

Risk and advice in child neurology

With an increase in inquisitiveness and availability of information about children's problems¹, parents often want to know the risks of various procedures or complications associated with drug treatment, outcomes, or recurrences in childhood neurological disease, (in particular where there is no available therapy).

How do you balance honest and open information about such matters without engendering unnecessary anxiety? Should we simply state the answers to questions only when asked or do we proffer the information anyway and, if so, how?

A mother recently told me that she had taken her child off haloperidol (for Tourette syndrome) because of 'side-effects'. The child did not have any side effects and the drug worked but her perception was that the risk was not justified.

Some of our colleagues, such as geneticists and oncologists, deal with risks all the time but within a somewhat restricted framework. Can we be as expert as they are supposed to be?

Despite information available on the web, there are risks we may be aware of our patients may not be aware of.

What should we tell the family of a child who has had one episode of optic neuritis, or two for that matter, and is otherwise well? Do we mention multiple sclerosis at all and should we test for it? Are we obliged to discuss the implication of every investigative test we do in a child with developmental delay?

Should we discuss all the possible complications of neurofibromatosis 1 (NF1) in a child who simply has café au lait spots? What should we say about the recurrence risk of stroke in children? Do we tell the parents of every child with epilepsy about sudden unexpected death, and if so, at what time in their illness should we tell them?

Surgeons do not usually inform patients of very low risks for operations but in the recent court case of Rogers and Whittaker in Australia (1996), the judge held that the extremely low risk of sympathetic ophthalmitis of less than 1 per 10 000 operations should have been imparted to a

particular individual prior to eye surgery.

Parents often seem aware of the risk of treatments when they are unaware of the risks of not treating at all. The risks of complications of anti-epileptic drugs, for example, must be balanced against the risk of further seizures. Presentation of the data on the effectiveness of anti-convulsant drugs is not easy to explain nor, indeed, always clear cut.

I believe we need good data on such recurrence risks or complications and in order to tailor the risk to the individual (e.g. in NF1 the risk of optic nerve glioma diminishes significantly with age). We must balance such a risk against other real life risks and learn how to communicate this effectively. Calman² has reviewed this concept very well and gives good examples of a hierarchy of risks. He used common words such as high, moderate, very low, and minimal, and gives examples of the level of such risks for a variety of situations which can relate to everyday life (Table I).

This is amplified further using different types of analogy by which risk may be more clearly conveyed, such as the chance of something specific happening to one particular person in a street or a village, a city or a country³.

Our job as health professionals is to treat and care for children and their families to the best of our ability with the most up-to-date knowledge and to inform them appropriately of risks involved for their particular child in a language they can understand, but this does not, I believe, imply that every possible complication or risk needs to be highlighted—any headache might be due to a brain tumour, most are not. As one of my teachers said 'we are paid quite well to reduce anxiety'.

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References

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Table I: Example of Calman's (1996) level of risk hierarchy

Level of risk		Rate of incidence
High	Gastro-intestinal complications of antibiotics	1:10–1:20
Moderate	Death from more natural causes at 40 years of age	1:850
Very low	Death in accident at home	1:26 000
Minimal	Vaccination associated polio	1:1 000 000