



Guide for secondary school teachers

Students with bloodvessel (vascular) malformations



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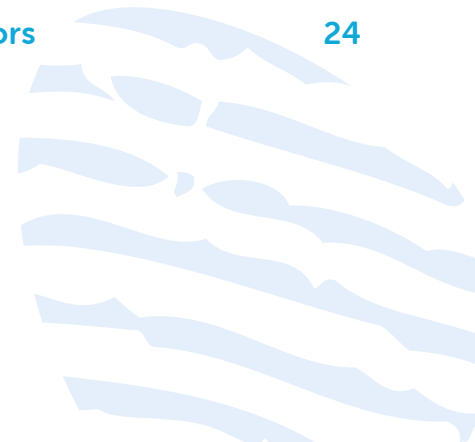
This guide has been reviewed and validated by
the VASCERN Vascular Anomalies (VASCA)
Working Group

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Content

1	Why this brochure?	5
2	Background	7
3.	What are vascular malformations?	9
4.	Possible medical complications	10
5.	Collaboration with students and parent(s)	11
6.	What to pay attention to	12
7.	Information for the teacher	12
8.	Possible psychological consequences and how to deal with this	15
9.	Possible psychosocial consequences and how to deal with this	15
10.	Do's and dont's	16
11.	Annual evaluation	17
12.	Start new school year	18
13.	Registration at the secondary school	18
14.	Informing classmates	19
15.	More information	21
16.	Checklist	23
	Contact information and authors	24



School is a very important phase in the life of a human being



1 Why this brochure?

The CMTC-OVM is a global non-profit patient organisation based in the Netherlands since 1997. One of our main aims is to support people with vascular malformations, their families and healthcare professionals in order to improve the quality of life of patients and their families.

We support our patients in multiple ways. A human being is more than a body. The person has also a psyche and is part of multiple social structures (such as family, school, sports clubs and friends). This implies that support is required medically, psychologically (self-image, self-trust, etc.) and psychosocially.

School is a very important phase in the life of a human being. Experiences during school can have a large impact on the person later on. Over the years we have gained a lot of knowledge and experience via our members from many countries. How did they handle 'being different' at school? Have they been bullied and if this was the case how did they deal with this?

Our main objective by means of this brochure is to support teachers in secondary schools in case they get/have a student in their class with a vascular malformation (blood vessel condition).

The scope of this brochure is limited to regular education. This means that schools for students with, for instance behavioural issues, are outside the scope. Although, some parts of this brochure could be applied at other schools for children with special needs.



Vascular malformations are often labelled as rare diseases



2 Background

Vascular malformations are often labelled as rare diseases. Rare diseases are most of the time chronic so they will be present until the end of life. This means that there are no quick fixes and that support and solutions need to be sustainable. The common definition of a rare disease is 1 person in 2000.

Around 7,000 rare diseases have been identified and described globally. The prevalence of rare diseases could vary per country. In the Netherlands one 1 in 17 has a rare disease. In the USA 1 in 10. In total these are large numbers. This implies that at every school there are students with a rare disease.

One of the main issues is that it takes an average of 5-7 years to receive a (proper) diagnosis. In over 40% more than 1 wrong diagnosis is made with big consequences for both the child as well as the family.



**Not every
vascular
malformation is
visible**



3 What are vascular malformations?

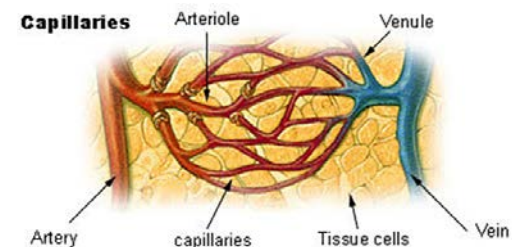
In our body, the blood flows through many thousands of kilometres of blood vessels. Some blood vessels are very large and thick, such as the veins and the arteries. Some blood vessels are very thin, such as the capillaries.

Within dermatology, there are hundreds of diseases of the skin. Vascular anomalies are defects that are visible within the skin (sometimes you only see a swelling) by the change of (blood) vessels. There are various types of vascular abnormalities.

In the case of vascular malformations, the family doctor will almost always refer the family to a specialist such as (children's) dermatologist or child surgeon for non-alarming abnormalities to get the correct diagnosis. For alarming defects the family may be referred by the doctor to a special multidisciplinary team of specialists.

Not every vascular malformation is visible and children can hide visible malformations for instance with clothes. This makes it harder to explain to others that he/she has for instance physical limitations.

One day the student can be full of energy and the next day have no energy.



Body temperature control could be an issue as well

4 Possible medical complications

First of all not all vascular malformations are visible for instance in the brain. In other cases the child might hide the markings under clothes.

In a number of cases the environmental temperature has impact on visibility such as with CMTC. In cases where the child is in a cold environment and upset, the markings become more visible. Body temperature control could be an issue as well.

Rather often limbs are affected which results in under- or over-growth on the limb (length and/or circumference). The healing of wounds or markings may take a long time (sometimes months). Markings around the eyes and/or forehead could indicate eye and/or brain issues.



5 Collaboration with students and parent(s)

You as a teacher have a key role in raising the child in collaboration with the parent(s).

First of all: the time at school should be a process of teamwork between the student, parents and the teacher. Every student is different and they don't want to be in a special position at school. They want to be 'normal'. However, they might have special needs due to their condition.

In the case of a child with special needs, collaboration is even more important. The child might need to go to a medical specialist frequently during school hours or being hospitalized for a while.

It is key to determine together what the needs are of the student and how this could be arranged. Be open and honest with each other. In some cases it could be possible that the school cannot offer what is needed.

The parent(s) need(s) to communicate these appointments well in advance in order to enable the teacher to prepare, for instance additional homework. The child is

part of a group and on top of the (medical) issues the child is facing, further impact should be limited as much as possible.

Many children with special needs don't want extra attention which they already receive due to 'being different'.

For example, one child shares what has happened at school coming home. The other child keeps school for themselves. Things might be looking perfect at school but in reality there are issues such as being bullied.

We advise to contact the parent(s) frequently (e.g. bi-monthly) and document this meeting.

However in the meantime things might change such as behavior. In this case contact the parent(s) from a preventive perspective. Of course this also applies to the parents. When they notice possible issues or behavioral change they should contact the teacher as well.

Examples of behavioral changes are homework issues, being tired, poor attendance at school, declining results or not being at school on time (frequently).

6 What to pay attention to

Due to limb length differences the child might not be able to run fast or play soccer. This could result in not being selected in a team during sports at school. The child literally stands aside. As you know this has a negative impact on the child's self-esteem and self-image. One way to make the child part of the group is to ask the child to support the teacher such as with counting of points.

Focus on what a student is able to do and not on what the student is unable to do.

7 Information for the teacher

As you know as a teacher probably better than a lot of parents: each child is unique and a user manual is not supplied.

Practical tips.

- Making contact with a student with a medical condition starts with showing understanding. Really listen to the student and her/his parents and take them seriously.
- Look at the student's ambitions and what he/she can do and not what he/she can't do.
- What is the best way for the student to learn (this is in fact a common question)?
- Offer other teaching material that fits the needs of the student and offer personal support.
- Share with a student what is bothering you as teacher. This could help the student with sharing what is bothering him/her.

- The self-esteem and self-image of a student with a medical condition are rather often not at the same level as other students. Pay extra attention to this.
- The student is dealing with his/her condition 24x7. He/she knows how to deal with this in relation to his/her condition the best way. The challenge for you as teacher is of course to connect with them.

Questions

- Do you know if medication is needed and how this should be taken?
- Do you have emergency contact information?
- Does the student need a special location in the class for instance close to the teacher in order to enable the teacher to have a better look at the student?
- How is the mobility of the student? Are there special requirements and can the student participate in gym class (limitations for instance)?

**The pupil
is dealing
with his/her
condition
24x7**



Think in possibilities rather than in limitations



8 Possible psychological consequences and how to deal with this

One of the main aspects is to look beyond the child's disease. A child is more than the disease itself. Next, think in possibilities rather than in limitations for the child, because this is often behavior that children would adopt themselves (avoid self-limiting beliefs). Look out for possibilities but aim to create and maintain a safe environment. Sometimes this may require more attention than for other children.

Another example of an optimal coping strategy is to help the child view their disability as a superpower. This could be to view it as something that makes them unique. Emphasize this without disregarding how hard it is. If you feel that the child is struggling with accepting their disease or avoidant towards students because of it, first ask age-appropriate questions to the child and then ask for advice from the parents. Since the parents and children are struggling with the disease for their entire life, they have become the experts in this condition.

9 Possible psychosocial consequences and how to deal with this

As mentioned in the previous item: the impact of the disease is on the entire family. And not only on the family but also on fellow students, friends, sports clubs and later on at work. In some cases this means that some social activities are less accessible for children with a disease.

As a teacher you are also responsible for the social domain of education in the child's life. Sometimes this means that roles can be reversed: ask the child for help when they know best about the disease. Let the child be the teacher sometimes.



10 Do's and don'ts

Do's

- I'm more than my condition. Pay special attention to what goes well.
- Look at my talents. Look at what I can do and not what I can't do.
- Listen to me and respect me. When I say 'no' it is no. I know my limitations.
- When I say I want to do something myself, let me do this myself.
- Stand up for me when there is no understanding or when I'm not present.

Don'ts

- I'm not looking for being asked frequently how it goes/feels.
- You don't need to ask how I'm doing (all the time). I'll let you know how I'm doing.
- Decide for me without discussing this with me first.
- Don't look at my limitations. Focus on the possibilities and solutions.
- Don't take me into account when I don't ask for this.
- Don't make me dependent. Let me do my own thing.
- Don't push me. When I say 'no' it is 'no'.

11 Annual evaluation

At the end of each school year it is wise to evaluate the student together with the parents and the student. Normally this is done for each student. Many schools have an electronic student record system which is being used during the entire time at school. In a number of cases the parents have access to (part of) this system as well (electronically) so they can monitor their child during the schoolyear too.

In this case items could be discussed, on top what is routinely being discussed, such as:

- Did you see changes over time regarding physical issues?
- How is absence over the schoolyear (e.g. due to hospital visits or being ill)?
- How is the student dealing with his/her condition?
- How are the other students dealing with the student?
- Do you have tips for the student and/or parents?

Steps to the next phase

12 Start new school year

In some cases the teachers remain with the group from the first class until the final class. In most cases a new school year will be with a new teacher. This means that there will be a transition from one teacher to the other.

We advise that this transition will be performed together with both teachers, the student and the parent(s). Normally at school a student file is maintained during the entire school period. This file should also contain the (medical) condition details.

13 Registration at the secondary school

The first step is to meet your mentor and share your story and (medical) information. As mentor/teacher you know that this is a huge step for each student. A completely new environment, being the eldest student turning to be the youngest, a new school system, etc.

The mentor could, with your permission, inform your teacher about your condition.



14 Informing classmates

In general it is important that classmates are informed. This stimulates empathy and could reduce bullying. Keep in mind that children with a condition don't want to be an exception.

Describe in practical terms for instance:

- Explain what the condition is and what this means for the student.
- Explain that the condition is permanent and not contagious.
- The condition and/or medication could have impact on the appearance and/or behaviour of the student. This could not only have an impact on the student itself but also on the classmates.
- Explain in case some adjustments in the class have been made and why.
- In case of e.g. regular hospital visits explain to the classmates why the student is absent and work together with the parents on how to minimize falling behind.

An option could be that the mentor and you (and maybe some other students with a condition) visit the classes and explain about your condition. Of course this could be very exciting!

Around the age of 12 years the body image becomes more important and prevalent to children so the psychological impact is likely to increase as is the social burden from bullying.

The mentor could document the following items for instance (on top of the standard items):

- The development of the condition over time at school.
- Physical (gym) or mental limitations (tests and exams).
- Independency and self-reliance.
- Medical issues and medication.

**More
information:
www.cmtc.nl/en**

15 More information

We have a lot of information in multiple languages about many vascular malformations. However, this is only one part of the entire picture. We also have a lot of material available about the psychological and psychosocial aspects of living with a rare disease.

This brochure is a summary of the main items. On our website we are constantly working on additional material. In case you have suggestions please do not hesitate to contact us.



16 Checklist

- Emergency contact details of the parent(s).
- Emergency contact details of the general practitioner.
- Condition(s) description in laymen's terms.
- Medication to be taken at school and the procedure.
- Possible limitations (mentally or physically).
- Possible complications.
- Informing other school staff.

The student (depends of course on the age)

- What can the student do independently.
- What is important for the student him/herself.
- How open is the student about his/her condition.
- How is information shared about the student, with whom and when. The privacy of the student is crucial of course.

- What absence is expected due to illness, hospital visits and (medical) treatment.
- How does the student travel to and from school.
- Is the student going to school care after 'normal' school (e.g. because the parents are at work). In this case the information needs to be shared with this organization as well (by the parents).
- What can school do to support the student the best way.
- Who can the student talk with in case of issues such as being bullied.
- Are special requirements needed in case of school activities such as school camp.

More information

Our CMTc-OVM organisation operates globally and has local representatives (Patient Advocates) in multiple countries.

These Patient Advocates know the local language and culture. They also have names and addresses for local support.

On our website you can find up-to-date information.
www.cmtc.nl/en

Our website can be translated to over 100 languages by means of 2 mouse clicks.

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