



Adel Bounif lives in the North East of France. He is the father of an 11 year old girl with Dravet syndrome, a rare genetic epilepsy condition.

Adel Bounif  
France



My daughter is 11 years old and is suffering from Dravet syndrome. It is a rare genetic epileptic encephalopathy.

The disease begins in infancy but is lifelong because there is no cure.

Infants have normal development at the time the seizures begin. Yet as seizures continue, most children develop some level of developmental disability and other conditions associated with the syndrome.



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About 8 out of 10 people with this syndrome have a gene mutation that causes problems in the way that ion channels in the brain work. This mutation is most often not inherited from the parents but is considered a de novo or "new" mutation in the child.

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In order to make people aware of this rare disease, I have decided to be an advocate for the epilepsy community.

I wrote a book in order to raise awareness about epilepsy and also to make politicians and pharmaceutical labs aware in order to develop research and laboratory tests.

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I have also published a comic for children which gives me the opportunity to go to schools in order to educate children about epilepsy and the stigma linked to this condition.

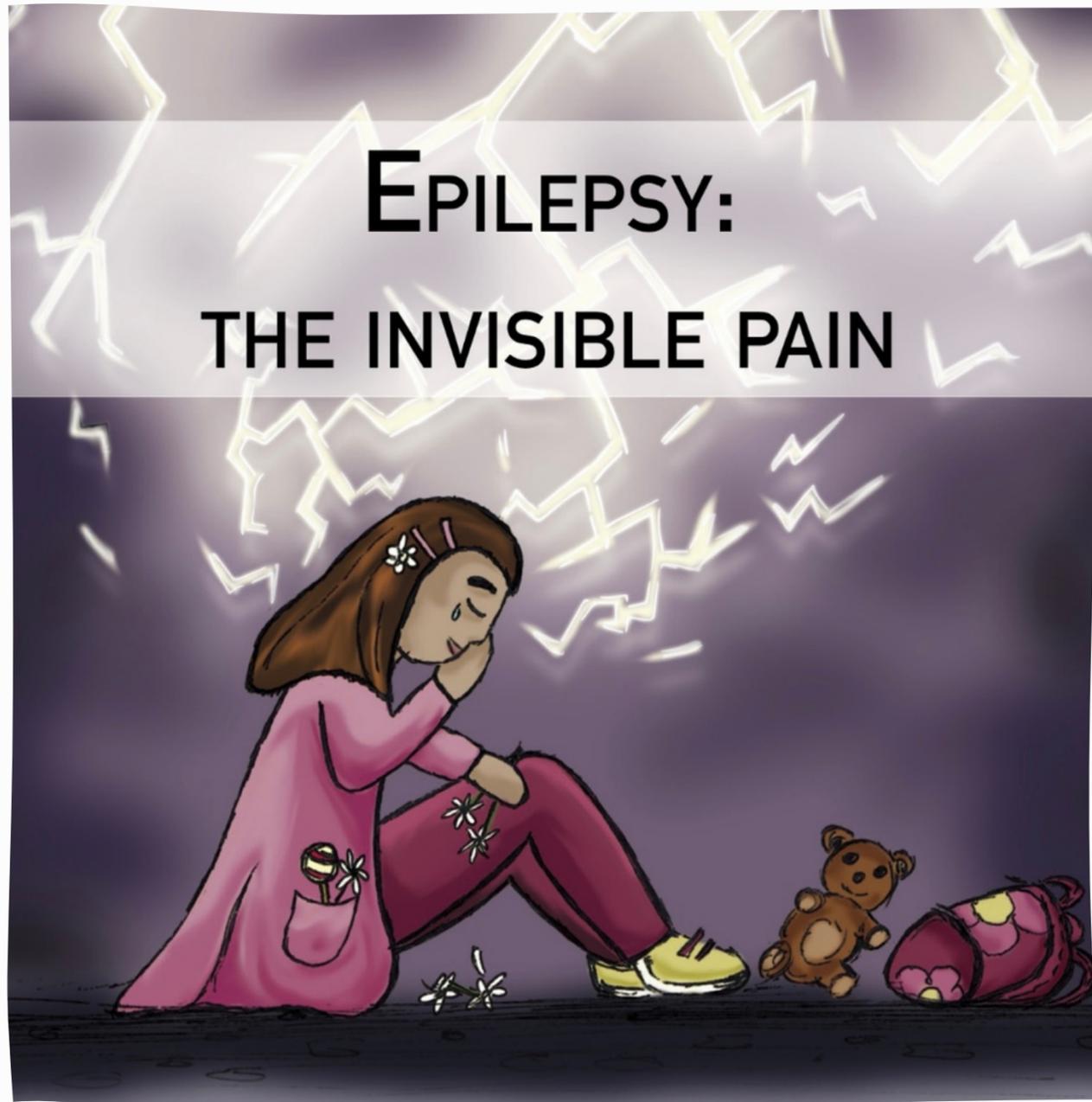
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Caregiving often calls us to lean into love we didn't know was possible. Caregiving gives you courage and strength despite chronic stress and restless sleep. It's not the daily issues that break you down, it's the way you carry them. Although your heart is broken, you try to push yourself every day for your child.

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# EPILEPSY: THE INVISIBLE PAIN



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Life is not a long stretch of a calm river but there's always a rainbow after the rain. As a caregiver, her fight is my fight!

I will never give up until we find a cure!

I will fight for her but also for all the epileptic people feeling alone and isolated.

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