

Practical issues with epilepsy in childhood

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Practical issues.....When dealing with EPILEPSY

In 30 minutes..

- Where to start...
- And maybe HOW to start.
- ..(many aspects / issues).



However; Practical issues....as a theme

-**Is VERY important and involves focus on:**
- Compliance
- Acute –medication
- Guidance of school / Kindergarten
- Safety
- Alarms
- SUDEP
- How to live everyday life

BUT.....



BUT in order to..

- **Guide on seizure monitoring..**
- **Inform on medication...**
- **Teach on acute medication...**
- **Inform on safety at home..**
- **Hand -out leaflets...**



We need to have the family ONBOARD !

- Meaning;

First of all pay attention in getting a good contact – LISTEN to their story, their *feelings, fear*, and if they are newly diagnosed;

- Have in mind that the initial phase is very burdensome for many families.
- Don` t jump to conclusions about how far people are in the process.



Having the family onboard....

- Ensuring that the ***seizure type, epilepsy classification, and prognosis are articulated*** (“personal medicine” ?)
- Particular be aware of the often severe comorbidity that in some families are more challenging than the actual seizures
- **Before ensuring these issues we will have trouble providing the more rational and concrete advice (*the practical issues*)**



From **THERE**, we can take our families “by the hand”..

- Personalize the approach to THEIR child`s epilepsy and do epilepsy guidance from **here**
- Acknowledge that people google more than anything and therefor need professional help to distinguish and as health professional;

Acknowledge that “One size doesn't fit all”



Why is this so crucial...?

- Numerous publications as well as my own clinical experience during the years illustrates the following themes;
- *The fear from when the first seizure appeared (maybe never talked about it to a health professional!)*
- *The constant uncertainty when trying to get the grip of the diagnosis*
- *The uncertainty, and feeling of GUILT*
- *The fear of next seizure*
- *The impact on the family (protection, isolation)*
- *The often challenging comorbidity (understanding the complexity)*
- **...Issues that will all *interact*, "*disturbs*" and "*block*" if we are not aware and pay attention.**



When a child is diagnosed with epilepsy

- Parents may experience a number of consequences and the family may face many issues.
- Often dealing with feelings such as:
 - *"I've lost my perfect child,"*
 - *"My child will be different now"*
 - *"Am I to blame in this?"*

Leading to the feeling of vulnerability and experience of anger, guilt, shock, denial and grief before finally accepting their child's disorder.

- Particular focus on the impact of the family.



- Family members also may report feelings of;
 - depression
 - helplessness,
 - frustration,
 - low self-esteem
 - high levels of stress (particular due to lack of sleep!)
-
- Parents may blame themselves or their spouse.
 - Siblings often blame themselves. These difficulties may continue as the disorder progresses.



A coping process

- A long process but important to address.
 - A process that starts being facilitated with us (*health professionals*)
 - By doing so we ease the process of integrating the individual knowledge and approach in every family
-
- ***Important: How you react to the diagnosis doesn't necessarily correlate with the severity of the diagnosis***



Coping

- Emotionally



- Socially



- And how to get the right support from the healthcare system as well as the local council.



Important epilepsy advice

Everyday Life:

- Compliance
- Focus on the aspects of each individual Childs 'epilepsy.
- E.g. sensitivity to:
- Lack of sleep
- Excitement
- Autistic features
- Ensure complete understanding of when/how to give acute medication
- **Ensure the child takes part in a normal everyday childhood as much as possible!**
- Alert re. safety: Keep an eye on any child with epilepsy when near water!!



Tailored care through specialist clinics

- Contact to Epilepsy Nurses in the Out-Patient Clinic.
- Parents call for more tailor-made approaches based on the specific needs
- Better self-management through health education
- Fewer epilepsy-related deaths and accidents through risk management
- Empowerment through advice, information & education
- Improved quality of life through counselling and support
- Fewer seizures and fewer side-effects through medicines management/ education



Overall goal

- Assist parents to achieve independence and confidence, helping them become experts in their child's epilepsy through *shared decision* making.





**THANK
YOU
FOR
LISTEN-
ING**

