



Caring about, taking care of ...

*The pupil with a sick
brother or sister*

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PREFACE

When a child is chronically ill, this affects all members of the family. The chronic illness becomes part of the family's daily life; a new member of the family that needs to be taken into account.

Siblings have a very special bond. They grow up together and learn a lot from each other. Sibling contact plays a large part in the development of social and emotional skills. When one of the children falls chronically ill, there is a great change within the family. Often the sibling will get a different role and position. The illness causes worries, and a lot of attention goes to the sick child.

School is to sibling a trusted environment, which offers (them) structure and safety. It is therefore important for normal school life to continue as much as possible.

This booklet is not meant to be a blueprint for all siblings of a child with a chronic illness. Every sibling is unique in their own situation and reactions. Through this booklet we wish to help call attention to the issue of siblings, in order to enable the sibling to learn as well as possible in a safe environment.

Kine Smith Larsen is a chronically ill child's sister. She noted down her feelings in a letter. You will find parts of this letter (translated from Norwegian and edited by Marianne Naafs) in the boxes in this booklet. We wish to thank Kine, as the letter beautifully illustrates the problems described in this booklet.

Ria Bakker
Janet Bootsma
Arnold Boom

Groningen, spring 2013

THERMS USED

Siblings	Well siblings of a chronically ill child
Chronically ill:	This term is meant to indicate a chronic somatic condition or a long term illness. A chronic somatic condition is usually a long term disorder. The condition is incurable but controllable with the help of medication and regimen. Many chronic somatic conditions involve a deterioration in quality of life.
Teacher:	Teachers of primary or secondary education or vocational training.
Parents	Parents, foster parents or guardians of the sick pupil.
Pupil:	A pupil, male or female.
He:	he or she.
Ziezon:	Dutch network for educational support for sick pupils.
Child:	child or youngster.

1 SIBLINGS – PERCEPTION OF THEIR ENVIRONMENT

Dear teacher, I have been uncharacteristically silent today. My sister is in hospital, you know, and my thoughts keep returning to her... I'm scared. I'm sure she is really ill. Everyone stops talking when I'm nearby, and I can see they're crying. That's why I've been so quiet today.



Siblings experience a violation of their family life. The safety of family life is disturbed. Their world is upside down and contradictory feelings arise, which from a sense of loyalty are not always expressed. A chronic illness becomes part of the family's daily life.

If in a family one child suffers from an chronic illness, this has a long term effect on siblings. A lot of flexibility is required of them.

Changes and worries within the family may cause siblings to draw attention at school, both in a positive and a negative sense. Socially and emotionally siblings may therefore react differently from what you have been used to see from them.

There is an increased chance of them in time developing psycho-social problems. This goes especially for siblings in secondary education. They may also experience more physical complaints than their contemporaries, and these problems occur more often in siblings in primary education.

The way siblings deal with the illness affects the experiencing of problems. Siblings with positive expectations about the course of the illness, who trust the doctors, experience fewer problems than siblings looking for information about and explanations of the illness. Another factor in experiencing problems is age: the older the sibling, the greater the chance of them experiencing problems.

A chronic illness in the family may also have other consequences for a sibling. They may feel more solidarity within the family, and they often appear stronger and more adult than their contemporaries. They may also stand up for others sooner and show more tolerance for differences between people. Siblings are more responsible than their contemporaries, are often more conscious of the value of life and do not take health for granted as much. They are often more patient too, and more creative in coming up with solutions when their sick brother or sister is incapable of something.

Teachers can play a role in spotting siblings' problems. In this chapter we will examine the different emotions and problems siblings may experience. Every sibling is unique, and the presence and intention of reactions will vary.

Jealousy

When a child falls ill, it is the centre of interest. Parents, family and friends all behave differently. And the sick child is treated differently too. It gets most of the attention within the family. Presents and postcards abound, but not usually for the sibling. Father and mother are constantly at the hospital, and all conversation is about the sick brother or sister. In short, everything around the sibling is focused on the sick child.

Fear

Siblings may be greatly worried about the sick child. Insufficient knowledge about the illness, its origin and its treatment may cause fear, misunderstanding, guilt and false ideas or expectations in siblings. Fear of

developing the illness themselves, fear of death, fear of confronting their brother or sister in hospital. But also fear of unpredictable or aggressive behaviour in their sick brother or sister. They may be afraid and think that they have caused the illness, e.g. by quarrelling with him or her. Ordinary remarks made before the sibling fell ill, such as 'Button up your coat' or 'You'll get ill' or a curse like 'Drop dead' may take on a dreadful meaning when the child does fall seriously ill. The sibling then awards himself a role in the origin of events, in order to better understand what is inexplicable.

Anger and frustration

Siblings feel there is little they can do, they are on the side line and may thus feel powerless and angry. They continually have to take the sick brother or sister into account. Their freedom is restricted. Social events cannot take place and friends cannot come and visit. This may lead to arguments and contact problems.

Dear teacher, I'm unusually angry and miserable today. My father and mother want me to visit my sister, you know, but I don't want to. She is so very ill, I can't bear to watch it. That's why I don't want to visit her. That's why I have been so angry and miserable today.

Grief

Due to hospitalization and outpatient treatments of the sick child, siblings regularly have to deal with parental absence. They miss the presence and attention of their parents. They grieve because they see their brother or sister suffer, because their parents are sad or because the tie to their brother or sister has changed. They miss the life they used to have.

Guilt

Siblings have difficulty accepting the feelings they experience. They feel they ought not to have these feelings, and then feel guilty if they do. They feel they are 'whining' when their parents are busy enough as it is. Some feel guilty because they do have good health. Siblings may deny themselves the liberty to have fun and enjoy the good things in life.



Shame

Because they look different, or cannot join in things other children can, siblings may feel ashamed of their sick brother or sister. Siblings may fear other people's reactions, and thus find themselves in difficult situations. On the one hand they want to stand up for their sick brother or sister, but on the other hand they want to be one of the group.

Then too, the changes in the family often create differences in the way of life compared to that of friends' families. This, too, may be something the sibling is afraid of.

Shame may prevent siblings from wishing to invite friends to their home, or make them retreat and avoid social contact with contemporaries. Thus they may become socially isolated.

Loneliness

Caring for the sick child requires - depending on the intensity of the illness - a lot of the parents' attention. Siblings may feel lonely, as there is little attention for them. The sick child and the parents are often together. Siblings may feel shut out and think that no one can see that things are difficult for them, too.

Rejection

For many parents the sick child comes first now, which may make siblings feel rejected. As a result, a sibling may then start rejecting the parents in turn.

Worries about the sick brother or sister

Siblings worry about their brother or sister. They feel bad that the sick child has to go through such awful things, that it is so ill or has to go in hospital again and again. They also worry about the outcome of the illness and the treatment.

Changing role of the sibling

Siblings often feel very responsible. They assume their parents' tasks, sometimes to such a degree parentification occurs. The sibling then comes to support his parents. He may for instance take care of his parents and listen to their problems, or take up (part of) the chores. Care of the other children may also be a sibling's task. Siblings may be used, consciously or not, as contacts with the outside world, and thus get saddled with (too) many responsibilities. Older siblings run a greater risk of ending up in such a role.

Family structure

When a family is confronted with a chronic illness of one of its members, this influences the family structure.

The balance within the family may unstable, as it depends on the course of the illness. The time will come when within the family a new balance will have been found around the sick child. This will not necessarily be the old, familiar situation for the sibling. At such a time a sibling may require more attention, for instance because they feel that now there is time for them.

The balance within the family may again be disturbed by changes in the course of the illness. A new balance will then have to be found. It is important that a family structure return, whether the same or different. Failure to provide structure affects the extent to which siblings experience the problems mentioned in this chapter.

Dear teacher, I've been unusually noisy and restless today. You know, I'm fed up with everyone continually asking how my sister is. All of them, they talk about it, at home and everywhere else. I've had it up to here. I'm angry with my sister. She gets all the attention ... I feel no one bothers about me. That's why I've been so noisy and restless.

2 SIBLINGS AT SCHOOL

School is an important place for siblings. They meet their contemporaries there, at a place where life goes on as usual.

School provides structure for siblings and as such contributes to the structure of the family system that has changed. To support a sibling it is important that normal school life continues as much as possible. The problem that siblings have to deal do not automatically require a different pedagogical approach. Siblings may be called to account for their conduct and results, just like other children.

In this chapter we examine the different school problems siblings may experience. Every sibling is unique, so the presence and intensity of their reactions will vary.

Concentration problems

Siblings may have more trouble concentrating. Worries about the sick brother or sister make their thoughts wander, or make them lose sleep so they are tired in class. But the changing role of the sibling within the family – as described in chapter 1 – may also make it difficult for siblings to concentrate on their work. This could have an effect on their school results.

Dear teacher, I have been uncharacteristically industrious off late. My sister 's very ill, you know, and my parents worry about her. If I really do my best it is a relief for them, and they may be proud of me. And if they don't have time for my sister, she may die. You get it? That's why I've been so industrious off late.

School results experienced differently

The changes in the home situation may make parents react differently to school results. Interest in results may lessen, and good results will no longer have the effect they used to have. Siblings may then start thinking that learning is not important any more, which can make them devote less energy to school.

What can also happen is that siblings concentrate more instead of less on their school results. The sibling starts to work harder to get better marks.

He hopes to draw attention to himself by performing better. Thus the sibling, by performing well, relieves his parents from care. The sibling is showing his parents they do not need to worry about him.

It is important for teachers to keep track of the changing (reaction to) school results, and talk this over with the sibling and his parents. Both a sibling's better and his worse performance may be signals of the sibling's need for help.

School absenteeism

The changes in family life, and such extra duties for the sibling as may arise, may cause school absenteeism. Siblings may be less motivated to go to school because they feel they are needed at home. This will be more of an issue in secondary than in primary education. Parents may deal with this in various ways. Some parents will support the sibling's absence from school, others will prevent this as much as possible. Moreover, the illness may have such impact that the sibling is unable to focus on education.

It goes without saying that school absenteeism can lead to various problems. It's important that school keep in touch, and show sibling and family their engagement. This will help get the sibling to come back to school, at least part of the time, as soon as possible. If necessary you can contact a social- educational worker for professional aid. A sibling, too, ought to be at school as much as possible.

Dear teacher, you may feel I require a lot of attention. I fully understand it tires you out, and sometimes make you angry with me. But it is so hard to tell you I need you. I'm showing you in various ways – with both conscious and unconscious signals- that I'm having a really hard time.

3 YOUR ROLE AS A TEACHER

School is a familiar and safe environment for siblings, one where things continue to go on the way they are used to. This provides stability and safety for the sibling. It is therefore important that normal school life continue as much as possible. As a teacher you can play a significant role in this. In this chapter you will read which actions you may take to maintain a safe and solid structure.

Step I: Talking to parents

In the early days, but also when your pupil's sibling has been ill for a while, it is important that you, as a teacher, keep yourself informed of developments.

- Make notes of important data and information about the illness
- Discuss what your pupil knows about the illness. How do the family talk about it? Does your pupil know what it implies, and what the treatment is like?
- Ask how your pupil is dealing with the situation. Have there been changes in behaviour or emotions?
- Find out what changes there are within the family that may influence your pupil.
- Agree in which way attention will be given to your pupil. Inquire into the parents' expectations of both teacher and school, and discuss whether you and school can fulfil these.
- Agree on whether you will inform the class, and if so, how. More information on this subject you will find in Step IV.
- If the parents cannot find room to talk to you, you can agree with the parents on a contact person to keep you informed. You might consider the parents of a friend of your pupil's.

- Inform the parents how your pupil is doing in class. Create a realistic picture; mention these things that you are concerned about, but also outline your pupil's positive sides.



Step II: Talking to your pupil

As a teacher it is your task to observe; note down your findings in the pupil file.

- Create a favourable time and atmosphere for a talk
- Show understanding of the situation
- Show you are there for your pupil. Ask questions such as 'What does it mean to you?' instead of 'How are you?'
- Give your pupil room to talk but respect their reluctance to do so.
- Stay in contact with your pupil, even if they indicate unwillingness to talk.

- Arrange for a trusted representative. This may be a teacher or tutor, but may also be another person at school. It is important for this trusted representative to have good ties with your pupil. Some pupils like to have a regular contact person; if this is the case you should look for someone, who will be available for several years.
- Do not try to obtain information about their sibling's illness from your pupil.
- Discuss which people at school are acquainted with the situation. This may create a feeling of safety.
- Agree on whether you will inform the class and if so, how. More information on this you will find in Step IV.
- Be on the lookout for pupils with a delayed reaction, who only react when the acute phase of the illness is over and the family have found a new balance.
- Take into consideration there are other ways of expressing oneself than talking. Your pupil may express himself during creative subjects. Be on the lookout for this and discuss it with pupil or parents; mention what you have seen or heard. If necessary ask the trusted representative or the social- educational worker for help.
- Observe lower elementary school pupils during their activities or take part in their play. During play, your pupil may act out or show what is bothering him. By taking part in his play you offer him the opportunity to tell you what is bothering him.

Step III: Internal and external support

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

Step IV: Informing classmates

If the illness and its consequences become noticeable for your pupil's classmates, it is important to inform them. This may occur, for instance, when your pupil is absent from school or is given an adapted timetable. Information prevents classmates from misunderstanding or feeling injustice, which may lead to teasing. When classmates know what is going on this may evoke sympathy.

Discuss this with your pupil, but respect his decision if he does not want to tell the class. If necessary, return to the subject at a later point in time.

The way to inform the class depends on the pupil, the parents, the class and the teacher. Some important points:

Preparation

- Be well aware of which information pupil and parents do and don't wish to share, and the way in which it is to be communicated.
- Before you inform the class, it is important to consider what the situation means for your pupil. What are the consequences? What is the best way to support your pupil within the class?
- Many siblings hate to hear the name of their sibling's illness used as a term of abuse. Discuss the relevance of this for your pupil and whether they want attention paid to this in class.



During the discussion

- Provide (general) medical information about the illness and its treatment. Discuss with your pupil if he wants to play a role in this, and if so, which one. Possibilities include a talk, a presentation or an interview. In the case of the latter, you should interview your pupil, so they merely need to answer. You will, of course, discuss this interview with your pupil beforehand.
- Sometimes your pupil will need to be absent or get an adapted timetable due to their sibling's illness. Explain clearly why this is, to prevent speculation or jealousy among classmates.
- Be clear and honest while explaining. This prevents classmates from developing their own ideas and feeling unnecessary fear.
- Invite classmates to show their feelings by asking questions. You might consider:
 - Classmates' experiences with illness in their family or surroundings
 - Classmates' associations, things that come to mind at the notion of 'illness' and the clinical picture that is meant
- You may want to make use of back-up materials such as a book, a game or an informative film. In the Netherlands these materials are available for several age groups.

4 SUPPORTING SIBLINGS

The teacher's role as observer combined with the parents' information, can provide an early recognition of the sibling's problems. This creates an opportunity for school to deal with these flexibly. Sometimes these turn out to be insufficient, in which case the teacher's task is to spot this. You need to recognize your limitations. School is a place which can mean a lot to siblings, but not a centre for social aid.

It is important for you to discuss your worries about siblings with their parents. You may then advise parents about the possibilities for support to siblings. Examples are:

- Information days
- Contacts with fellow-sufferers
- Patient organizations and their websites
- Family days
- Holiday camps

Possibilities may differ in various countries. Inform on the options.

Should the above mentioned possibilities offer insufficient help you may refer to professional (therapeutic) help. The school social worker may also play an important role in this.



Adaptions to the school programme

Although the aim is for your pupil to have a regular timetable, there may be reasons to deviate from this. Some of these have been dealt with in chapters 1 and 2. Engage both pupil and parents in a discussion and get help when necessary. When your pupil appears to (temporarily) need an adapted programme look for the possibilities your national curriculum offers.

The following is based on Dutch regulations. They are meant as examples and may not always be applicable in other countries.

During the school career

School may deviate from school rules and is autonomous in its decisions.

School may:

- Grant a postponement for texts and exercises;
- Choose to provide substitute exercises;
- Condense teaching material; the pupil works his way through the most important or necessary material only;
- Exempt the pupil from part of the teaching material or from certain subjects;
- Adapt the rules for moving up.

Concerning tests and exams

End-of-school tests (primary school) and final exams (secondary school) may be dealt with flexibly. You might consider:

- Setting substitute exercises or condensing material;
- Postponing deadlines for papers/ projects (school exams have to have been handed in by three days before the final exam at the latest) to the second or third period;
- Spacing the final exam or end-of-school test.

If and when a school wants to adapt the final exam, the inspector's permission is required.

ACKNOWLEDGEMENTS

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Als je broer of zus ziek is.

www.opvoedadvies.nl

Siblings have a very special bond. They grow up together and learn a lot from each other. Sibling contact plays a large part in the development of social and emotional skills. When one of the children falls chronically ill, there is a great change within the family. Often the sibling will get a different role and position. The illness causes worries, and a lot of attention goes to the sick child.

School is to sibling a trusted environment, which offers (them) structure and safety. It is therefore important for normal school life to continue as much as possible. Through this booklet we wish to help call attention to the issue of siblings, in order to enable the sibling to learn as well as possible in a safe environment.

