

A photograph of a classroom with a red wall. In the background, a boy in a red shirt is lying in a white hospital bed, writing in a notebook. In the foreground, a girl with blonde hair in a ponytail, wearing a dark floral shirt, is sitting on a wooden stool and typing on a large, colorful keyboard. The room has various educational materials, including a microscope, a printer, and children's drawings on the wall.

Caring about, taking care of ...

*Pupils with chronic
or long term illnesses.*

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Janet Bootsma
Mieneke Engwerda

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COLOPHON

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PREFACE

One in ten children suffers from a chronic somatic or long term illness. This means that on the average in every school class there are two or three children with a chronic illness.

In the Netherlands, the law on the education sick pupils (WOOZL) came into force on 1 August 1999. As a result the school where the sick pupil is enrolled retains responsibility for the continuation of education. Hospitalschools were closed down and hospital teachers became Consultants Education Sick Pupils (ESP) . These consultants are employed at University Hospitals or 'Educational Advisory Bureaus'. Consultants ESP advise and support schools, parents or care professionals about education and illness.

The Dutch version of this booklet has been written to inform teachers about the consequences of illness and treatment for education. It provides information about support and guidance for sick pupils and is meant to offer a hold, a first step towards guidance. In this English version we left out descriptions for typical Dutch situations.

This booklet is not meant to be a blueprint for all pupils with a chronic illness as every pupil is unique in their own circumstances! Through this booklet we want to contribute to a school career with as few interruptions as possible.

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Groningen, summer 2012

USED TERMS

Chronically ill:	<p>This term is meant to be a chronic somatic condition or a long term illness.</p> <p>A chronic somatic condition is mostly long term disorder. The condition is incurable but controllable with the help of medication and rules of life. Many chronic somatic conditions go with a deterioration of quality of life.</p>
Sick pupil:	<p>We are aware of the fact that a pupil is more than ill alone. For the sake of readability we choose the term 'sick pupil'. By this term we mean a pupil with a chronic somatic condition or a long term illness.</p>
Teacher	<p>Teachers of primary or secondary education or vocational training.</p>
Parents	<p>Parents, foster parents or guardians of the sick pupil.</p>
Pupil	<p>A pupil, male or female.</p>
He	<p>he or she.</p>

1 BEING ILL AND YET ATTENDING SCHOOL ?

It is possible ! What is more, your pupil is entitled to it. When a pupil is chronically ill, education can be very significant ! In this chapter you will read why.



What does education mean for a pupil who is ill?

Familiar

Education is something that is familiar. In an unfamiliar medical world education may offer something to hold on to.

Structure and distraction

Being busy with schoolwork provides distraction and daily structure.

Preventing social isolation

The pupil normally spends a major part of the week with classmates and friends. Regular admission to hospital means the pupil will not be present at the daily activities. Yet these remain important. Attending school, even at a distance, means belonging to your friends.

Appealing to what a child is still be able to achieve

When a child is ill the focus tends to lie on what is wrong with the pupil and what he is unable to do. Education appeals to the healthy part of the pupil.

The focus is on what he can achieve and that will be the starting point.

Reducing arrears in homework

By doing his homework a pupil may keep up with the class as much as possible.

Offering a perspective

If school achievements are important, sick pupils have a sense of belonging. They offer them the possibility to work on their future.

2 FIRST APPROACH TO DEALING WITH A CHRONICALLY SICK PUPIL

First steps towards a curriculum for your sick pupil. Talking to parents, asking for support, informing classmates, contact between pupil and classmates and giving attention to siblings. Each step comprises a number of actions. You can follow the steps from the moment you come to know that your pupil is ill.

Step I: Talking to parents

- Make notes of all important data and information about the illness. Pay attention to calamities and to how to handle them.
- Assign one person in the school to contact the parents.
- This is the person the parents keep in touch with and make appointments with. This person need not be the pupil's teacher or mentor.
- Agree on fixed moments of contact. With the parents or someone appointed by the parents
- Ask parents for expectations they have of the teacher or the school and discuss whether you and the school can live up to these.
- Ask your pupil what he would like and be able to do in the short (and possible longer) term. Consider the degree of involvement of the school, school attendance and doing schoolwork.
- Agree on what information can be given out and in which form.
- Agree on who is going to be informed, by whom and in which way
- Agree on the way the sick pupil will be kept in touch with classmates
- Agree on the way attention is given to siblings.



Step II: Internal and external support

Schools vary in the way colleagues pass on important information. It also depends on agreements with parents. If you need practical or emotional support, discuss this with the members of your team. And, of course, an 'internal school counsellor' or coordinator may play an important role.

Step III: Informing classmates

If the illness and its consequences will be noticeable for classmates it is important to inform them. This prevents classmates from misunderstanding or feeling injustice, which may lead to harassment. It may also evoke sympathy.

Most children do not want to be exceptional, particularly during puberty. You should discuss the advantages and disadvantages of informing the class and respect your pupil's decision. Return to this subject at a later time when this seems advisable.

The best way to inform the classmates depends on the pupil, the classmates, the teacher and the parents. The following points may be of help:

Preparations:

- Be well aware of which information pupil and parents want or don't want to share and the way in which it is communicated.

Structure of the discussion

- Provide medical information about the illness and its treatment
- Discuss infection/ contamination.
Provide honest information about risks of infection related to the illness, even if the illness is not infectious. Fear of infection, even if not justified, may affect contacts with classmates.
- Prepare classmates for a change in appearance or conduct.
An illness or medication may sometimes change the pupil's appearance or conduct. You can prepare your pupils for this e.g. by showing them a picture of the sick pupil. This prevents a shock reaction from classmates. A shock reaction by classmates can be very hurtful, both for the sick pupil and for themselves. Shocked classmates may also feel guilty about their reaction.
- Tell about adaptations and for what reason they have been made.
In case the sick pupil needs adaptations other classmates may feel that he is given preferential treatment. This may hamper the contact between the sick pupil and his classmates. It's important to explain what adaptations are need for the sick pupil and why. Feelings of jealousy and injustice can then make way for understanding and support.
- Be clear about the reason for absence
This prevents classmates from speculating about it.

During the discussion

- Be clear and honest while explaining.
This prevents pupils from developing their own ideas and precludes unnecessary fear.
- Make room for emotions.
The discussion may evoke emotions in you or in classmates. There is nothing wrong with showing emotions but this should not gain the upper hand. Should you fear this may happen don't hesitate to ask a colleague for support. It may be helpful to examine your own emotions in advance or discuss them with colleagues.
- Invite classmates to show their emotions by asking questions.
Think of:
 - Classmates' experiences with being ill themselves
 - Classmates' experiences with illness in the family or among their acquaintances
 - Classmates' associations with the concept of 'illness' and the illness concerned
 - Think of questions to ask sick pupils
 - A way to understand/ help/ support the sick pupil. Think of classmates' experiences when they were ill themselves. What did they like to get?
- When necessary, make use of auxiliary material
You can clarify an illness by using auxiliary material such as a book, a game or an informative DVD.

After the discussion

- Make use of a 'question box'
Some children don't dare to ask their questions in class. Also, the discussion may raise new or other questions with the classmates. For this purpose you may install a 'question box' at the back of the classroom.
- Keep informing classmates
If the illness is subject to change: Arrange frequent class talks in order to inform classmates about the sick pupil.

Step IV: Agree on how to keep in touch with the sick pupil

Support and concern by classmates and peers are important for a sick pupil. In case of a long-term absence, chances are that contacts may disintegrate. As a teacher you can play an important role in keeping in touch with the sick pupil. You can structure contacts, e.g. by regularly sending emails or calling on the sick pupil.

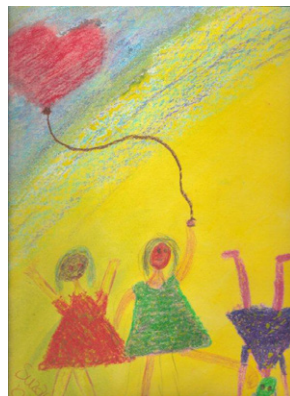
Personal and creative

It's also worthwhile to show support and concern in a more spontaneous, personal and creative way, e.g. :

- Having the classmates made a big postcard together
- Making a video message or a film
- Keeping track of a class book and sending it
- Compiling a picture book
- Making use of IT possibilities

School parties and outings

When, during the absence of a sick pupil, an outing or school party is being organized, it's a good idea to invite the sick pupil. Depending on the pupil's age you determine to ask them directly or through their parents. You may think along with the parents about the necessary support or adaptations to enable his presence/ participation. If participation is not possible you should still try to involve him, e.g. sending a postcard or pictures of the outing or party.



Step V: Attention paid for siblings

Siblings of the sick pupil are confronted with feelings of sadness, anxiety, anger or lack of understanding, and may therefore be upset. Changes in their home environment will often involve a decrease of structure and stability. Fixed school structures may be felt to be recognizable and pleasant.

Often a lot of the family and friends' attention is going to the sick sibling. When siblings' classmates have been aware of the circumstances they may be supportive and understanding. The handling of the siblings, and the information that should or should not be passed on have already been arranged with the parents. This may help make the hard times more tolerable. Sometimes siblings don't want to be an exception, in which case you may decide not to inform their classmates.

Siblings are not to be considered as contact persons, either by the school or by the teachers. The assigned school contact keeps in touch with siblings.

Step VI: Go on with upbringing

Parents and grandparents are confronted with a (severely) ill child. A lot of attention is paid to the illness, the treatment and its consequences. As a result the child's upbringing may end up to the second place. Yet it is important for children with a chronic illness to experience rules and limits. In this, teachers may play an important role.

3 AND THEN... BACK TO SCHOOL

In this chapter you will find adaptations enabling the sick pupils to continue education. They will not all be applicable to every pupil; just consider them as possible interventions.

A deteriorating or bad physical condition may be a consequence of the illness itself or may be caused by the treatment or use of medications. Most of the sick pupils want to go on with school as soon as possible. Because of the fact that they are in arrears in their curriculum they will not be able to participate fully with their classmates. A sick pupil may be uncertain about changes in capability or looks and therefore not be able to face their classmates. Sometimes a pupil may even depend on aid to attend or get to school.

Adaptations for education can lower threshold for going back to school. It's important to inform classmates about the reason for the adaptations. This prevents the sick pupil from feeling stress or pressure and classmates from feeling neglected.

Mobility

Going to school

The sick pupil's condition may have deteriorated to such an extent that travelling to school is too strenuous. Alternative means of transport, e.g. pupils' transport or an electric bike, depend on the distance from home to school and on the means parents have at their disposal.

Within school

Going from classroom to classroom in secondary education can be exhausting. Some aids:

- A key to the elevator helps the pupil move more easily to other classrooms
- Give the pupil more time to move to other classrooms
- Have lessons take place on the ground floor

Carrying a heavy school bag takes a lot of energy. An extra set of books at school relieves the sick pupil. If subjects are taught in set classrooms, the books may be divided among those classrooms.

The use of a wheelchair or a segway may make school attendance possible in case of immobility, pain or a deteriorated condition. Keep the

accessibility of classrooms in mind.

Adaptations in the classroom

Place in the classroom

Your pupil might have a reduced ability to concentrate, either temporarily or permanently, due to illness, use of medications or fatigue. In that case a place in the classroom where distractions by his classmates or other stimuli will be minimized may help.

Sometimes doing schoolwork is less important than attending school, and contact with classmates has priority. In such a case it may be preferable to have your pupil work in (small) groups or pairs.

An individual curriculum

Whether the pupil studies fully or partially, at school or at home, curriculum adaptations are often necessary. For example adaptations in timetables, duration of the courses, teaching material and tests. An individual curriculum will prevent the pupil from lagging behind. Below some points of interest have been mentioned, divided up into primary and secondary education.

Primary education

Make a clear and realistic plan, together with parents and, if so desired, the pupil to inform classmates and the team of teachers. Possible adaptations are:

- A concentrated curriculum: the pupil only studies what is strictly necessary or the most important parts of lessons.
- The sick pupil only studies the main subjects such as arithmetic, language and spelling.
- Allow for fatigue and reduced concentration by varying the order of the subjects. This will preclude the pupil from having the same subject every time he is least concentrated.
- Have a test done at a time when the pupil can concentrate well, e.g. in the morning or immediately after the pupil has taken a rest.
- Put together a package consisting of textbooks and notebooks in such a way that the pupil may study at home or in hospital. Make a clear plan so that the pupil knows what to do and what is expected of him.

Secondary education



Possibilities for adaptations vary for countries. Mostly adaptations need approval by the competent authorities.

Below you will find some examples of adaptations:

- Extra time for making tests or handing in assignments
Have a test done at a time when the pupil can concentrate well, e.g. in the morning or immediately after the pupil has taken a rest.
- A reduced timetable
This makes room for the necessary process of treatment, recovery or rehabilitation. It's important to schedule the subjects in such a way that the pupil has a maximum of consecutive lessons and thus have free daily periods instead of hours. Classmates and the teaching staff should be aware of these adjustments.
- A concentrated curriculum:
 - The pupil in the first years of secondary education can get exemptions for parts of the curriculum of a subject, for certain subjects.
 - The pupil (in the third or fourth year) is entitled to make an early choice for his final exam subjects. In that case the pupil only studies the subjects for his final exam.
- Adaptations of exams:
 - Spreading a year's tuition or the (final) exam over two years
The pupil reserves half his subjects for the next school year.

In this way he continues to coincide with the planning and in comparison to his classmates.

- Doing an exam at another location than at school.
- Adjustment of the official start of an exam.
- Extra time to do the exam

Caring for the sick pupil

Signing out

A sick pupil will have periods during which he feels himself relatively well and times when he does not. Let the pupil know that you understand that he excuses himself when he is feeling unwell. Make a clear-cut agreement, both the parents and the pupil, that the pupil will be present as soon as he is mentally and physically able to. This prevents the pupil from experiencing too much pressure concerning his presence and from exceeding his limits. With such agreements in mind the pupil knows that he will also welcome for just one hour.

Reduced exertion tolerance

Physical Education (PE)

A sick pupil may tire quickly. This may manifest itself in e.g. PE. In secondary education, you may grant dispensation for PE. PE, however, also has a social element. By giving the pupil other tasks, such as being referee or the teacher's right hand, he remains involved with the class. He may also participate in those parts that he is able to join. It's important that the PE teacher knows the pupils' capabilities. The aim is for the pupil himself to indicate his limits. Respect those limits. Afterwards, talk with the pupil and if necessary his parents if you feel the pupil drops out (too) soon.

Outings

Discuss with the pupil and his parents what will need to be done in order to allow participation. Also keep in mind that after the activity the pupil will have to return to school or home.

Moments of rest

When, during a break, your pupil is not able to go outside, you may discuss how the breaks may be filled where, and who with. Sometimes moments of rest are required outside the breaks.

Assistance with general daily vital functions

If your pupil needs support with general daily vital functions, like eating or going to the toilet, you may request additional support. Possibilities may vary by countries.

If the sick pupil is required to eat at different times or take medications at set moments you may, after consulting the sick pupil, inform the classmates. It prevents the pupil from feeling embarrassed and the classmates from feeling neglected.

IT tools

IT tools in education are now widely developed. They may present a good alternative for or complement to other changes in the curriculum or timetable. With IT tools a sick pupil may keep in touch with his classmates, through e.g. a webcam, a video film or an IT set for long distance learning. He may still participate in school life at a distance. Therefore, the starting point for using these tools is encouraging social contact. With an IT set for long distance learning it is also possible to attend lessons at home or in hospital.

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In the Netherlands, annually, approximately 3.2 million pupils attend primary, secondary, special and vocational education. One out of ten has a chronic illness. It means that everyday 320 thousand pupils are struggling with their health to a greater or lesser extent. Many of them attend regular schools. Due to a change in the law on 1 August 1999 schools are held responsible for the education of their sick pupils. Also in case they are in hospital or chronically ill at home.

Because of their illness, these pupils are not always capable of optimally taking advantage of the regular curriculum. This booklet contributes to a school career for sick children with a minimum of interruptions. The booklet is no blueprint for all pupils with a chronic illness; each pupil is unique in its own situation!