

VCFS 22q11 Foundation

Velo Cardio Facial Syndrome 22q11.2 Deletion Syndrome

An Introduction for Teachers & Carers

www.vcfsfa.org.au



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References:

Brandeis University/Children's Hospital of Boston - Laura Ritinski-Mack, Dita Obler, Leslie Smoot, and Judith Tsipis

Childhood Development Institute

Children's Hospital Research Institute (CHERI)

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www.specialed.about.com/od/iep/a/IEP-Plan.htm

This introductory guide to Velo Cardio Facial Syndrome (VCFS/22q11.2 DS) will offer basic information on some of the specific learning problems and medical issues associated with the condition. For individuals with VCFS 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 VCFS is no different. However, children with VCFS 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 Velo Cardio Facial Syndrome (VCFS/22q11.2DS)?

VCFS (also known as 22q11.2 Deletion Syndrome) 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 VCFS, but expression of the syndrome is highly variable from person to person and no individual has all the anomalies. VCFS has broad reaching effects on development and behavior, speech, language, personality, mood, learning, attention, and temperament.

2. General Information

By the time an individual with VCFS starts in your education setting they may have had numerous surgeries and stays in hospital. Most major medical problems should be stable by the time they enter your care; however there are some children that will require ongoing medical support or may be awaiting further surgeries. It is important to get a good medical history from the parents to keep on file while the child is in your care. For those with ongoing medical concerns that require long term hospitalisation, strategies can be put in place to limit the affect these absences can have on their learning.

Developmental delay is present in over 95% of individuals with VCFS. For some this will have a global affect and for others the child may only be delayed in certain areas. As each child with VCFS has different areas of strengths and weakness each child should be fully assessed in all areas including: speech, language, gross and fine motor skills and have a full psychometric report. These reports will also help you, as their educator, understand the specific needs of the child in your care and will also be needed to apply for funding where applicable.

One of the first things to consider when a child with VCFS starts school is an Individual Education Plan (IEP). This can be a useful tool in planning the students' education. Parents, teachers and support staff should be involved in the preparation of the IEP and it should be reviewed regularly to ensure the students' needs are being met. See page 9 for more information on IEPs.

A communication book is another important way of keeping everyone informed about the current goals and techniques being used to help a child with VCFS. The book is kept in the student's bag and is written in by the parents, teachers and therapists about what the child is working on in each setting. It is often hard to find time to have regular meetings so this is the perfect way of keeping the lines of communication open.

A child with VCFS can achieve good results and should be encouraged to be the best they can be. Always give the child the opportunity to try an activity no matter what the result. Words and phrases like "I can't or it's too hard" should be discouraged. It should be noted that a lack of understanding by the child can be misinterpreted as lack of effort. Most of the time a child with VCFS wants to please those around them. They tend not to ask for assistance for fear of ridicule by their peers. Encouragement and empathy by the teacher can reduce anxiety in the child.

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

Personality & Social Skills

Individuals with VCFS 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.
(Most children with VCFS will require intense speech therapy and some may require surgery to repair the palate).
- Have trouble reading facial expressions, following conversations and appear not to listen, changing the subject to whatever is on their mind.
- Tend to appear very immature making it difficult to keep up with their peers, the conversation in the playground and the latest fads etc.
- Be literal thinkers and interpret words verbatim. Most children will learn the meanings of idioms without being taught, but children with VCFS 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"*.

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.
- Playground 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. By school age most children with VCFS who have CHD will have had their CHD corrected however some may still be restricted in the amount of exercise they can do. A typical child who has a CHD will squat to recover from an activity they have found strenuous. This is the body's way of getting them more oxygen. If you see them squatting, encourage them to rest for a short time and have a drink until they feel they can join in again.
- Leg pains during activity are also an aspect of VCFS to be aware of. If they complain of leg pain encourage them to sit and rub their legs. While this is not life threatening it can be quite unpleasant for the child so allowing them sufficient 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.

3. Education and Schooling

Children with VCFS tend to 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 used to teach them. However, as they move onto extracting meaning from a paragraph or page, they have great difficulty. Concepts are difficult to grasp, even things as seemingly basic as "opposite" or "reverse." Therefore, learning is best done by repetition and breaking things down into the smallest units, then using revision to ensure the concepts are retained by the child.

For the large majority of children with VCFS, specific learning difficulties become obvious by 7 to 10 years of age. The research of children with VCFS in this age group reports a drop in IQ scores around this time. This drop does not represent a loss of intellect; rather, it reflects the specific type of learning flaws that children with VCFS have. Many IQ

tests, particularly the Wechsler Scales, depend heavily on language mediated problem solving and abstract logic. These are specifically the areas in which children with VCFS do the poorest. Difficulty with abstraction and problem solving tend to interfere most with mathematics and reading comprehension.

While each student with VCFS will have a unique learning profile there are areas that are common to most with VCFS. Some of the learning difficulties reported in the literature for children with VCFS are:

- Difficulty discriminating size, shape, colour.
- Difficulty with time concepts.
- Poor organisational skills.
- Difficulty with abstract reasoning and/or problem solving.
- Disorganised thinking.
- Poor short term or long term memory.
- Poor visual perception.
- Hyperactivity.
- Difficulty concentrating.
- Overly excitable during group play.
- Poor adjustment to environmental changes.
- Difficulty making decisions.
- Poor performance compared to IQ.
- Difficulty copying accurately from a model.
- Slowness in completing work.
- Easily confused by multiple instructions.
- Difficulty with tasks requiring sequencing.

Identifying which of the above issues relate to a child with VCFS in your educational setting will help you plan their individual learning goals.

It is reported students with VCFS usually have more success with (Brandeis University/Children's Hospital of Boston By Laura Ritinski-Mack,¹ Dita Obler,² Leslie Smoot,² and Judith Tsipis¹)

- 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 & decoding.
- Auditory perception & memory.
- Rote verbal learning & memory.
- Arithmetic.
- Willingness to learn.

Relative to their overall intellectual functioning and nonverbal skills, many children with VCFS 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.

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 VCFS often lacks this instinct and will require help to learn these concepts.

A child with VCFS 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 others names.
- Teaching functional (meaningful) and spontaneous communication.
- Teaching the child to take turns.
- Teaching the child how to join a group.

Using clear short verbal prompts such as;

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

A child with VCFS 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 is it 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.

Once a child has been accepted into their next school placement it is a beneficial to invite the new school to come and see them in their current preschool placement. It will give you a chance to discuss what has worked for you over the time you have taught them and help with a smooth transition into their next school placement.

Infants and Primary School

As stated in section 3, children with VCFS 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 play group 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. There are many informative websites on peer support in the playground. Refer to our website for details www.vcfsfa.org.au

Children with VCFS 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 VCFS questions to ensure understanding is a great strategy to counter this problem.

Visual prompts are very helpful for children with VCFS. 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.

Once the learning has become much more abstract (ages 8- 12) you may find that a child with VCFS 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.

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.

Strategies for Cognitively Impulsive Children *(Information obtained with permission from the Child Development Institute)*

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. 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.

Fine motor coordination in children with VCFS (writing skills) *Prepared by Neil Nicoll, Psychologist (Psychologist No. PS0003047), published by CHERI*

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 VCFS 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.

These areas of skill development are very important in the development of academic proficiency and success, independence in daily living activities, social interaction, play, leisure and recreational skills, and feelings of self-worth. Weaknesses in these areas should be recognised and assessed, appropriate skills modeled and practiced, and alternative solutions to these problems considered.

At school, the most obvious and pervasive example of these problems is difficulty with handwriting.

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 cassette recorder to be transcribed later by someone else.
- Teachers can photocopy their notes for students (this is very useful in high school).
- The child may need to develop keyboard skills.
- In some severe instances the child may need to be provided with a laptop computer.
- In external exams such as the Higher School Certificate, the child may be eligible for ‘Special Provisions’, for example a reader/writer, and extra time. The student will need to practice these strategies prior to exams.
- Some projects or assignments can be done orally, or on video, or through pictures or some other medium.
- Writing should be a productive element of a child’s day at school, not an onerous and unpleasant task to be avoided because it is too difficult. This should be paramount in the education and support of children with VCFS.

In order to keep a monitor on a student who has VCFS it is important that the student be placed in a position where they can clearly see the smart board, blackboard, computer monitor etc... Many children with VCFS have hearing loss and vision impairments. Being placed at the front of the room can assist with communication and the ability to follow instructions.

Having a well organised classroom with a list of duties clearly marked for each student to see will lessen the anxiety of a child who has VCFS. A structured daily routine and timetable will also lower the child’s stress and anxiety levels.

High School

High school can bring many new challenges for a student who has VCFS. The larger school size and new school expectations, new peers, new subjects and getting used to having multiple teachers, even organising to have the correct books and equipment can be challenging for any student but more so for those with learning issues. There are a number of things that can be done to make the transition easier for the student. These include:

Before they start:

- Collect all relevant documentation, test results etc, from the existing educational setting. Have a meeting with the educational team from the primary school, the student and parents so that the specific learning needs of the student are known.
- Have a transition plan in place until the formal IEP is completed.
- Ensure reports for funding are up to date.
- If the student has friends going to the same school, timetabling them together in the first year so they have someone to follow until they are familiar with the new setting and routines will lessen the impact on the student.

At their orientation days:

- Have an example timetable and a map of the school. Discuss how they will get to each lesson.
- Have the child meet as many teachers as possible.
- Run an extra transition day/s for students with disabilities or learning difficulties so they have an extra opportunity to familiarize themselves with the new educational setting.

When they start:

- Buddy systems are used successfully in many schools.
- Encouraging the student to practice writing important information down in a diary.
- Colour coding their books and textbooks (a different colour for each subject). This is useful for easy identification. They could also have a weekly timetable for home, with a colour coding grid to match their books. This will help to remind them what to pack in their bag for the day.
- Introduce them to the school counselor so they know who they can talk to if they feel overwhelmed or anxious settling in.

Tests/Exams

Some students with VCFS struggle with anxiety and the pressure of exams. The results of the test may therefore not reflect the ability of the student. Strategies to help may include:

- Give extra time to complete the exam.
- Give a verbal test instead of written.
- Sit the test in a separate room.
- Have the font size of the exam paper increased.
- Have a special needs teacher read the papers.
- For those with handwriting issues have access to a computer or a writer for the student.
- Assist the student with exam preparation by offering pre exam notes and study techniques.
- Assure the student that as long as they do their best that is all that matters.

Homework

Teachers play a vital role in the selection, assignment, and use of homework. When homework assignments are meaningful and relevant, student achievement increases. Some things to consider:

- Modify the homework to the learning needs of the VCFS child.
- Set it out in a clear and precise manner.
- Specify the amount of time to be spent each evening on homework. Take this into consideration when assigning tasks.
- Consider alternatives to long-term written assignments.
- Explain the homework and give the student extra handouts to assist them.
- When setting the amount of homework take into consideration that students are given homework from many different teachers.

School Counselor

Approximately 30% of individuals with VCFS are affected by mental health issues. These issues range from depression through to schizophrenia. Using the school counselor to monitor the student for possible early warning signs is one way of ensuring early diagnosis and treatment of mental health issues if they present.

Individual Education Plan (IEP)

An IEP is a written plan that will describe the program(s) and special services the student requires to be successful at school. The IEP is developed collaboratively by school staff, parents, therapists and medical staff if appropriate. An IEP can focus on social, academic and independence needs (daily living). IEP meetings are usually held once term to ensure the IEP goals are being met.

The IEP generally includes:

- A description of the student's current skill levels based on formal assessment.
- Measurable and observable goals for improvement in each area of educational need.

- Measurable and observable objectives describing specific skills needed to reach IEP goals.
- What types of specially designed instruction will be provided.
- When, where, and for how long specially designed instruction will be provided.
- Additional, related services the student will need to support specially designed instruction.
- Allowances for time away from school due to medical issues

Adjustments to support the learning for students with disabilities include all actions which increase the capacity of a student to access, participate in and achieve their intended learning goal. Schools need to explicitly plan the required support and ensure that this is provided in ways that are consistent with the dynamic and unique features of the school and the student.

Transition to Work or Higher Education

The transition to work process begins in year 12. An area support transition teacher comes to the school around April and a meeting is held with the student, teachers and parent/guardian to provide an evaluation that allows the student to acquire funds from ADHAC. An evaluation is given to determine if the student is eligible for transition to work or community participation which is an extension of community access. Community access begins early in the secondary years for students in special needs classes and involves travel training, shopping, paying bills and accessing necessary government departments to gain independence. The majority of special needs students will be eligible for one these programs. When accepted into a transition to work program you gain access to a job agency. These agencies have programs for 2 years which prepare the student for work. After this period they remain in the employment program and are allotted an employment consultant who assists them to find work. They are supported in their new job until they can work independently.

For those not eligible for one of these programs then the school can assist in organising an effective individual transition. An assessment process involving parents, teachers, counselors, psychologists, as well as representatives from government disability employment agencies, community mental health and social services agencies can help identify the relevant transition needs of the VCFS student and plan appropriate services. This team should investigate all assistance available for the student. There are many government websites to assist with this. If the student would like to go onto further education there are many courses available that offer support for the a student with special learning needs. Most universities have disability support services and TAFE offers a wide range of courses designed for those with extra learning needs. Choosing a path that is realistic and of interest to the individual is very important in providing successful transition.

4. Guide to Educating Children with VCFS

The Book "Educating Children with VCFS" by Donna Cutler-Landsman is a practical and current guide for educational strategies to better meet the needs of children with VCFS and other developmental disabilities.

The first part of the book addresses the scientific information that is needed to understand the syndrome and the implications of current research; expert contributors present the results of studies involving brain abnormalities, language/learning profiles, and psychiatric/behavioral difficulties. These valuable chapters are written in a reader-friendly manner to help parents, professionals, and teachers gain useful and necessary comprehension of the unique characteristics of the VCFS population.

The second part of the book is a practical guide to educating a child with VCFS from birth through adulthood. Divided into the various stages of development from preschool to adulthood, it includes information regarding the necessary tests special education teams should run, typical difficulties associated with learning, changes that occur with ability as the child matures (drop in IQ scores and increased learning challenges), as well as behavioral problems in the school setting. Each section includes discussions of the learning challenges and accommodations that can be used at school and at home during that stage of maturity. The authors also present meaningful advice on issues such as friendships, private vs. public school placement, job training, and other pertinent decisions that affect the VCFS child's everyday life. A pioneer of its kind, this book is an essential resource for teachers, parents, physicians, and therapists of children with Velo Cardio Facial Syndrome. For information visit www.vcfsfa.org.au (publications)

5. Information and Websites

This section has useful links to websites and information that may assist with the education of children and young adults with VCFS/ 22q11.2 Deletion Syndrome.

VCFS 22q11 Foundation - www.vcfsfa.org.au

Velo-Cardio-Facial Syndrome Educational Foundation, Inc - www.vcfsef.org.au

Donna Cutler-Landsman- www.cutler-landsman.com

Department Health and Aging- www.health.gov.au

Department Education (NSW) - www.det.nsw.edu.au/disabilityaccess/

NSW Public Schools - www.schools.nsw.edu.au/studentssupport/programs/lrngdifficulty.php

QLD Education Learning & Disability Support - www.education.qld.gov.au/studentsservices/learning/index.html

Dept Education Victoria - www.education.vic.gov.au/healthwellbeing/wellbeing/disability/programsupp.htm

VIC University Disability Support- www.vu.edu.au/facilities-and-services/student-disability-support

Dept Education Western Australia- www.det.wa.edu.au/studentssupport/statewidespecialistservices/detcms/portal/

Dept Education South Australia- www.sa.gov.au/subject/Community+Support/Disability/School-ged+children+with+disability

Dept Education Tasmania- www.education.tas.gov.au/school/health/disabilities

Dept Education Northern Territory- www.det.nt.gov.au/parents-community/students-learning/special-education-disability

Job Access (help & workplace solutions) - www.jobaccess.gov.au

CHERI- Children's Hospital Education Research Institute - www.cheri.com.au

Childhood Development Institute - www.childdevelopmentinfo.com/learning/teacher.shtml

Max Appeal UK- www.maxappeal.org.uk

Great Schools - www.greatschools.org

Disclaimer

The information provided in this booklet was obtained from the many different resources listed above. It is only a guideline. All children should be treated based on their own needs or requirements. The VCFS 22q11 Foundation does not guarantee that any of the information provided in this booklet will work for every child. This information does not replace the advice of your physician or mental health care provider. Before undertaking any course of treatment, the reader must seek the advice of their physician or other health care provider. VCFS 22q11 Foundation does not represent or endorse the accuracy or reliability of any information or materials provided by the sources or any information, data, or analysis derived from these sources.