Often, when we think of people living with epilepsy and its impact, we think of the person experiencing seizures and their parents/caregivers. The siblings are often overlooked but the impact on siblings is not trivial. Due to the pressing needs of the person with epilepsy, parents often focus their attention on them. According to our survey, this can mean that the sibling(s) do not receive the attention they need. This can have negative repercussions on their quality of life.

Moreover, when it comes to younger siblings, our evidence suggests that they often do not understand epilepsy, and this can cause fear and anxiety – particularly when they witness seizures. An older sibling was described as “very scared” at seeing their sister’s seizures and deeply affected by seeing their sister suffer generally.

They have been robbed of the full attention, support and love that they use to receive as individuals from us their parents because we need to give much attention, love and support to the other child living with epilepsy

Youth Team member Lorraine Lally reflects on the impact on her younger sibling:

Epilepsy can be lonely, but we are not always alone in our daily routine. Epilepsy is not always easy to understand, especially for a child sibling.

I remember my younger brother being upset and angry with me for having seizures, particularly once when I had a full tonic clonic seizure when we were home alone together at Christmas. The sound I had made frightened my brother (and the cat), and he couldn't understand how I could not know. His anger, fear and sadness surprised me, but it makes you realise that the epilepsy lives in the house with you all.

The worry and fear that siblings experience can be as substantial as that felt by parents.

Despite the worry and fear they experience, siblings are also an incredible support system for their brother or sister with epilepsy. Many reported educating themselves about epilepsy and taking responsibility for ensuring their loved one does not miss out or fall behind. Siblings can also be fierce protectors, and caregivers themselves.

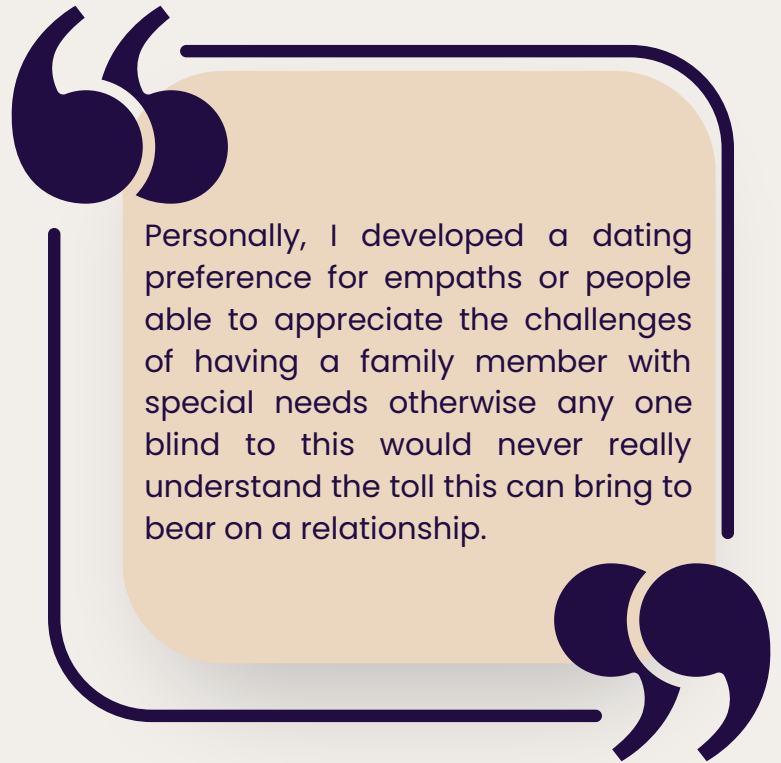
“One day my son asked me if I knew how hard all this was on him. He said “do you know when I am not home and my phone rings especially at night and it is your name, my heart stops and I am afraid to answer because what if this is the call where I hear I lost my sister, that her epilepsy took her away”

“Her older sister was in charge of bringing her notebooks from school so that she would not fall too far behind in her studies”

“My biggest fears were that I'd lose my sister or that something terrible would happen to her as a result of her living with epilepsy. Later my fears changed more to a concern about how the community would be accepting of her.. Over time I became protective and more deliberate about creating more safe zones or spaces where she could interact.”

“They are always there for him. They are sympathetic and understanding.”

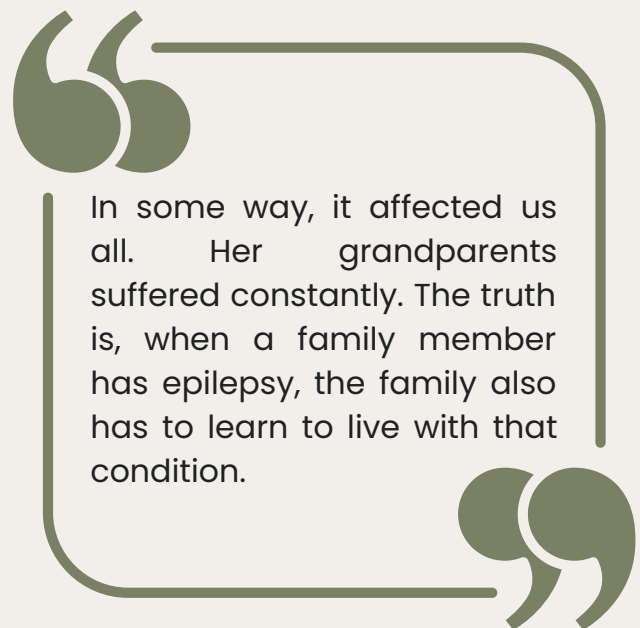
The impact on siblings can also impact their life decisions, such as who they choose to be with as a partner.




THE ROLE OF THE WIDER FAMILY

Some family members described the devastation felt by the wider family, as well as their vital role in supporting the care of the person with epilepsy and/or their siblings.

The psychological impact of worry for the parents and the person with epilepsy can be hard to communicate to others. Wider family not being there to witness the lived experience can, it was reported, lead to a lack of understanding of the impact of epilepsy. This can include misunderstanding the side effects of medication, the time that is spent recovering after a seizure, or that epilepsy can often cause broken bones, bloody nostrils, bruises and cuts and other injuries. According to respondents, this can lead to family members thinking parents are just being overprotective, 'helicopter parents'.





Some people do not actually believe she has many limitations stemming from the condition. The medication alone has some negative physiological and psychological effects that to date even some family members have challenges understanding.

In addition, social stigma, which people with epilepsy can experience in every part of the world, can also be present within families.

Youth Team member Lorraine Lally reflects on the different responses to her epilepsy and acceptance from her own wider family members:

“You are perfect as you are and you change for nobody.” The famous words of my grandmother who was filled with unconditional love for me as a granddaughter. She was not familiar with my medication and she never asked any questions about the seizures. She prayed for me and she was convinced that everything would be fine.”

“My uncles were so good...they were farmers and builders were supportive with practical actions not with words”

“My aunt worried that I spent too much time talking about my condition. My aunt loves me and she wants a full, happy life for me without epilepsy. She has a beautiful dream and I understand her position.”

It's taken while but I've also understood that stigma can also happen within the family. It can present as shame and a fear of being associated with having someone in the family with the condition. This realisation comes with an understanding that not everyone will be supportive.

IMPACT ON LOVED ONES WITH EPILEPSY

Whilst this article is focused on exploring and sharing the experiences of family members of people with epilepsy, those we heard from overwhelmingly shared their thoughts, love, and admiration for their loved one with epilepsy.

As well as stories of adversity, and continued challenges, family members shared their pride about people with epilepsy who went on to achieve amazing things. This includes going to university, holding successful careers, working or volunteering to raise awareness of epilepsy, or serving and supporting others with epilepsy.

I have seen her seizures impact her mental health, I have seen her be tired and frustrated... The memory loss, the missing out on events and milestones impact her. However, she takes the time to decompress, rethink and figure out how to look at it in a different light.

She never thought that people living with epilepsy could go further and pursue their education. It really impacted her negatively.



I have witnessed his struggles with depression, anxiety, and self-doubt... I have also witnessed his acceptance of his disease, and watched him provide assistance and encouragement for others with epilepsy. He has found his voice and is willing to help himself and others.



A clear sense of pride is apparent from the responses, but also a message of hope.

We heard that with love and support, people with epilepsy can go on to achieve everything that others can achieve, and more! The IBE Global Youth Team are an example of just that.

SUMMARY

Reflecting on the data collected, common themes emerged.

- Almost all respondents spoke about constant fear, worry and loneliness due to the impact of epilepsy on their loved one, particularly the unpredictability of seizures. This was not just limited to parents, but to siblings and the wider family, who can also be caregivers.
- Despite the heavy burden, all respondents expressed a desire to maintain a 'normal life', and showcased resiliency, optimism and hope for the future.
- A major gap, worldwide, was highlighted in terms of providing support to people with epilepsy and their loved ones – as well as improving the health literacy of those directly impacted and wider society.
- Decreasing stigma is essential if we wish to create a more epilepsy-friendly society where people with epilepsy are not exposed to such high levels of social stigma, discrimination and exclusion – and the burden of care does not weigh so heavily on the shoulders of their families.

FURTHER WORK

The IBE Youth Team would like to expand this work to gain a deeper understanding of the experience of family members. Having heard from a majority of mothers, the team would like to hear from more fathers, siblings and members of the wider family. The team is also interested in exploring how these experiences differ in terms of country and region, despite many commonalities emerging across the geographies in this small sample. Generating more quantitative data to support the qualitative sharing of insights and experience would also be useful.

RECOMMENDATIONS TO THE EPILEPSY COMMUNITY AND BEYOND

1. Recognising, raising awareness of the impact of epilepsy on siblings, as well as providing adequate support for siblings is of major importance. Epilepsy organisations around the world should ensure siblings have adequate support and are able to get involved in and contribute to epilepsy related projects and activities.
2. Reducing stigma and increasing health literacy is essential. We know that the stigma of epilepsy is experienced no matter where you are in the world, and its impact can be devastating [5]. We must raise awareness of epilepsy, do more to reduce stigma and encourage, support and enable people with epilepsy and their families to have more open conversations about epilepsy.

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GET IN TOUCH

If you would like to comment on this article or the topic, share your views, or further information or resources on this topic please get in touch by emailing engagement@ibe-epilepsy.org

ABOUT THE AUTHORS



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My experience of epilepsy during my childhood lead me to become a neuro-pediatric physiotherapist, and gain an MSc in Clinical Neuroscience at University College, London. I am also working with others to develop a Latin American Epilepsy Youth Group.



LORRAINE LALLY, IRELAND

I'm a practicing barrister and mediator and a member of the Bar Council of Ireland. I believe there is a need to support people with the condition and to educate others about life with epilepsy. I am also a member of the Irish National Disability Authority.



CASSIDY MEGAN , CANADA

I am the founder of Purple Day. which is an international grassroots effort dedicated to increasing awareness about epilepsy worldwide. I am also a competitive archer, a model and a professional Sound Recordist, working in the film industry.



SCARLETT PAIGE, AUSTRALIA

I am the Chair of the IBE's Global Youth Team, and an Epilepsy Ambassador in Australia. My role as Chair of the Global Youth Team sees me lead and mentor 16 young people from around the world to work together. I'm proud to have such a strong team.