



Factsheet 14

Patterns of early development in CHARGE syndrome

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Children with CHARGE syndrome enter the world facing many challenges. During the first three years, hospitalisations and medical procedures play a significant role in delaying development – which can be mislabelled as cognitive impairment (Davenport, 2011). It is important to take into account the medical difficulties and sensory losses faced by these children before attempting predictions about future abilities.

Medical Issues

Medical issues that must be resolved, and that may require surgical procedures, can include breathing and swallowing problems, heart irregularities, ear infections, and many others. (Salem-Hartshorne and Hartshorne, 2011). Struggling to breathe, eat and sleep takes an enormous amount of energy. Pain can also be significant. Therefore, children with CHARGE may not be as available for learning when educators attempt to keep their focus on specific tasks.

Senses and walking

Vision and hearing are the primary senses for learning and for language development and many children with CHARGE have problems in both of these areas (Salem-Hartshorne and Jacob, 2005). Language development and incidental learning can be severely affected. Other senses may also be absent or affected, including smell, taste, touch, and the very important vestibular (balance) system, which is essential for learning to walk. (Salem-Hartshorne and Hartshorne, 2011).

Given all of these problems, it is surprising that these children learn to walk at all. The average age at walking is about three years (Hartshorne *et al.* 2005). A later age of walking can be a marker for more serious



developmental complications, including:

- more challenging behavior (Hartshorne and Cypher, 2004)
- more autistic-like behavior (Hartshorne *et al.* 2005)
- poor adaptive behavior skills (Salem-Hartshorne and Jacob, 2005)
- more executive dysfunction (Hartshorne *et al.* 2007),
- the number of psychotropic medications taken (Wachtel *et al.* 2007)
- communication difficulties (Thelin and Fussner, 2005)
- sleep problems (Hartshorne *et al.* 2009).

Some individuals with CHARGE report that light touch can be very annoying and they prefer a firmer approach (Davenport, 2011). Sensory integration techniques such as using weighted vests are often found to be a calming influence for many of these children. Touch can also



be used to develop consistent ways to approach and communicate with a child with CHARGE. It can be a powerful means to develop a sense of anticipation of what will come next.

Early school years

It has been reported that many children with CHARGE manage to keep up with their peers academically until about age nine (Salem-Hartshorne and Hartshorne, 2011). At this point in school, the focus on rote learning lessens in favour of a focus on abstract concepts. Seated desk-work and homework become more prevalent. This type of work may be difficult for many children with CHARGE, requiring enormous powers of concentration to keep their hearing and vision focused on academic tasks, while managing their vestibular and proprioceptive issues. The resulting exhaustion and frustration, along with challenging academic work, create stress that can develop into challenging behaviour and lead to falling behind academically.

Although many children with CHARGE are able to read (some at further education level), many have difficulty with comprehension. In one study, 40% of parents indicated that their children who could read understood only a little to half of what they read (Salem-Hartshorne *et al.* 2011). The complexity and diversity of children with CHARGE means that other factors should be taken into account when giving them reading and other instruction. Educators should become familiar with each child's needs (medical, cognitive, and sensory), and pay close attention to their learning style.

Developing friendships

Making and keeping friends in school can be challenging for this group of children (Salem-Hartshorne and Hartshorne, 2011). When entering school they find friends and may be invited to social engagements. As they move to middle childhood this can happen less often. Part of the difficulty seems to be problems with keeping up with their peers' physical, cognitive, and social-emotional development.

Because of varying developmental ability levels, personality and psychological quirks, asymmetrical facial features, appearance, walking gait, incontinence issues, educational placements, and lack of free time, children with CHARGE are less likely to be successful in making friends with students without disabilities. It is important to find ways to facilitate friendships for these children, as they may foster future social support and meaningful relationships.

Although children with CHARGE syndrome face many uphill challenges, physically, educationally, and socially, they are often remarkably successful.

GLOSSARY

Adaptive behaviour: a type of behaviour that is used to adjust to another type of behaviour or a situation

Executive dysfunction: an impairment of the cognitive processes that control and regulate behaviour; they also coordinate the execution of cognitive abilities and social interactions

Psychotropic medications: drugs that affect the mind/perception, behaviour and mood. Common types of psychotropic drugs, including antidepressants, anti-anxiety agents, antipsychotics, mood stabilisers

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