



22q Foundation Australia & New Zealand

Introduction to 22q11.2 Deletion Syndrome
For Parents, Care Givers and Teachers

Infants and Primary School

This introductory guide to 22q11.2 DS will offer basic information on some of the specific learning problems and medical issues associated with the condition. For individuals with 22q11.2DS these issues may impact on their ability to learn and therefore their education. Educating any child can be a challenge and rewarding at the same time. Educating a child with 22q11.2DS is no different. However, students with 22q11.2DS will require specialised assistance with some of their challenges. The amount and type of assistance required will vary as each case is different and each child should be treated individually.

1. What is 22q11.2 Deletion Syndrome (22q11.2DS)

22q is a genetic syndrome caused by a submicroscopic deletion of genetic material from the long arm of chromosome 22. More than 180 anomalies have been reported in people with 22q11.2DS, but expression of the syndrome is highly variable from person to person and no individual has all the anomalies. 22q11.2DS has broad reaching effects on development and behavior, speech, language, personality, mood, learning, attention, and temperament.

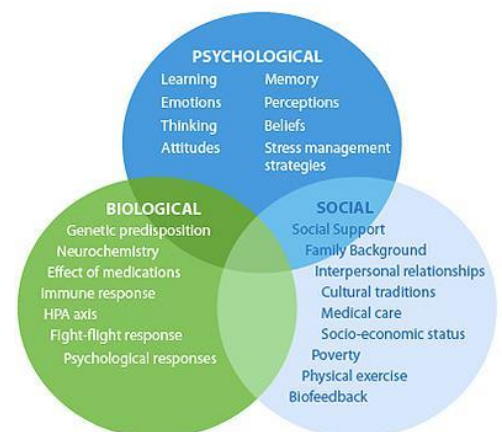
2. General Information about people with 22q11.2DS

- Many students with 22q11.2DS have had **multiple surgeries** once they reach school age.
- **Developmental delay** is present in most students with 22q11.2DS, however this doesn't tend to be recognisable until the child is around 8 years of age.
- Students should be fully assessed in all areas including: speech, language, gross and fine motor skills and have a full **psychometric report (ideally every 2 – 3 years)**.
- An **Individual Education Plan** (IEP) is instrumental in assisting the students to reach their full potential through their schooling journey
- A **communication book** is an important way of keeping everyone informed about the current goals and techniques being used to help a student with 22q11.2DS
- Students with 22q11.2DS **can achieve** with encouragement, personalised strategies and patience.

Whatever the student's difficulties, there are ways in which they can be helped to learn. The student, parents, teachers and carers are the keys to success. Constant monitoring is essential to ensure the student is receiving the best possible education. A student with 22q11.2DS **can be successful** and become an independent adult with assistance from teachers, parents and support staff.

3. Personality & Social Skills - Individuals with 22q11.2DS may:

- Have an **obsessive** personality.
- **Worry** about future events rather than what is happening right now.
- Become **anxious and stressed** without structure or routine.
- Have **speech and language problems**, making it hard to communicate with their peers
- Appear **very immature** making it difficult to keep up with their peers.
- Be **literal thinkers** and interpret words verbatim. Most students will learn the meanings of idioms without being taught, but students with 22q11.2DS may need to be taught the meaning of these very **common** idioms eg: "you drive me up the wall" or "I've lost my head".
- Have **trouble reading facial expressions**, following conversations and appear not to listen, changing the subject to whatever is on their mind.



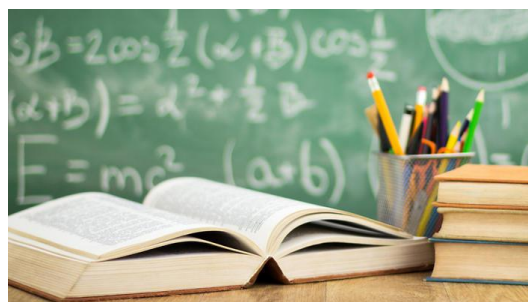
4. Motor Skills, Physical Education and Sport

- **Gross motor problems** may hinder performance in sport.
- Tasks involving **balance and co-ordination** may be extremely difficult making them appear clumsy.
- Games and **Physical Education** may be difficult if they involve words such as left, right, up, down, backwards, forwards, etc.
- **Medical problems** such as Congenital Heart Disease (CHD) may also impact on the child's ability to fully participate.
- **Chronic leg pains** are typical for children with 22q11.2DS. While this is not life threatening it can be quite unpleasant for the child so allowing them enough time to recover is important.
- **Regulating body temperature** is often an issue. Encourage them to always have a drink bottle with them. Rest them frequently on hot days and ensure they are adequately hydrated.



5. Education and Schooling – General Information

- Children with 22q11.2DS do well early on as the **learning is concrete**.
- Letter recognition, sounding out words for reading and times tables is usually learnt well due to the **repetition/rote learning**.
- **Comprehension can be difficult** once extracting meaning from a paragraph or page is required.
- Concepts are difficult to grasp, even things as seemingly basic as “opposite” or “reverse.”
- Learning is best done by **repetition and breaking things down** into the smallest units, use revision to ensure the concepts are retained by the child.
- For most children with 22q11.2DS, specific learning difficulties become obvious by 7 to 10 years of age. 22q11.2DS research shows that IQ scores change or drop frequently over time. This drop does not represent a loss of intellect; rather, it reflects the specific type of learning flaws that children with 22q11.2DS have. Focusing on the specific areas within the IQ testing is required to develop strategies for both strengths and weaknesses.



While each student with 22q11.2DS will have a **unique learning profile** there are areas that are common to most with 22q11.2DS. Some of the learning difficulties reported are:

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| <ul style="list-style-type: none">• Poor organisational skills• Difficulty discriminating size, shape, colour & difficulty with time concepts• Difficulty with abstract reasoning and/or problem solving.• Disorganised thinking.• Poor short term or long-term memory. Poor visual perception• Overly excitable during group activities | <ul style="list-style-type: none">• Poor adjustment to environmental changes. Difficulty making decisions• Poor performance compared to IQ• Difficulty concentrating.• Difficulty copying accurately from a model. Slowness in completing work• Easily confused by multiple instructions. Difficulty with tasks requiring sequencing• Hyperactivity |
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Identifying which of the issues relate to a student with 22q11.2DS in your educational setting will help you plan their individual learning goals. Giving the student with 22q11.2DS **a chance at success** is paramount. Setting unrealistic goals will only cause anxiety and stress not only with the student but also within the family unit.

Relative to their overall intellectual functioning and nonverbal skills, many students with 22q11.2DS show a strong ability to learn and retain repetitive verbal information. Their performance often improves when they receive frequent feedback and are asked to focus on tasks that are brief and highly structured. Their verbal strengths often include memory of factual information, knowledge of words, and an understanding of practical/concrete situations.

Infants and Primary School

As stated previously, children with 22q11.2DS normally **do well in the first years** of their schooling. They are usually very **happy to 'work'** in class because it is **structured, concrete and repetitious** and they generally know what is expected of them.

It is important in those early years to continue to support their **social development**. The primary school playground is usually much larger than the small preschool playground. A **buddy system** can help in the playground, friendship groups and lunchtime clubs can also assist.

Children with 22q11.2DS tend to have a wonderful way of developing strategies to deal with situations and are **often missed** as being candidates for special needs education. Asking a student with 22q11.2DS questions to ensure understanding is a great strategy to counter this problem.

- **Visual prompts** are very helpful for children with 22q11.2DS. They can help them feel secure and confident with their daily routine.
- A **visual timetable** of daily activities helps understanding of language, sequence and memory difficulties and supports the child's need for a structured routine.
- **Photos, line drawings and symbols** placed on the desk to help keep the child on task, e.g. a picture of someone reading to keep them focused on the reading task or a plus sign to keep them focused on mathematics. These symbols could have a general use in class or be specific to the individual.
- **Extra assistance** whether it is one on one or part of a small group may be needed to help the student understand and practice new concepts. It can also be used to ensure they have retained concepts previously taught before they build on these with new concepts

Once the learning has become much **more abstract** (ages 8- 12) you may find that a child with 22q11.2DS has difficulties with regards to mathematics, science and English comprehension. It is wise to continue with the visual and practical approaches mentioned earlier – particularly with math and science.

Some children may experience problems with their fine motor skills, which can be very frustrating for school aged children and can attract teasing from others. This should be monitored, and occupational therapy may be required.

Children with 22q11.2DS often present with signs of **low muscle tone**, clumsiness, motor coordination difficulties and motor planning problems. These weaknesses can cause difficulty in specific areas: Eye and hand coordination, drawing and writing, catching, throwing and hitting, dressing and undressing and daily self-care, organisation and planning, cutting, folding and pasting, tricycle and bicycle riding, and balance.

At school **difficulty with handwriting** is a common issue for students with 22q11.2DS. Teachers need to be aware of the signs associated with handwriting difficulties:

- Sore hands and wrists
- Excess pressure applied to pencil Tiredness
- Avoidance of work which requires considerable writing
- Negative comments such as “I can’t do this”, or negative behaviors and refusal Anger or other behavioural issues that relate to specific subjects

If it becomes clear that a child’s handwriting difficulties are too severe to remediate easily, **alternative strategies** can be considered:

- School work can be copied by the teacher, a teacher’s aide, or another child.
- A child may dictate work and ideas into a recording device to be transcribed later by someone else. Teachers can photocopy their notes for students
- The child may need to develop keyboard skills
- In some severe instances the child may need to be provided with a laptop computer



Students with 22q11.2DS usually have more success with:

- A **direct approach** to learning rather than a discovery-based approach.
- **Rote** memorization, repetition, and concrete examples
- Instruction on **how to learn**, including memory techniques and test taking skills. Small group instruction or assistance within a large group/regular classroom
- Several **small tasks** rather than multiple directions or large assignments
- A **structured environment** with clear rules to follow
- **Additional opportunities** for participation in individual and group physical activities

- **Computer assisted** learning
- Reading aloud and books on tape
- **Additional handouts** or notes to assist with difficulties with note taking and large group presentations
- **Study notes** prior to a test
- Use **multi-sensory** activities
- **Visual aids**

Common areas of relative strength include:

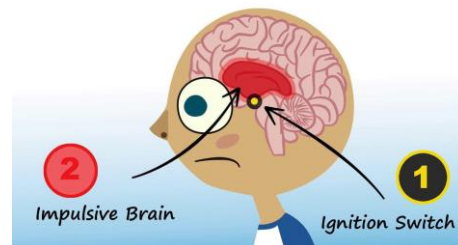
N.B Not all students will have these strengths it is just a guide.

- Simple focused attention & initial auditory attention. Verbal comprehension, word reading and decoding
- Auditory perception & memory
- Rote verbal learning & memory
- Arithmetic
- Willingness to learn

Strategies for Cognitively Impulsive Children

(Information obtained with permission from the Child Development Institute)

Some children have **difficulty staying with the task** at hand. Some possible ideas to try out in this situation include the following:



- Provide as much **positive attention** and recognition as possible. Clarify the social rules and external demands of the classroom. Establish a cue between teacher and child.
- Have children **repeat** questions before answering.
- Probe irrelevant responses for possible connections to the question. Get in a habit of **pausing** 10 to 16 seconds before answering.
- When introducing a new topic in any academic area, have the children **generate questions** about it before providing them with much information.
- **Play** attention and listening games.
- Remove **unneeded stimulation** from the classroom environment. Keep assignments short.
- **Communicate** the value of accuracy over speed.
- Using the wall clock, tell children how long they are to work on a task. Require that children keep a file of their completed work.
- **Encourage** planning by frequently using lists, calendars, charts, pictures, and finished products in the classroom.

Useful Resources:

22q Foundation Australia & New Zealand | www.22q.org.au

The International 22q Foundation | www.22q.org

Guide to Educating Children with 22q11.2DS | <https://cutlerlandsman.com/>

22q Family Foundation USA | <https://22qfamilyfoundation.org/what-is-22q/22q-for-teachers>

NESA | <https://educationstandards.nsw.edu.au/wps/portal/nesa/k-10/diversity-in-learning/special-education/life-skills>

References:

- The Mind Institute California
- Children's Hospital of Philadelphia
- Brandeis University/Children's Hospital of Boston
- Dr Linda Campbell Ph.D
- Childhood Development Institute
- Karen J. Golding-Kushner, Ph.D
- Learning Difficulties Assoc. Texas
- Neil Nicoll, Behavioral Psychologist
- University of Newcastle
- NESA
- Donna Cutler Landsman