



Factsheet 21

A parent's perspective

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Where to start?

Should this be a personal rant about what it means to be a parent whose child was born with CHARGE – or an impersonal observation of what a parent and their child needs from any professional involved with them? I'm going to try to find a balance.

It should be one of the happiest days of your life when your child is born, but your baby is rushed off to NICU where staff spend the night trying to keep her alive. The next 14 weeks are spent in different hospitals during which time you start to plan a funeral for your baby; there are life saving operations; caring consultants telling you that your baby is deafblind and other less caring ones mislead you over test results.

Your child over the years accumulates and discards different practitioners – according to her medical, educational and social needs. Her number of surgeries reaches double figures. For school, she has to travel across London for the appropriate primary education and then attend a residential school at secondary level.

You become an expert on CHARGE and have to deal with welfare benefits and direct payments, education and numerous uncoordinated hospital appointments. Having spent two years planning the secondary school transfer you are already looking at 16-plus transitioning within a few weeks of term starting.

You lose friends and family because they do not understand or cannot cope with your situation.

None of this happens with your other child.



So what do parents need?

CHARGE is a rare and complex condition with each individual professional having an expertise in their own area. It is important that each practitioner liaises and collaborates with colleagues from other specialisms and departments for them all to develop a better overall knowledge of CHARGE. This will help to provide more joined-up support for individuals with CHARGE.

Parents need to have as much information as possible from everyone who is involved with their child – this will enable them to make the best decisions on their behalf. Practitioners should provide parents with as much information as they have without needing to be asked. This needs to be in clear and simple terms so that parents understand what they are being told. Ideally this should be backed up in writing.



As a parent, I prefer a practitioner to acknowledge that they have no experience of CHARGE. I respect someone who says "I don't know" and is prepared to go away to search for information. This is positive, whether in an educational, social care or medical setting. Why? It shows that a person is comfortable with their own expertise and enables them to accept advice from other practitioners from different areas. A good example is my daughter's former primary school, a school for the deaf. They informed the Teacher for Visual Impairment and Sense's MSI teacher that they knew deafness but not visual impairment or multi-sensory impairment and so were seeking advice. This school also sought input from us as parents.

As a parent, I should be treated as an equal or partner by practitioners. With a syndrome such as CHARGE, parents are often likely to have a better global knowledge than the practitioner with a specialism. Prior to one major surgery, a surgeon dismissed our specific CHARGE concerns. Although the surgery was a success, our concerns were proved right. Conversely, when our daughter was having difficulties with sleep a consultant agreed to medication we suggested – despite it not previously having been prescribed to a child with CHARGE in the UK.

I do not need a practitioner to make an assumption about the abilities of my daughter. With CHARGE, the many and varied issues make it easy to assume a child is less able. Many children with CHARGE do not fit in with the standard assessment tools used to assess a child's ability. One practitioner assessing my daughter initially made certain assumptions but before making a second assessment sought external advice about what a child with CHARGE might experience. Her subsequent assessment acknowledged that standard assessment frames of reference may not apply.

In summary I will advocate for my child to receive the best services, education and care. I will work with all practitioners involved with my child to achieve this. If necessary I will fight, but please remember – it's not personal.

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