



22q Foundation Australia & New Zealand

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

**PRE-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, children 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.

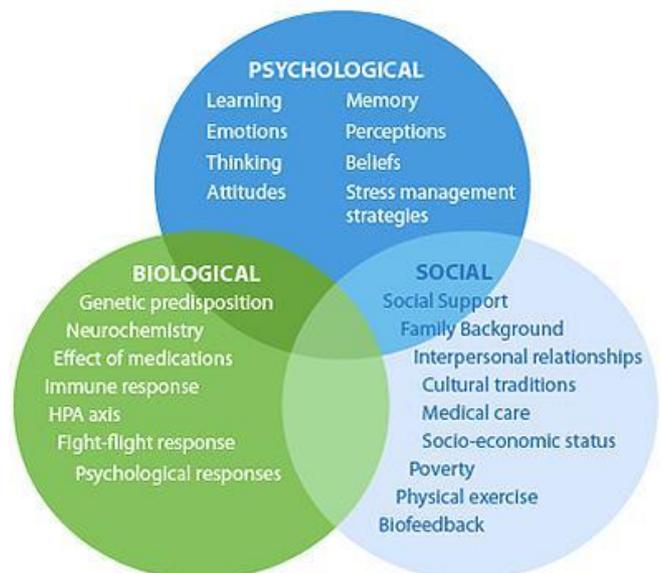
## 2. General Information about people with 22q11.2DS

- 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 recognizable 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**.
- 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.

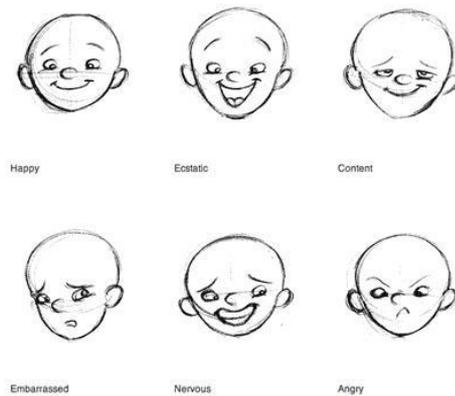
Whatever the student's difficulties, there are ways in which they can be helped to learn. The student, parents, teachers and carers are the keys to success. Constant monitoring is essential to ensure the student is receiving the best possible education. A student with 22q11.2DS **can be successful**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

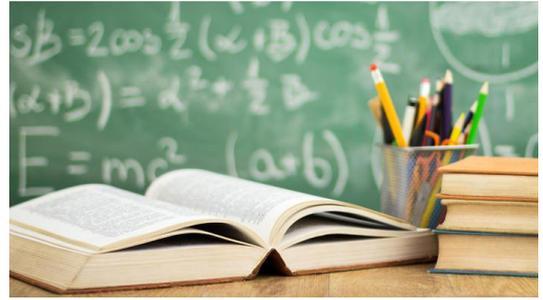
- **Gross motor problems** may hinder performance in sport.
- Tasks involving **balance and co-ordination** may be extremely difficult making them appear clumsy.
- Games and **Physical Education** may be difficult if they involve words such as left, right, up, down, backwards, forwards, etc.
- **Medical 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:

Source: *Brands university*

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| <ul style="list-style-type: none"> <li>• Poor organisational skills</li> <li>• Difficulty discriminating size, shape, colour. Difficulty with time concepts</li> <li>• Difficulty with abstract reasoning and/or problem solving. Disorganised thinking.</li> <li>• Poor short term or long-term memory. Poor visual perception.</li> <li>• Hyperactivity</li> </ul> | <ul style="list-style-type: none"> <li>• Overly excitable during group play.</li> <li>• Poor adjustment to environmental changes. Difficulty making decisions.</li> <li>• Poor performance compared to IQ.</li> <li>• Difficulty concentrating.</li> <li>• Difficulty copying accurately from a model. Slowness in completing work.</li> <li>• Easily confused by multiple instructions. Difficulty with tasks requiring sequencing.</li> </ul> |
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Identifying which of the above 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.

### Student 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:

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

## Pre School



Preschool is often a child's first formal educational setting. While many children will take time to adapt to a new learning environment, instinctively they pick up the concepts on how to relate to other children, become part of a group, turn take and follow the teachers' instructions. The child who has 22q11.2DS often lacks this instinct and will require help to learn these concepts.

A child with 22q11.2DS should be encouraged to join early intervention programs as an extra to their pre-schooling program. ***(When a child has multiple educational settings and therapists it is important that they all communicate so that the same concepts are being reinforced using the same methods. IEP's and communication books are two proven methods to achieve this).***

A child with 22q11.2DS will usually be a good visual learner. They imitate the behaviors of others so using modeling to teach them how to socially interact is a very successful method.

Shadow the child in the educational setting and when needed model the correct response to the different situations for them. As time passes extend the amount of time before your modeling begins to give them the opportunity to respond

### Examples of situations where modeling is useful are:

- Learning to respond to their name and use of other people's names.
- Teaching functional (meaningful) and spontaneous communication. Teaching the child to take turns.
- Teaching the child how to join a group.

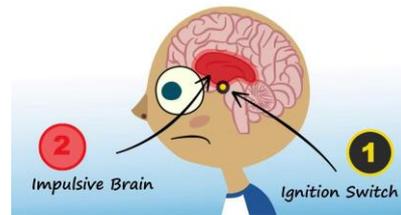
### Using clear short prompts such as;

- Eye contact – to prompt them to look up when they speak;
- Invisible circle – to remind them not to stand too close invading someone's personal space; and
- Listen – to remind them not to talk out of turn is a very useful strategy.

Some children have difficulty staying with the task at hand. Their verbalisations seem irrelevant and their performance indicates that they are not thinking reflectively about what they are doing.

### Strategies 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.
- Communicate the value of accuracy over speed.
- Remove unneeded stimulation from the classroom environment.
- 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.
- Some children have difficulty staying on task. Play attention and listening games.



### Useful Resources:

22q Foundation Australia & New Zealand | [www.22q.org.au](http://www.22q.org.au)

The International 22q Foundation | [www.22q.org](http://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>

### 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
- Robert Shprintzen, Ph.D
- Donna Cutler Landsman