FOR THE TEACHER

SAKKS

Supporting Aussie Kids with Kabuki Syndrome

Kabuki Syndrome is a relatively new syndrome. From a parent's point of view - and as the greatest advocate for our child, we will try to give you some background information into some of the challenges of Kabuki Syndrome.

Each child is very unique although they often share many similar physical attributes and often have similar personalities/traits.

Children with KS love routine and can be organised and reliable. They often don't like change. It is common to hear that they bat their eyelids and try to avoid challenging tasks. However, with perseverance and patience, they usually complete the task and thrive from their achievements when encouraged.

Physically, they are challenged. Children with KS have, or have had, a list of medical problems, and often have very low muscle tone. This will prevent them "keeping up", but they enjoy sports in their sometimes limited capacity. Their enthusiasm, however, more than compensates!

Children with KS are very happy natured and a joy to know.

We often hear that education is one of the hardest challenges for parents and this can be attributed to the lack of understanding and knowledge surrounding Kabuki Syndrome at this stage.

We have included information on Kabuki Syndrome - a personal page about the child you will be teaching, some insightful information written by a pre-school teacher and an ESO, also a page detailing some great websites and more.

Thank you for taking the time to read our new KABUKI SYNDROME Information Pack.

Please contact us at petal@sakks.org for futher information.

Kindest Regards,

The SAKKS Team.

What is Kabuki Syndrome?

Kabuki syndrome is a rare disorder. There are more than 300 individual cases published worldwide, but many more that are not published. It was first described in 1981 by Niikawa and Kuroki who observed several children with similar characteristics.

There are many features which can occur in Kabuki syndrome but not all are seen in every child. Features seen in Kabuki syndrome are:

Unusual facial features;

- wide eyes with arched, interrupted eyebrows
- large and low-set ears
- depressed nasal tip

Short stature; most children with Kabuki syndrome are below the 50th centile for height for their age. Occasionally, growth hormone deficiency has been found.

Skeletal abnormalities such as short fingers, loose joints

Intellectual disability - which varies from mild to severe. Most individuals with Kabuki syndrome have a mild to moderate intellectual disability.

Many other abnormalities are sometimes seen:

- Cleft lip and palate
- cardiac abnormalities
- urogenital and kidney problems
- ano rectal and intestinal problems
- immune abnormalities
- ear infections and hearing loss

The cause of Kabuki syndrome is not known. It is thought to be a genetic problem and research is ongoing to try to identify the cause. In most cases of Kabuki Syndrome, there is no family history of the syndrome. Kabuki syndrome is found in males and females equally.

There is no cure for Kabuki syndrome but there is a lot that can be done to ensure good health in a person with Kabuki syndrome, and to make sure that each person with Kabuki syndrome achieves their full potential.

Health care professionals that are likely to be involved include a paediatrician, geneticist, and other specialists depending on the problems in the child. Most children will require the input of speech therapists, physiotherapists and other allied health professionals.

Reference: American journal of Medical Genetics 127A:118-127 (2004)

Introducing:

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Strengths:

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Personality:

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Social:

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Siblings:

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My Photograph

A discussion – My time supporting a child who suffers from Kabuki Syndrome – preschool

Teaching Bryce
Some suggestions for helping a "Kabuki Kid" get the most out of pre-school.

Let me start by saying that these are only suggestions and most would work for any child with or without a development delay. Any early childhood educator will devise a program that suits the individual child after lots of observations. In Bryce's case there is the great unknown of "Kabuki" with very little information to back up my ideas. Most strategies were developed with trial and error. However observations showed that Bryce has some behaviour that could easily fall under the "Autism" umbrella – mild obsessions with toys or activities, and recently with another child, some self gratifying repetitive gestures, a propensity for visual learning and cues and difficulty with routine changes. So think visual clues, and gestures, short positive directions and allowing the child "down" time in a quiet place with a soothing sensory activity.

In no specific order of importance here are some suggestions we can offer:

- Get to know your child. Find out what relaxes, excites, and scares them. Have the calmers or relaxers at hand always! In Bryce's case this is a Wiggles song or a favourite book or as he has matured sensory play with water or other free flowing materials.

- Bryce has a very short attention span so that we are aware to keep instructions short and while we expect Bryce to finish all activities we are mindful that 10 minutes is about the length of his interest at this stage. (Last year the time increased from about 2 minutes to 5 !)

- We increased this time by having an adult work individually with Bryce and reminding him to stay on task and that finishing is important.

- Bryce learns more successfully visually so we have used Board maker to help him make activity choices and to get him to practice skills that we thought important.

- "First (an activity that Bryce was reluctant to choose) this" Then (An activity that Bryce had shown he enjoyed.)

- We make sure that Bryce knows well in advance of any routine changes or special visitors we may be having.

- I have been known to say "Bryce is like a goldfish!" He has a very short memory. We learned not to expect Bryce to remember instructions or skills from 5 minutes to the next. It takes lots of repeated practice over a longer than usual time for Bryce to "internalize" a skill or concept. It is very easy once you remember this to gently remind him of what to do. It is very rewarding to observe Bryce independently using a skill that has taken a long time to develop!

- Bryce mouths objects all the time (Although with less frequency as he matures) you obviously need to be very vigilant but constant “Out of mouth, Bryce” helps.

- Bryce has a habit of gagging by putting his fists down his throat when he is unsure or hurts himself. Strategies that helped Bryce mostly overcome this reflex response have been:

  Physically hold his hands down while comforting him at the same time saying “hands down, Bryce.”

  Distracting him with a special toy or activity and saying “hands down, Bryce.” Just saying “Hands down Bryce” and giving a visual clue – moving your own hands down.

  (This has taken nearly two years so don’t give up!)

  When giving instructions or reminders Bryce responded best to affirmation of the desired behaviour. For example if Bryce was wriggling at group time it is better to say “Bryce, Still, Looking at me.” Than “Stop wriggling.” Give the behaviour you want not reinforce the one you don’t want.

Most of all, remember that your “Kabuki Kid” is a beautiful individual child who will a hundred times over give you more joy than heart ache. I have learned so much more from Bryce than I could ever teach him if he were in my class for the rest of his time at school. Everything and anything is possible it may just take a bit longer!

Thank you to Kristine - Kindergarten Teacher - Victoria

A discussion – My time supporting a child who suffers from Kabuki Syndrome – Primary School

Working with Zachary - a nine year old boy with KABUKI SYNDROME is the highlight of my day!

He is such an enthusiastic student always happy and willing to try new things. His friendliness puts a smile on many faces within our school community.

When I first met Zachary we began a thirty lesson program called 'Bridges'. The program gives students the opportunity to become proficient readers, writers and spellers in the early years. The structure of the program, four half hour sessions per week, really built up Zachary's confidence. He began the lesson himself, set the timer, opened his vocabulary pack read his sight words & chose his own reading material. With the exposure to three different readers each day Zachary's reading has improved beyond belief. He was presented with his Certificate of Completion for the Bridges course at a whole school assembly.

Gradually Zachary is gaining control of his pencil and his writing.

To help strengthen his wrists we use a tennis ball in each hand and roll them up and down a wall or on a table while keeping the balls under control. I also find that getting Zachary to cut out shapes is great exercise for his dexterity. Our challenges have been in areas of Numeracy including time and money but we continue to find new and interesting ways to engage students in this area.

We have built a good selection of resources to support our lessons.

There are many websites worth having a look at. I found the Cherry Carl site very useful with an abundance of ideas and games.

The selection of 'Blend Dominoes' is an enjoyable way for students to become familiar with the sounds and blends at the beginning of a word.

The Magic 100 words have also been a great starting point for Zachary. M100W as its known also provides many useful resources.

I have included a list of sites which you as parents will find helpful in your quest to support your child. (Recommended educational websites)

Thank you to Ann - Educational Support Officer – South Australia

Children with Kabuki Syndrome are likely to be supported on an ongoing basis with the following professionals:

Speech pathologist/therapist

Speech delay is common for our kids with KS. Some contributing factors are the associated problems with the palate including cleft palate and cleft lip and sometimes this involves dental anomalies. A large percentage of children with KS experience some form of hearing loss, for most, hypotonia or muscle weakness can contribute to problems with their speech also. Most children with KS will regularly see a speech therapist. Many of the children will have learnt sign language in the early years to support communication and language.

Occupational Therapist

Most children with KS have muscle weakness and joint laxity and it is necessary to have occupational therapy during their lives, usually the early years. Their main aim is to strengthen muscle tone, and develop coordination for fine and gross motor skills.

Physiotherapist

Physiotherapy and physical activity are important to strengthen the muscles.

For additional support: SAKKS website www.sakks.org has a private page for professionals and encourages information sharing amongst the professionals who are involved with a child with Kabuki Syndrome. To enrol please follow the link: http://www.sakks.org/prof_contact_list.html , your password is available from Peta at petal@sakks.org

Other medical professionals that may be involved with children with KS are:

General Practitioners
Paediatrician
Pulmonary Specialist
Cardiologist
Nephrologists
Neurologist
Gastroenterologist
Ear Nose and Throat specialist
Immunologist

Further information on Kabuki Syndrome

Websites for further information on KABUKI SYNDROME

SAKKS – Supporting Aussie Kids with Kabuki Syndrome www.sakks.org SAKKS offers information, external links to genetics departments and research as well as links to medical information, a forum and a stories page with personal accounts of the challenges of coping with a child that has KABUKI SYNDROME. It also offers photographs, contact with other parents, membership, sibling information, early Intervention and educational links and of course - support. There is a private contact page for professionals including educational persons. SAKKS has representatives and parent contacts in every state.

KSN – Kabuki Support Network (Canada)
www.kabukisyndrome.com

PARENTING AND CHILD HEALTH -
http://www.cyh.com/HealthTopics/HealthTopicDetails.aspx?p=114&np=304&id=2524

OMIN – Definition
http://www.ncbi.nlm.nih.gov/entrez/dispomim.cgi?id=147920

ROYAL CHILDRENS HOSPITAL MELBOURNE
http://www.rch.org.au/kidsinfo/factsheets.cfm?doc_id=11054

GENETICE SUPPORT NETWORK VICTORIA
http://www.gsnv.org.au/pages/supportGroups/sgmeet.php

EURORDIS
http://www.eurordis.org/article.php3?id_article=1435

BIRTH.COM
http://www.birth.com.au/npo.asp?view=390&lasturl=search=&index=disabled&searchsubmit=go

SOCIETY FOR THE STUDY OF BEHAVIOURAL PHENOTYPES information sheet.
http://www.ssbp.co.uk/ssbp/media/syndromes/kabuki_syn.pdf?wb_session_id=a2554c08687d36f821336aa613ddca6f

Recommended Educational websites

PRIMARY GAMES Teachers, will find games and activities on our website to meet your school's curriculum needs.
www.primarygames.com

MES ENGLISH Free resources for the teachers of young learners. All of the resources are designed to be versatile and useful in many K-6 classrooms.
www.mes-english.com

BUSY TEACHER'S CAFE
www.busyteacherscafe.com

PRINT ACTIVITIES is full of fun and free printable worksheets, activity sheets, free printable preschool worksheets, kid puzzles and mazes, and more
www.printactivities.com

EDUCATION WORLD
www.education-world.com

KABOOSE
www.kidsdomain.com

DO2LEARN
www.do2learn.com

ENCHANTED LEARNING designed to capture the imagination while maximizing creativity, learning, and enjoyment.
www.enchantedlearning.com

KIZCLUB provides lots of educational activities in language arts for preschool and elementary age children.
www.kizclub.com

CARL'S CORNER
www.carlscorner.us/

TEACHERVIEW - This site was created by Susan Shuey Beasley.
www.teacherview.com

The VIRTUAL VINE is a resource for early childhood teachers.
www.thevirtualvine.com

GALES PRESCHOOL RAINBOW - Preschool education activities and early childhood education lesson plans that give preschool children choices.
www.preschoolrainbow.org

DLTK's Crafts for Kids features a variety of fun, printable children's crafts, colouring pages and more
www.dltk-kids.com

SENSORY INTEGRATION AND MUSIC THERAPY **by G. Chrysostomou**

Sensory integration is an innate neurobiological process and refers to the integration and interpretation of sensory stimulation from the environment by the brain. www.Autism.org the sensory system can be broken down in to different systems, the most well known being visual, smell (olfactory) and auditory. In fact the most fundamental systems we use to function properly, which are explained below, are Vestibular, Proprioceptive and Tactile. If these systems are not communicating with each other this can lead to problems with perception and affect development and behavior. Music or music-related activities can help in these situations because it can be a distraction to the senses. This can open a window of opportunity for therapists to influence and stimulate the learning process.

Three basic sensory systems:

• Vestibular – Receptors found in the inner ear along with sight help us to deal with gravity and spatial orientation based on position of the head.
If this system doesn't work properly it can lead to: constant vertigo experience, low muscle tone, disorientated feeling, a sense of falling or the ground being slanted.
Methods of Treatment: Spinning, Jumping (trampoline) provides constant stimulus to this sensory system leading to brain learning how to make changes in body position to maintain balance. Constant rhythm important to aiding adaptive process. (Fisher 1991)
E.G. Jumping in rhythm to a song with words. (Vestibular and proprioceptive)

• Proprioceptive – perception of energy and position of muscles, joints and tendons needed to perform any physical action. Touch and movement senses again work together with sight to create awareness of body position. Trial and error in normal development helps to refine these skills.
If this system doesn't work properly it can lead to: Not being able to do physical tasks properly (e.g. dyspraxia), when motor planning is weak this can lead to difficulties in walking, running, writing, speaking.
Methods of Treatment: Role of therapist is to teach or re-teach actions or movements through activity allowing the brain to establish new connections about body awareness.
E.G. Learning to hold and play an instrument correctly. (Vestibular, proprioceptive and tactile)

• Tactile – First sensation along with hearing. Receptors found on skin, in mouth and other areas of body. Two main channels: Protective (potential danger such as extremely light touches like a mosquito bite, unexpected touches and pain, burning, stabbing and other touch sensations). Discriminative (how and where body is touched and also how hot, cold, wet, dry, tasty etc. it is).

If this system doesn't work properly it can lead to: Tactile and sensory defensiveness, a hypersensitive tactile system can put a person on full alert constantly which disrupts the ability to function properly, living in constant stress. Avoidance of physical contact, over sensitive to light, certain types of food or textures and even hyperactivity.
Methods of Treatment: Music in this situation can (but not always) act as a relaxant and make the body feel safe. Brain is attending to the sounds and person temporarily forgets the tactile hypersensitivity and is able to pick up instruments and play.