



Factsheet 25

The role of the Occupational Therapist

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CHARGE may be the only disorder that presents with difficulties of all the senses. (Hartshorne *et al.* 2011).

“People with CHARGE syndrome are truly ‘multi-sensory impaired’, having difficulties not only with vision and hearing but also with the senses that perceive balance, touch, temperature, pain, pressure, and smell, as well as problems with breathing and swallowing, eating and drinking, digestion, and temperature control.”
(Brown, 2005, p.1)

Where an OT might be needed

Individuals may present with any of the following difficulties which would benefit from intervention by occupational therapy:

- Poor posture
- Delays in reaching developmental milestones – especially sitting reactions, standing and independent walking.
- Difficulties with head control and poor ability to resist gravity
- Becoming tired quickly after standing, walking and general physical activity
- Decreased joint stability with low tone. A tendency to ‘w’ sit to give a broader more secure base
- Poor co-ordination
- Proprioceptive dysfunction
- Vestibular dysfunction. The semi-circular canals may be absent or malfunction, or there may be anomalies of the auditory cranial nerve
- Balance problems
- Bone and muscle malformations of the hand
- Increased tightness and shortening of the muscles in the shoulder area leading to decreased shoulder mobility. Some individuals may also have a congenital torticollis
- Difficulties with self-regulation. Sensory overload is often seen, especially when the individual is under



- stress and this may lead to challenging behaviour
- Sensory seeking behaviour. This may involve repetitive movement patterns, e.g. spinning or mouthing
- Sensory defensiveness
- Communication difficulties
- Problems with development of oro-motor and feeding skills

Input from the Occupational Therapist

- It is important to work with other members of the therapy team including Physiotherapy and Speech and Language Therapy as CHARGE requires a multi-disciplinary approach.
- In the early days, input may focus around equipment to help with positioning, e.g. seating, bathing, sleeping, and guidance to parents on how to develop basic skills such as reaching, grasping and release.



Youngsters with CHARGE show a high level of developmental delay, compounded by their vestibular dysfunction which results in poor postural control which in turn affects the development of effective hand/eye co-ordination.

- As the child develops there may be a need for adapted seating to give greater support. Support when bathing or using the toilet may also be required.

These children often require longer to process information and establish a firm base before they can begin to undertake a task.

- As these children tire easily, they may need time out either lying down or resting their head on the desk. They find extended periods of time sitting or standing unsupported very fatiguing. Many CHARGE children will spend extended periods of time in a horizontal position on their back to reorganise their sensory system.

Encouraging the child to use different working positions may also be beneficial, e.g. in prone over a wedge, using a sloped board or supported in a hammock.

- Advice on the development of skills for activities of daily living – such as dressing, feeding and toileting – may help parents and carers to support the development of greater levels of independence in the children.

Modifications to equipment may be necessary, e.g. larger handled cutlery, adapted cups.

- Liaison with pre-school and school are important to explain the difficulties a child with CHARGE may be having, and how they can accommodate these within an education setting, e.g. special seating, writing equipment, use of a laptop, need for regular breaks and rests.

Sensory integration dysfunction appears to be inherent in CHARGE due to the anomalies in the vestibular system.

“The vestibular system is the unifying system. All other types of sensation are processed in reference to this basic vestibular information. The activity in the vestibular system provides a framework for the other aspects of our experiences.” (Ayres (date unknown), cited in Brown, 2007)

The use of sensory integration principles is of paramount importance to these children and may include the use of equipment for swinging and spinning, joint compression, specific brushing techniques, vibro input and weighted items.

It can also include a ‘sensory diet’ to ensure the child has a regular, carefully chosen set of sensory activities to promote a ‘just right’ sensory state.

Using a sensory integration approach may help CHARGE children to attend to sensory information in the environment, improve muscle tone and decrease tactile defensiveness, improve attention and communication skills and reduce challenging behaviour.

Conclusion

Given the wide ranging difficulties of children with CHARGE, a number of OT approaches can be used to support them. These will be adapted to the specific needs of the individual child but are always likely to include a sensory integration approach along with other frameworks OTs are well placed within the multi-disciplinary team to provide a service for these children.

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GLOSSARY

Congenital Torticollis: literally means a ‘twisted neck’. It is a deformity of the neck present at birth and is due to a shortening of the neck muscles so the child tends to tilt to the side where the neck muscles are shortened.

Proprioception: refers to the sensory information that we receive from our joints and muscles. This information tells us about the position, movement, force, and direction needed for activities.

Vestibular dysfunction: an impairment in the functioning of the vestibular system which is located in our inner ear and is activated by head movement. It tells us where we are in relation to gravity; whether we are moving or standing still, and how fast or slow we are going.

REFERENCES

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