



Factsheet 1

An overview of CHARGE syndrome – A practitioner's viewpoint

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Children with CHARGE syndrome have significant complications that may include medical, vision, hearing, sensory, self-regulation and behaviour, cognitive, and communication. The severity of these complications may prompt the question: What will the quality of life be for this child? And as this child with CHARGE survives and grows, parents may also ask, how will my child learn?

The family

Based on practitioners' experience, the best responses to these questions come from other families of children with CHARGE. These families embrace the challenges, and ultimately have a positive influence on the medical practitioners and educators in the field.

One might be tempted to conclude that "life is good" and that the children's quality of life just happens. In fact, the work of a team in collaboration with the parents enhances the quality of life of a child with CHARGE.

It is the family, however, that builds and will continue to build the foundations. The focus is constant and for many years will be on the medical and sensory challenges as well as the special strategies for learning. The resounding and common outcome is that a child with CHARGE thrives, learns and becomes an active member in the family and in the community.

A network of support

As a child with CHARGE continues to grow and develop – both medically and educationally – the families continue to meet people who want to help, who have met a child with CHARGE, and who often remain committed to supporting this family.



The layers of complexity that a child with CHARGE presents with can be overwhelming for both the family and the practitioners. More and more medical practitioners are better informed about diagnosing a child with CHARGE and, as a result, children are identified at a very young age.

There are impressive networks becoming more established and, as a result, families may have access to support almost immediately after the diagnosis. The team of people who come in contact with the baby with CHARGE will continue to expand over the life of the child. When the child is young, the emphasis is to ensure that all medical disciplines are involved.

The wider team includes practitioners in the fields of vision and hearing and communication, physiotherapy, occupational therapy, and other disciplines. Practitioners



have a unique opportunity to support and educate the family as well as to learn from the family about this wonderful baby with CHARGE.

Families need to develop a network of support from a wide variety of people who become involved in the caretaking, nurturing, and overall education of the child. As they work with suppliers of equipment, speech therapists and audiologists, vision specialists, behaviour support, and nursing agencies they share what they know and the networks grow.

These networks often include other families who have a child with CHARGE. As a group, these families are often very well informed and consistently reach out to meet other families of a child with CHARGE, with all benefitting from this network of support.

The web of support is too complicated to draw or to illustrate. It would have lines and circles and arrows that criss-cross. The child with CHARGE experiences this every day when one considers the physical, medical, behavioural and sensory challenges, the impact of deafblindness, and the integration of the complexity of all these issues.

Describing the child with CHARGE

When practitioners ask parents to describe their child with CHARGE, the list is not only impressive but also shows common personality characteristics from one child to another.

The list could include:

- extreme determination
- a 'doesn't give up' attitude and incredible resilience
- an ability to learn and be successful, especially when practitioners respect the family and the child and 'listen' to the family's description
- communicates in atypical ways and will want help with this – behaviour is communication for the child with CHARGE
- enjoys repetitive things, likes routines and structure
- endearing
- brings new life to the family
- has a great sense of humour.

Making decisions

At the end of the day, the parents/carers are the ones who know the child best. It is ultimately up to them to make the treatment/educational decisions as the 'boss' of the team. They must be respected and supported. It is the job of the practitioner to stay up to date with the child's progress and to share with parents/carers all information that might contribute to the best decisions for the child.

It is not easy to make all of these seemingly never-ending decisions. However, it is easier if the family has a team that supports them to ask questions and get some answers – even if not all questions can be answered at this time.

In the end, the **determination**, the **smile**, the **sense of humour** and the **love for life** all win out.

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