



Factsheet 11

Sensory integration and CHARGE

ALISON HAMPSON, DIP COT, SROT, Senior Occupational Therapist, Seashell Trust, (Royal School), Manchester

Sensory integration is the neurological process that organises sensation from one's own body and the environment – and makes it possible to use the body effectively within the environment. The senses are all designed to work together as a team, and when any sense is impaired it may affect the processing of information being received through the other senses.

“Good sensory processing enables all the impulses to flow easily and reach their destination quickly. Sensory integrative dysfunction is a sort of ‘traffic jam’ in the brain. Some bits of sensory information get ‘tied up in traffic,’ and certain parts of the brain do not get the sensory information they need to do their jobs.” (Ayres, 1972, p. 51).

Without well organised sensory processing, the sensations cannot be internalised and work together to produce a co-ordinated response. Children with CHARGE tend to have difficulty in using all their senses together in a co-ordinated way. This is due to either under or over reactive sensory systems that interfere with the smooth processing of sensory information.

Sensory defensiveness is also a common feature of CHARGE. It is an overreaction of our protective senses and is seen as a defensive reaction to non-noxious stimuli across one or more sensory systems.

The sensory systems

In CHARGE, all of the following systems may be affected:

THE SENSE OF TOUCH (THE TACTILE SYSTEM)

The tactile system is the largest sensory system and plays a major part in determining physical, mental, and emotional behaviour. Touch sensations flow into the brain to tell us that something is touching us and play an important role in body awareness and movement.



When a child has combined visual and hearing impairments, touch may be the primary source for information.

An over-reaction to touch may appear as ‘challenging’ behaviour, e.g. self injurious behaviour, aggression towards others, when in fact it is due to poor awareness and tolerance of touch. It may also cause high levels of stress and anxiety.

THE SENSE OF BODY POSITION AND MOVEMENT (THE PROPRIOCEPTIVE SYSTEM)

Proprioception refers to the sensory information that we receive from our joints and muscles. This information is telling us about the position, movement, force and direction needed for activities such as buttoning clothes, writing, screwing a lid on a jar or playing with a toy without breaking it.



Proprioceptive difficulties may include:

- using excessive force
- an abnormally high pain threshold
- repetitive behaviours that provide strong sensory input, e.g. hand flapping, shoulder shrugging, craving deep pressure, and
- adopting postures to provide extra tactile and proprioceptive input.

GRAVITY, BALANCE, AND MOVEMENT (THE VESTIBULAR SYSTEM)

The vestibular system 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.

Many CHARGE children have malfunctioning or absent semi circular canals and vestibular dysfunction is an on-going problem. Features of vestibular dysfunction include:

- persistent low tone and poor ability to resist gravity
- a preference for lying on the back or side
- delayed physical development including achieving sitting balance, mobility
- seeking out of strong sensory input, e.g. spinning, rocking, bouncing, hanging upside down
- fatigue and postural control difficulties
- poor walking pattern and head position
- difficulty in organising all sensory information.

THE SENSE OF SIGHT (THE VISUAL SYSTEM)

The visual system helps us to navigate in the world and judge the speed and distance of objects and people. In CHARGE there are specific eye defects which can cause visual impairment and affect visual abilities. This may be compounded by vestibular difficulties. The child may adopt compensatory behaviours to cope with their visual and vestibular difficulties, e.g. hanging upside down to see things.

They may also appear to be less able to use their vision than usual if their postural stability is too challenged and may particularly struggle when outdoors – where there are fewer vertical markers. There may be photophobia which can be seen as covering the eyes when in bright light. There may also be ptosis (where the eyelid covers part of the eye).

THE SENSE OF SOUND (THE AUDITORY SYSTEM)

The auditory system is located in our ear and relates to the ability to receive sound.

As many as 92% of CHARGE children have hearing impairments. Hearing impairment results in language delay and overall difficulty in communication and social interaction.

THE SENSE OF SMELL (THE OLFACTORY SYSTEM)

Smell plays an important role in establishing and receiving memories and associations that influence some of our choices and preferences – such as a specific type of perfume or type of soap. A baby can recognise his mother just through smell and our food choices are greatly dependent upon the sense of smell. It also supports our social interactions, and has an alarm function.

Due to dysfunction/anomaly of the first cranial nerve, in over 90% of cases there may be difficulties with the sense of smell (Hartshorne *et al.* 2011).

THE SENSE OF TASTE (THE GUSTATORY SYSTEM)

Taste helps us to survive and provides us with essential information about bitter, salty, sweet, and sour flavours. These tastes are important in our selection of food or to inform us whether certain tastes might be harmful for our body. Taste is closely linked with smell and this coupled with the high levels of facial palsy often lead to eating and drinking difficulties in children with CHARGE.

How to help CHARGE children with sensory integrative dysfunction

- Following a sensory integration assessment by a suitably qualified and experienced paediatric Occupational therapist, a 'sensory diet' can be created which incorporates a range of activities to address the identified area of dysfunction. The sensory diet helps the child to feel calm, alert and organised more of the time and should include:
 - specific time-oriented activity routines
 - adaptations and changes in routines and interactions
 - changes to the environment or routines.

Within a class room environment this may include providing ball chairs to work on, a safe space for the child to hide in if overloaded, and facilities for heavy work such as swinging and jumping.

By meeting the sensory needs of these children within their school environment they will be able to focus more easily on learning without the distractions which surround them.

- It is important to remember that many of these children are prone to having a high level of fatigue due to the constant need to work at the integration of senses, a process which occurs naturally in most people. This may be seen as a need to lie down, resting their head on the desk, lack of concentration and focus and challenging behaviour because they can no longer 'hold it all together'.

The challenging behaviour may be an adaptive response to the severe level of multi-sensory impairment. The child may need to be provided



with a quiet area away from the other children where they can be quiet, and may benefit from some deep pressure or lying under a weighted blanket.

- Using a total communication approach.
- Using multiple sensory channels for learning.
- Alternate active and passive activities through the day; function may be better once the child has organised their sensory state.
- Sensory breaks are essential to allow the child to refocus and organise all the sensory information that continually bombards them.
- Specific techniques such as a Wilbarger protocol and therapressure programme for sensory defensiveness, use of weighted items, vibration work, use of suspended equipment.
- Consistent and predictable environmental supports.
- Working collaboratively with a practitioner qualified and experienced in working with children who are multi-sensory impaired.

Created: November 2013
Review due: November 2015
www.sense.org.uk



REFERENCES

- Ayres, A.J. (1972) *Sensory integration and learning disorders*. Los Angeles: Western Psychological Services.
- Hartshorne, T.S. *et al.* (2011) Introduction. In: *CHARGE Syndrome*. Abington, Oxfordshire: Plural Publishing. pp. xi – xv.