Guideline for the management of a child aged 0-18 years with a decreased conscious level

Appendix E

Patient / Parent Representation and Contribution

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1. Patient / Parent Representatives

Patients and parents need to be involved in the development of clinical guidelines as the recommendations will directly affect their clinical care. Parent representation during the development phase ensures the guideline will be patient-centred.

In all aspect of the guideline, parents have been involved.

Contribution	Name
Guideline Development Group	Mr Gordon Denney, Guildford Mr Fountain, Nottingham Mrs Fountain, Nottingham
Stakeholder Groups	National Reye's Syndrome Foundation CLIMB (Children Living with an Inherited Metabolic Diseases) The Encephalitis Society
Patient Testimonies	Mrs P Quinn, Belfast Mr and Mrs Fountain, Nottingham Mrs P Johns, Brighton Mrs J Good. Mr and Mrs Harrington
Patient information leaflet	National Reye's Syndrome Foundation CLIMB (Children Living with an Inherited Metabolic Diseases) The Encephalitis Society Drugs and Therapeutics Bulletin, Which

2. Patient / Parent Testimonies

As part of the guideline development process, parents of children who had suffered illnesses causing a decreased level of consciousness were asked to provide their stories. The testimonies were analysed for common themes. These were then incorporated into the recommendations of good practice points.

Below are the testimonies received (anonymised):

Son had Reye's 1985
Diagnosis delayed by 3 days – guideline could have helped on admission "Drowsy" or the following day when he had a prolonged convulsion.
Background – ex prem 30/40 NEC aged 7.5 months had viral symptoms, given aspirin, became drowsy, needed oxygen but sats not coming up. couldn't get a drip into him, he picked up a bit but then had a fit 5am. Blood glucose about 2.5 at one point. transferred to bigger hospital (without cannula), he arrested twice in the ambulance with adrenaline injected into his heart. Eventual diagnosis made by peter robinson / john Glasgow. No LP done. ICP raised but not dramatically. ?ammonia level.

Son had Reye's 1986
Diagnosis delayed by 24hrs – guideline could have helped on admission with blood tests, prevented LP and earlier management of raised ICP.
Background – healthy boy aged 13 had nasty flu like illness. Took aspirin became drowsy over 24hrs, saw GP 3 times sent in to hospital early saturday with decerebrate posturing. LP performed, to PICU not ventilated, diagnosis reached on the Sunday ?ammonia level sent. Raised ICP with monitoring in situ. Died on Monday peri-op for relieving pressure.

My daughter, *******, was taken ill at the age of 6 months in August 1971 with what, at first, appeared to be something like meningitis.

Meryl was rushed into hospital by our quick-thinking G.P. as she had been sick and had become very drowsy. She was admitted to the Royal Alexandra Hospital for Sick Children in Brighton, and tests were done for everything the paediatrician could think of. This included lumbar puncture which I was excluded from witnessing as ******** was so very ill. Dr.********* (the paediatrician involved) was unable to come up with a diagnosis but contacted a liver specialist and a brain surgeon from London who came down to Brighton to examine *********l. This produced the diagnosis of Reye's Syndrome.
******** had sunk into a very deep coma and apparently had to be resuscitated several times. Her liver had swelled and there was a blood clot which, luckily, was between the skull and her scalp and this dispersed on its own.

My daughter had not been given aspirin, but one of her older siblings (I have four children in total) had suffered from a mild tummy bug about a week prior to ******** becoming so ill.

I cannot praise Dr. ********** highly enough. He shielded me from some of ********'s symptoms which I fully understood as I had other children to care for, but kept me informed as to how she was being cared for and her progress. For the first week or so ******** had a nurse with her 24 hrs. a day which I think was of tremendous help as any slight change could be monitored.
Sadly, ******** has been left with learning difficulties and epilepsy (which is not totally controlled, but is so much improved by the advent of new medication).

I believe I was fortunate in having a very alert G.P. and the care of dedicated staff in the hospital. The early diagnosis is immensely important, and we are very lucky indeed to have ******** with us.

There is no-one else in the immediate family, including my grandchild, who
have ever shown signs of this type of illness.

I have been sent details of the above via the Reyes syndrome foundation, asking for my comments. I am not sure I can be of help.

My son died 15 years ago with what was first thought reyes, but the diagnosis was revised very shortly afterwards when test results were received, to the inborn error of metabolism MCAD. My son had a very short episode of D & V, a visit to the GP, advice given to fast for 24 hrs!! - in hindsight this was obviously the worst thing to do.

My son went to bed that evening, I assumed sleepy from being unwell, and sadly I found him dead the following morning.

So I dont think I can be of help with your guidelines, however, if you think I can, or can answer any questions that may help you, please let me know

Our eldest daughter ***** was atypical Reye's sydrome patient. Recovering from a viral infection, she began to vomit and on 15th October 1981, the doctor was called to visit her. He arrived at the house around 12.00 noon and prescribed an anti vomiting drug (Maxelon - not sure how one spells the name). He gave a number of tablets to us with instructions on how often and when to give the tablets to *****.

She was given one tablet which she ingested just after the doctor left. At that time she was sleepy. As the afternoon wore on the vomiting became more acute and at 16.30 when she was given a get well card she looked at and was unaware it was upside down. At 19.30 she was unable to rouse herself and was unaware when she was vomiting. Another doctor from the practice was called and he arrived around 20 00 hours.

An ambulance was called and ***** tried to put her arm into her dressing gown - she was unable to do this. We carried her into the ambulance and she was unconscious for the whole journey that took around 20 minutes.

At the hospital the doctors thought she was suffering from Maxelon poisoning. She had ingested one tablet and vomited another whilst yet another was not given as she was unable to respond to us and the tablet was thrown down the lavatory. The first G.P. stated he had prescribed 30 tablets but only 18 could be accounted for. We knew that ***** could not have reached the tablets which had been placed in a kitchen cabinet in an egg cup - high out of reach of children. ***** was therefore given an anti - dote for maxelon poisoning but to no avail. Subsequent blood tests revealed that she had not over dosed on maxelon.

***** began to be very aggitated - both of us spoke to her continuously to reassure her we were there. She was given a lumber puncture and we recall that Doctors had some difficutly as she was so aggitated. Very gradually she slipped violently into a coma around 2.30. The paediatrician told us at 10.00 that she had encephalitis - there were 3 possible outcomes he said - "She could recover fully, she could live but be very brain damaged or she chould die - don't know which one it will be but I'll leave you now."

***** was admitted around 16.30 on 16th October to Great Ormond Street Hospital and never regained consciousness. ***** died on 20th October 1981.