

Full Inclusion for Children and Young People with Epilepsy

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**This is Jim.
He is six years old. He has black hair and
brown eyes. Jim likes to run, swim, play
and have fun.**

**One day,
while he
was playing,
Jim fell down.
He went stiff
and then he
shook all over.
This lasted for
only one or
two minutes,
but it scared Jim
and his parents.**



Two challenges of epilepsy

1. Epilepsy is a brain impairment that needs to be managed.
2. But children with epilepsy are also at greater risk of being misunderstood and excluded.



Medical condition must be addressed

- Access to proper investigation.
- Control of seizures as much as possible through medical and other procedures.
- Monitoring of effects of medication.
- Continuing medical research.



Different types of epilepsy and seizures

Sally said that at times she just stops what she is doing and stares. These times don't last for very long but she has many of them each day. Sally told Jim that this is called EPILEPSY.



As Jim left, Doctor Smith asked Sally to come into his room. Jim smiled. He knew he had epilepsy and Sally had epilepsy but they were not the same.



Psychosocial impact must be addressed

- “Epilepsy in itself is not a bar to happiness.”
- Attitudes of others about epilepsy have more impact on people than the epilepsy itself.
- Focus on potential to learn and develop as fulfilled persons despite their impairment, rather than on the impairment itself.



Effects of stigma

- Tendency for being viewed as strange and abnormal.
- Anxiety about possible embarrassment.
- Restriction of child's relations with peers and adults.
- “Stigma and the factors that contribute to it should be addressed as the top priority in epilepsy self-management and advocacy.”

Epilepsy and underachievement: Findings

Despite normal intelligence, students with epilepsy:

- Tend to be 1 year behind the expected reading level;
- Had variations in IQ scores by over 10 points over 4 years;
- Tended to repeat grades more often;
- In adolescence drop out of school at higher rates;
- Have deficits in language, visual-spatial function, problem-solving, and adaptive behaviours;
- Have dramatically reduced educational and professional attainment, employment status and likelihood of marriage and future childbearing.

Epilepsy and underachievement: Direct impact on child

- Fear for health.
- Anxiety about unpredictable seizures in public.
- Anxiety about effects of medication.
- Difficulties to cope with school demands.
- Low self esteem as 'different'.
- Depression.



Children need an explanation



'Imagine that your brain is like a still pond. The water is flat. If we throw a stone into that pond, it makes waves.' The waves mess up the still pond, but when the waves stop, the water is still and flat again.'

Doctor Smith says, 'Epilepsy is like those waves on the pond. The waves pass over the brain and make you fall down. After the waves stop you are all right again.'

'What we must do is find out what is making those waves.'

Impact through parents

Parents can greatly influence child's adaptation.

- *May be overprotective, rejecting, or have low expectations of him/her.*

Parents need support to assist their children in attaining the skills which will help them to have fulfilling lives through:

- *accepting and supporting their children as they are;*
- *knowing when to let their children have their own freedom,*
- *encouraging their children to have new experiences*

Impact through educators and peers

Uninformed teachers and peers

- May fail to recognise absences and partial seizures or effects of medication;
- see and treat the child with epilepsy as different;
- feel anxious, confused and unable to meet his or her needs;
- reduce expectations and opportunities for the child's time at school and learning and social development.
- Link with other disabilities may lead to their social exclusion.

Need for collaboration

Two major problems arise in schools:

- a. Parents are in a dilemma about whether to inform the school or not about their child's epilepsy.
- b. Educators have anxieties about taking responsibility for managing a potentially damaging medical condition.

A system for regular communication between home and school, meetings among all who care and educate the child (also including medical personnel) are essential for reducing anxieties and enabling proper management.

Parents can pass on management tips to teachers

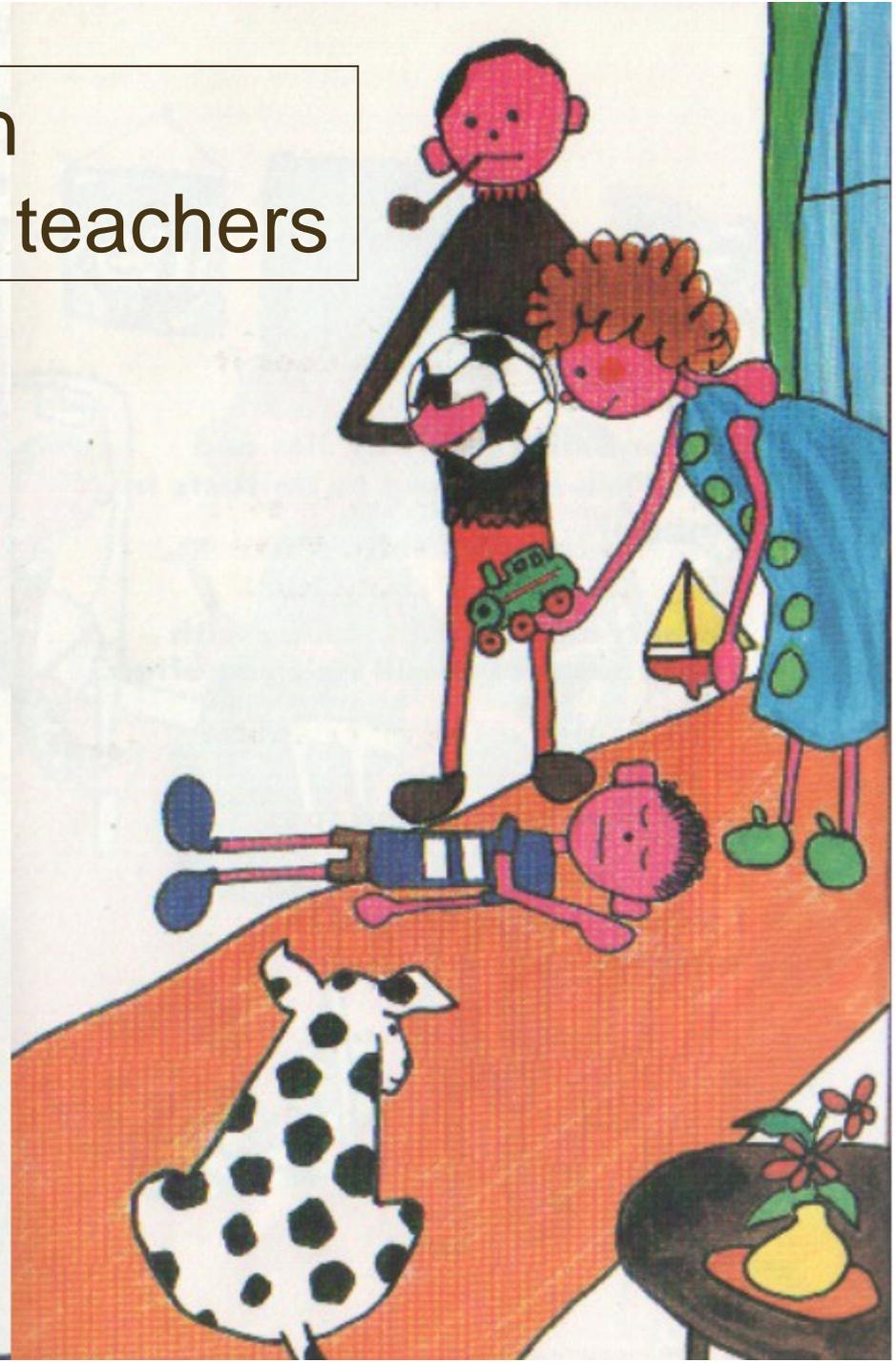
**Mummy asked,
'What do we do if Jim does it
again?'**

**'Stay calm!' Doctor Smith says.
'Roll Jim onto his side. Move
things away that could hurt
him.**

**DO NOT put a finger or spoon
in his mouth.**

**Watch him so that you can tell
me what he did.**

**If he does it again, tell
me, so that I can find out why
the medicine is not working.'**



CONCLUSIONS:

Promote understanding

1. While ensuring best medical assessment and treatment for epilepsy, **we must be aware that stigma, lack of understanding and exclusion have the greatest impact on children's quality of life.**
 - We must support **The Caritas Malta Epilepsy Association** in its efforts to raise wide awareness and understanding of this condition.
 - Research should be undertaken on the experience of Maltese students with epilepsy.

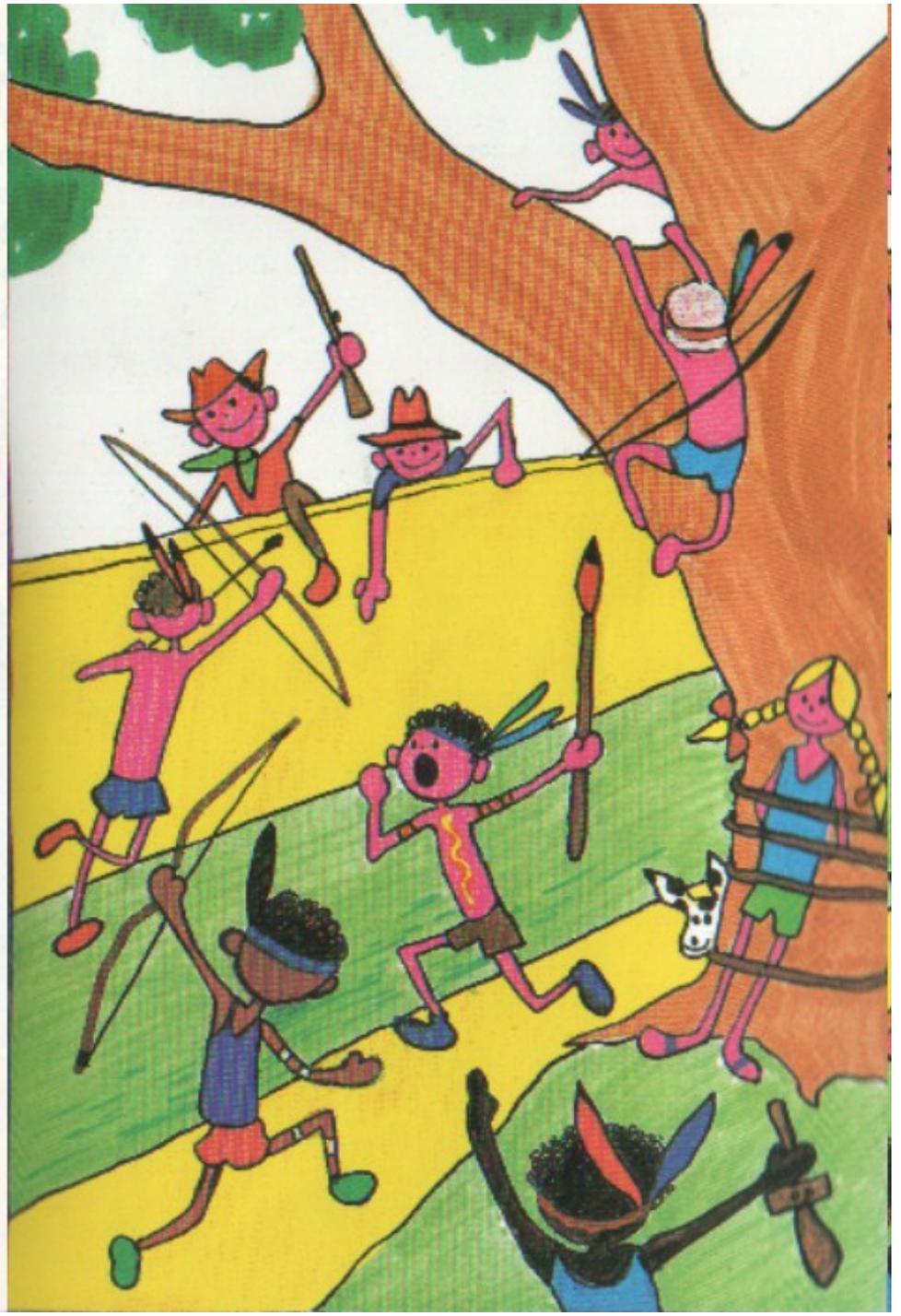
Minimize psychosocial impact

- 2. The negative psychosocial impact can be minimized** through attention to the impact that a diagnosis of seizure has on individuals and their families, and through techniques for motivating children and their families to learn and participate in decision making.
- 3. Parents and teachers** need to be provided with positive information about the child's type of epilepsy, and be trained in its management. They need to be made aware of the learning potential of children with epilepsy, and that "Epilepsy in itself is not a bar to happiness. But the child with no friends will certainly not be happy."

Jim is happier now.



Doctor Smith had answered the questions. Jim knows that if he takes his medicine he is just like the other children who like to run, swim, play and have fun.



Provide direct support to children

4. Help children understand, gain control and learn:
 - Provide general positive approach, counselling and social skills training as needed.
 - Reduce overprotection and allow opportunities for full participation in learning and all other activities with peers.

A collaborative approach

5. An interdisciplinary and collaborative approach is essential.

Develop an effective, accessible system of inter-communication between

- home and school and medical staff;
- parents, teachers, peers, facilitators, health and safety teachers, guidance teachers, psychologists, social workers;

Organise opportunities for sharing feelings, information and skills in understanding and supporting the child's participation and learning in all school activities as well for management of seizures.

Useful references

- www.epilepsyaction.org (UK)
- www.epilepsyfoundation.org (USA)
- www.epilepsyontario.org (Canada)

- Fenwick, P., & Fenwick, E. (1996). *Living with epilepsy: A guide to taking control*. London: Bloomsbury.