Australian Galactosaemia Support Network

Galactosemia Foundation Conference 2012

Neurological Impact on Learning and Speech Update

It is well established that learning and speech delays are symptoms of galactosaemia. However, less is known about why galactosaemia affects learning and speech and the best ways to intervene effectively. It is now thought that the learning and speech problems experienced by people with galactosaemia are caused by damage to the brain from excess galactose, which occurs either before or shortly after birth. It is, therefore, important to properly identify and diagnose any problems early and to intervene effectively, taking into account these neurological complications.

Learning

The key point to take out of the conference in relation to galactosaemia and learning disorders is that the disorders are thought to be caused by problems in the right side of the brain and the brain's ability to process information. This means that people with galactosaemia process things differently to the general population and that the learning process needs to be adapted to deal with this where possible. One clear message that came out of the conference was that people with galactosaemia are not, as a general rule, less intelligent than the general population. Rather, their brains work differently and this difference can often be mistaken for lower intelligence or other learning problems such as Attention Deficient Disorder.

As a result of this it is very important the learning programs for children with galactosaemia are adjusted to accommodate the different neurological processing methods. Generally, children with galactosaemia are good at processing ordered and written instructions where the process involves step-by-step tasks. Where children with galactosaemia tend to struggle is with imaginative, spontaneous or creative tasks. They can also struggle with instructions delivered verbally. Some tips that were given at the conference for dealing with this are outlined in the teaching guide published by the New England Consortium, which can be found at:

http://newenglandconsortium.org/brochures/Galactosemia-Resources-for-Educators.pdf

Speech

According to information presented at the conference approximately 60% of people with galactosaemia suffer from some form of speech disorder. The

disorders range in severity and can be problems with either or both of phonation and motor skills required for speech. However, in all cases it is now thought that the problems are caused by neurological defects.

Phonation

One problem that is commonly seen in children with galactosaemia is that they are unable to sustain their phonation for long enough to physically say full sentences. This limits their speech to very short sentences or even single words. A simple test that can be done at home is to see how long a person can sustain an "ah" sound. Ideally, adults should be able to sustain this for 20 seconds. For children aged seven and over this should be able to be sustained for a minimum of eight or nine seconds. Studies have shown that only one in eight children with galactosaemia can achieve this, as opposed to two thirds of children in the general population.

It is interesting to note that the ability of children with galactosaemia to sustain phonation is similar to that seen in adults and children with cerebellum disorders. This is why it is thought that the phonation problems seen in children with galactosaemia have a neurological cause, as opposed to being caused by muscular or other physical problems. This is quite different to most speech delays involving phonation troubles, which are usually caused by physical problems. Early intervention and treatment of phonation problems in children with galactosaemia, therefore, need to focus on rectifying the neurological problems. It is important that this is raised with the medical teams managing speech therapy, as it may not be something of which all therapists are aware.

Motor speech disorders

The types of motor speech impairments seen in children with galactosaemia are childhood apraxia of speech, dysarthria and other motor speech impairments.

Features of childhood apraxia of speech include inconsistent errors on consonants and vowels in repeated production of syllables or words, lengthened and disrupted transitions between sounds and syallables and inappropriate rhythms in speech. Features of dysathria are decreased strength and coordination, low or high tone and reduced breath and/or voice support for speech.

The reasons presented at the conference as to why people with galactosaemia suffer from these speech disorders were largely related to brain function. In particular, it appears that the right side of the brain and/or the white matter used for transporting information from one side of the brain to the other are damaged by high levels of galactose before or shortly after birth.

The general consensus from the conference was that early intervention focussing on right side brain development can make a real difference. One of the main activities to work on is audio (as opposed to visual) processing. This includes

reading stories and listening to music. It was mentioned at the conference that audio books are a particularly good tool.