

My student is
terminally ill!

What
now?



TANJA VAN ROOSMALEN



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Certain textual choices were made for readability. Where the book talks about the involvement and needs of the sick student, the needs of the parents are of course also meant. Where 'children' are mentioned, young people are also meant. If it specifically concerns young people, this term is used. Finally, where 'he' is mentioned, it goes without saying that 'she' is also meant.

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Colophon

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INTRODUCTION

In recent years, the care for children with a short life expectancy worldwide is developing. The importance of education for this group of children and young people is increasingly being included in palliative care for children. After all, education highly contributes to the quality of life of children, even until the last days of their life. To reach as many teachers and healthcare professionals as possible to contribute to this, was the main reason for me to write this book.

The challenge for a school is to look for opportunities to add life to the days of terminally ill students, when it is no longer possible to add days to their lives. The model for palliative student support is a guide for this.

This book does not provide ready-made answers. It does provide support, considerations and tips for your own practice. These can help finding the specific support the student needs. This book can be used for the support of students with a chronic, progressive or life-threatening illness, who have a limited life expectancy. Although the emphasis is on students who are unable to be cured for cancer, the basic principles in palliative student support also apply for a broader group of students receiving (palliative) care.

Palliative student support is an intensive form of support that requires a firm commitment of involved teachers, their colleagues and school management. The palliative phase may be an intense experience for the student, parents, siblings, school team, fellow students and their parents. When the support works out well, this is an enrichment for everyone involved. Parents with a terminally ill child may live by the day, together with their children, who want to live as normally as possible, for as long as possible. This book provides guidelines for living life, however short it may be.

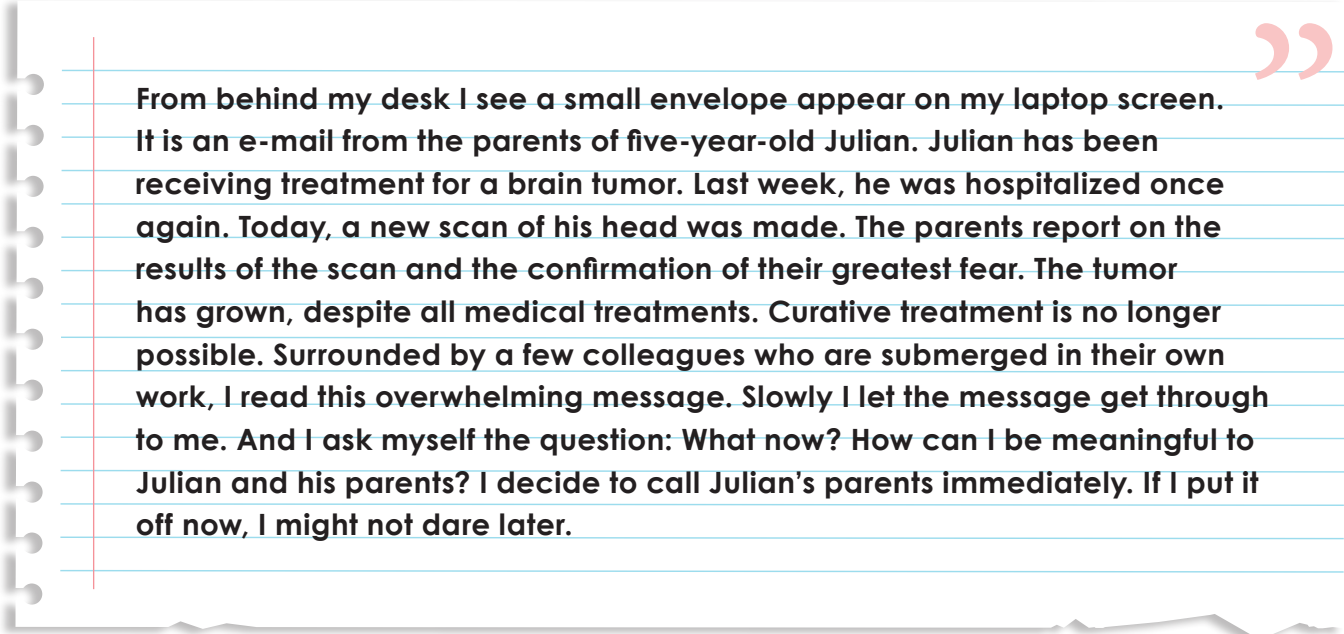
I could not have written this book without the children, their families and school teachers who taught me everything in this book. They are all, sometimes anonymous, intertwined in this book. I feel honoured for the opportunity, given by Jan Haverkate, president of HOPE, to share my vision on palliative student support with an international audience. A big thank you to Amber Everhardus en Bram Verhoeff for their support on the English translation. Tom Peters, thank you for sharing the cover photo of the original book for this edition as well.

Last but not least, thank you reader, for taking the time to read and learn what you can contribute to the quality of life of children and young people. It makes all the difference!

Tanja van Roosmalen
Grief therapist for children and youngsters

March 2021

1. PALLIATIVE STUDENT SUPPORT: THE STARTING POINT



From behind my desk I see a small envelope appear on my laptop screen. It is an e-mail from the parents of five-year-old Julian. Julian has been receiving treatment for a brain tumor. Last week, he was hospitalized once again. Today, a new scan of his head was made. The parents report on the results of the scan and the confirmation of their greatest fear. The tumor has grown, despite all medical treatments. Curative treatment is no longer possible. Surrounded by a few colleagues who are submerged in their own work, I read this overwhelming message. Slowly I let the message get through to me. And I ask myself the question: What now? How can I be meaningful to Julian and his parents? I decide to call Julian's parents immediately. If I put it off now, I might not dare later.

Cancer is the leading cause of death for children and adolescents around the world¹. In addition, there is a large group of children with a limited life expectancy as a result of chronic or progressive disorders. For their parents, education will change into a different perspective. Very sick students, however, usually want to continue living as normally as possible. A life in which they go to school, interact with friends and try not to have to deal with their illness every minute of the day. The daily school rhythm gives them something to hold on to in an uncertain period of time.

A school, confronted with a student, who is life-threateningly ill and who will die prematurely, faces a difficult task. The student needs customized education. The school is faced with the challenge of looking for the possibilities to meet its needs, within or next to the learning paths of the other students. At the same time, it is necessary for the school to prepare for the (possible) loss of the student. At first glance, these assignments seem incompatible. After all, how can the school offer a future perspective, while at the same time preparing for a major loss? It requires a very careful approach, in which the parents and the sick student play a key role.

In this chapter, a model is presented for the support of a student with a limited life expectancy. This model offers leads to guide the sick student and support his immediate environment at school. But before we go into that, let's first determine which students we talk about in this book. And secondly, let's address the importance of education and school attendance for seriously ill students.

1.1 STUDENTS WITH A LIMITED LIFE EXPECTANCY

An estimated number of 21 million children with life-limiting conditions between the ages of 0 to 18 years worldwide depend on care and treatment without the possibility of a cure². We call this ‘palliative care for children’. Palliative care is for children with very diverse chronic, progressive or life-threatening disorders³.

It is a misunderstanding that every patient who receives palliative care can no longer take care of himself and will die within a very short period of time. Even when a cure has been deemed impossible, participation in daily life is still possible and desirable in many cases. This palliative phase can stretch over a period of days, weeks, months, but also several years. Only the last phase of life, in which the condition of the child deteriorates rapidly, is what we call the terminal phase. Because the role of the school in the life of an severely ill student in the palliative phase is so fundamentally different than in the terminal phase, we look at this separately in each chapter.

This book is mainly aimed at students who are life-threateningly ill and for whom curative treatment is not or no longer possible. This is especially true for a number of students with cancer. Their lives are suddenly put in a different perspective when it turns out that they can no longer be cured. Even though the average life expectancy of this group of students varies greatly⁴, the threat of a sudden loss is immediately imminent. This has a huge impact on the school.

In addition, this book provides sufficient tools for the support of students with chronic or progressive syndromes, in which the life-threatening character is less prominent. As will appear below, in these situations different emphasis is put on student support.

1.2 PALLIATIVE STUDENT SUPPORT

Julian’s mother picks up the phone with a weary tone of voice. I tell her that I have read her e-mail and that I just wanted to call them. Julian’s mother tells her story. About their fears which were confirmed, their worries about the near future and about Julian, who is now playing on the floor so quietly. I listen to the pain she expresses in her words. Julian has medicine and feels pretty good right now. He would like to go to school, she tells me. Immediately all kinds of questions flash through my mind: Has the school been informed yet? Can and will the school team cooperate with Julian’s wish to go to school? Can his teacher handle that? Do we have to inform all parents immediately to prevent rumors?

In palliative care for children, a number of basic principles are applied to which care should comply⁵. Two of those relate to education:

- Every child has the right to education and should be provided the opportunity to continue attending their old school.
- Every child must have the opportunity to participate in games and other activities for children.

Therefore, school and education are an essential part of good palliative care for children.

In addition, there is the fundamental right to education, one of the ten most important rights under the Convention for the Rights of the Child. This right also remains valid for children who are severely ill and may even die in the foreseeable future. Adults tend to let go of the objectives of education in such a situation. This is done with the best of intentions, but unfortunately this gives the signal to a student that it is no longer important to keep going to school.

School is a substantial part of the world of children. When this (partially) disappears, they miss an important distraction, but above all they lose grip and regularity on their lives.

The school can and should therefore make a major contribution to the quality of life of a terminally ill student. This care requires a specific approach, which can best be described as 'palliative student support'.

Palliative student support encompasses all pedagogical and didactic measures that the school can take to support the terminally ill student, but also any siblings at school, involved fellow students and the involved school teachers.

Palliative student support has three key points:

- intensive communication with the family;
- education in agreement with the psychological basic needs of the student;
- providing emotional support to all those involved in school.

Palliative student support is shown schematically in the model below.

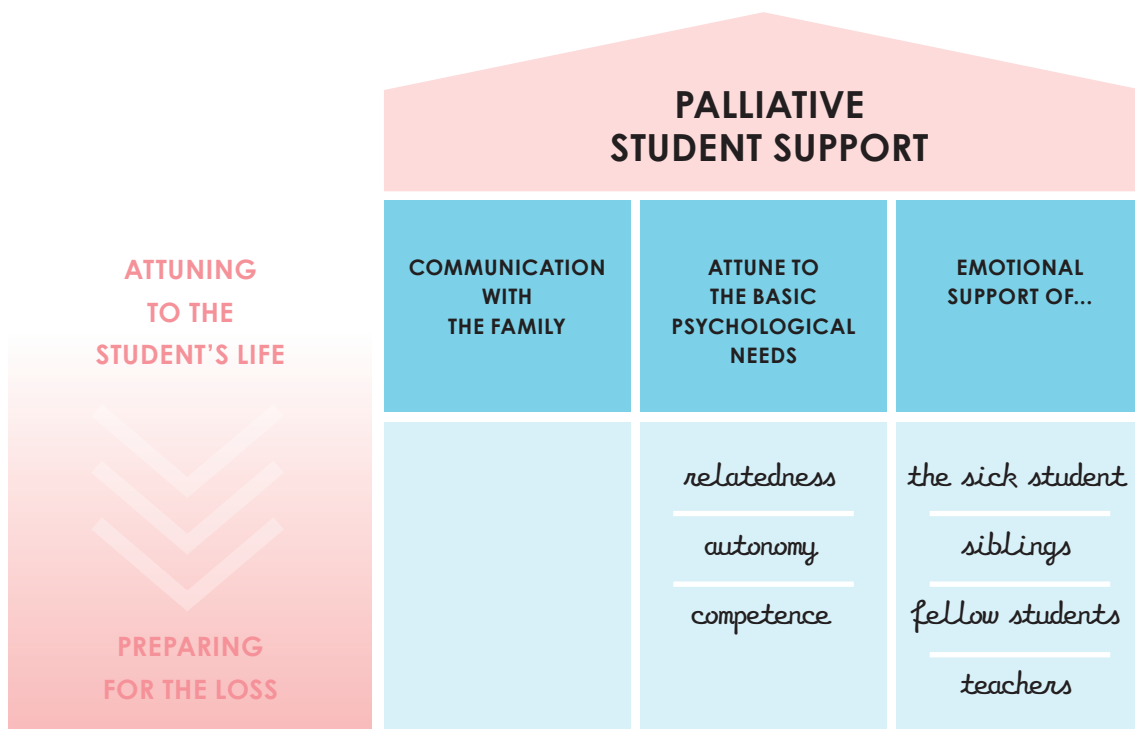


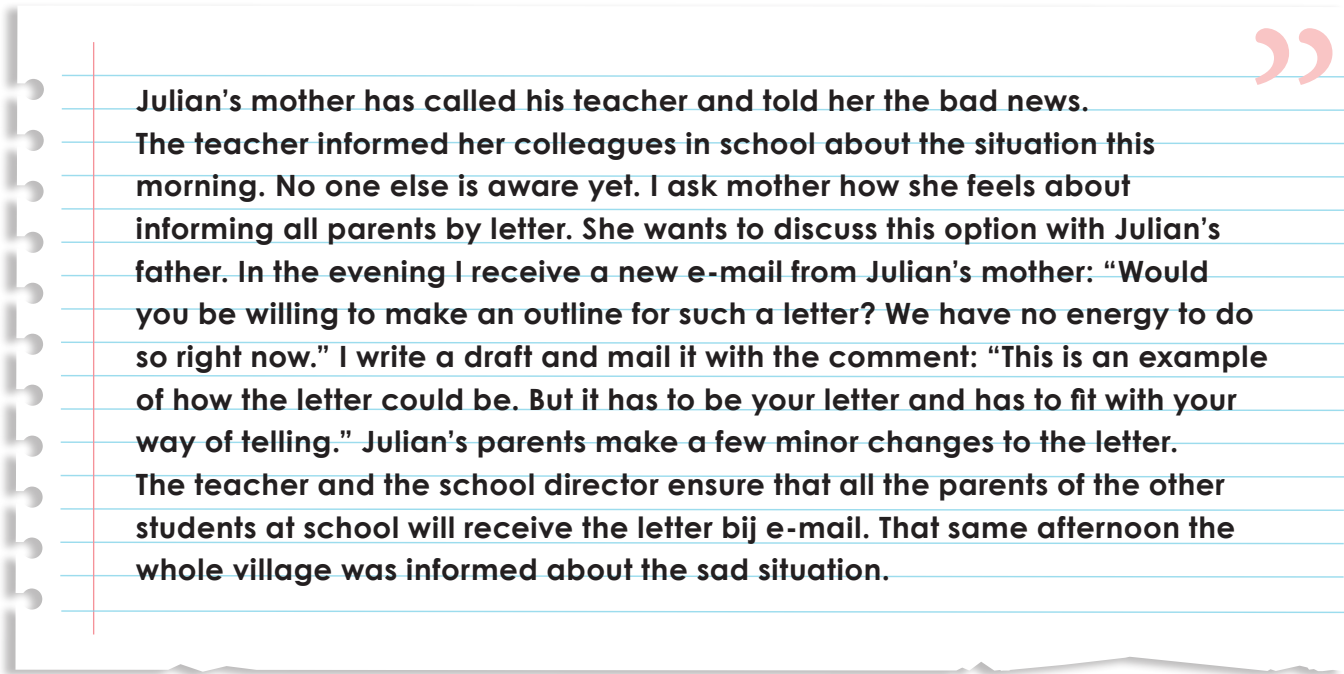
Figure 1: Model of Palliative Student Support

The three key points run like a red thread through the student's disease process. The school can emphasize on the aspects that are required in their specific situation. When it has recently been discovered that the student cannot be cured, the emphasis can be on the key point of communication with the family. When a student regularly goes to school, palliative student support focuses more on the student's psychological needs and what the school can offer. As the student becomes increasingly ill and does not or hardly ever attend school, it can be necessary to shift more to the emotional support of the siblings at school, fellow students and the school teachers.

On the one hand, the support focuses on attuning to the student's life. When a student's condition deteriorates, the focus shifts towards the direction of preparing for the loss of the student. Regardless of the life expectancy, both aspects are part of the palliative student support throughout the entire process. Because the course of the disease process cannot be predicted exactly, the model for palliative student support is a framework.

The key points in the model will be specified in more detail in the following chapters. In chapter 2 we discuss the communication with the family. Chapter 3 is about attuning to the psychological basic needs of the student. Chapter 4 describes the emotional support of the sick student, siblings at school and fellow students. The emotional support for the school team is the focus in chapter 5. Each chapter describes the school challenges in the different phases of the disease process.

2. COMMUNICATION WITH THE FAMILY



Julian's mother has called his teacher and told her the bad news. The teacher informed her colleagues in school about the situation this morning. No one else is aware yet. I ask mother how she feels about informing all parents by letter. She wants to discuss this option with Julian's father. In the evening I receive a new e-mail from Julian's mother: "Would you be willing to make an outline for such a letter? We have no energy to do so right now." I write a draft and mail it with the comment: "This is an example of how the letter could be. But it has to be your letter and has to fit with your way of telling." Julian's parents make a few minor changes to the letter. The teacher and the school director ensure that all the parents of the other students at school will receive the letter by e-mail. That same afternoon the whole village was informed about the sad situation.

From the moment the parents hear the bad news, it is important for the school to determine, in close consultation with the parents, on any communication between school, students and parents. Not only the wishes and expectations of the parents are leading, but certainly also those of the sick student and possible siblings. In this chapter we will discuss the way in which the school can be involved in communication.

2.1 TERRIBLE NEWS

For some parents the message that their child can not be cured, comes as thunder in clear skies. For others, the message confirms their anxious suspicions. For every parent it seems as if the ground is sinking from under their feet. One way or another parents will have to live with the fact that their child will not get the future they so desired.

Despite the fact that a disease cannot be cured, some children receive a palliative treatment (e.g. palliative radiotherapy in childhood cancer). This treatment is aimed at reducing complaints and improving or maintaining the quality of life for as long as possible. In such cases it may take a while before everyone realizes that the treatment is not meant to cure.

Four-year-old Sarah has a malignant tumor in her head from the age of eighteen months. Medical treatment has stabilized the tumor, but it is expected that it will eventually grow again. If that happens, no treatment is likely to be possible. Sarah knows she has a 'bump' in her head, as her parents have told her. She knows that she sometimes has to go to the hospital for the bump and that it is not possible to remove it. After each scan, the parents are naturally very tense about the result. Mother says that Sarah shows little interest in the results. Sarah only finds it annoying to make the scan (which takes place under anesthesia).

It is up to the parents to determine when, how or whether or not their sick child will be informed about the prognosis. Sometimes parents choose not to tell their child - precisely or immediately - what is going on⁶. When children are told what is going on, it is important that this is done in clear, understandable language, in words that are adapted to the level of development of the sick child.

Even if the child is informed, it is not self-evident that a child understands that after a diagnosis, in the event of a return of the illness or when stopping the medical treatment, he or she will eventually die. This question can also come up at a later moment in time. Even if it is stated that the child will eventually die, it still depends on the age and level of development how much the child understands.

Although the school is mainly focused on life, it is important to have some knowledge about the concept children have regarding death.

What do children and young people understand about death?

To have an idea of what children understand about death, you have to compare it to their developmental age. The following is a guideline. Know that every child is unique.

Very young children (1-4 years old) have no real understanding of death. They do not yet distinguish between living and non-living things. They do react anxiously to the situation because they notice all kinds of changes, for example in the amount of stress of the parents. That can make them feel very unsafe and stressed. Two- and three-year-olds are already more aware of a loss.

Children from age four to six know the difference between life and death. They know that someone can die. They use the word 'death' in their game, without really knowing exactly what death means. For them death is temporary, like sleeping, after which you wake up. They are therefore not afraid of death, unless they have experience in losing someone they loved. Preschoolers won't see an approaching farewell as a final farewell. However, they do react on the stress of their parents, which they are very sensitive of. This can make them anxious.

Children age six to nine begin to realize that 'being dead' is irreversible. In most cases, they do not realize that it can happen to anyone (including themselves or a sibling) at any time. They do not yet fully understand what a 'definitive end' means. At this age, feelings of fear and confusion about death can arise.

Children between nine and twelve years old discover that everything that lives will also die at a certain moment. At this age, children are very curious about death and what comes after. However, they do not always show their own fears and grief, because they want to be more independent of their parents.

Nine-year-old Tom experiences many complications from medical treatment. With every complication, he is admitted to the hospital and every time he feels better afterwards. When he is readmitted, he is firmly convinced that the doctor will make him well again. This time Tom gets sicker. He asks his mother what happens when people die and what will happen after death. When the doctor tells him that his medical treatment will end, Tom gets terribly angry, because he does not want to give up.

Young people from the age of twelve understand that death is inevitable and that it can happen to anyone, not just old people. At this age, feelings of fear and confusion about death can arise. Young people understand in an adult way what is going on. They can deal intensively with existential questions. The confrontation with death becomes extra difficult, because young people depend less on their parents during puberty and are looking for their own identities⁷⁻⁸.

Robin (15 years old) has been feeling down since joining a school and career selection programme. He openly asks himself: "Why do I have to do this? I will not get old anyway."

Informing siblings

At any moment, parents will also have to inform their other children about the prognosis. It is up to the parents to decide what is the right moment for this, depending on the situation and the developmental age of the sibling. In communication with siblings, the same applies to the sick child: information must match their age and level of development. Children have a special antenna for feelings in their own family. Even though they are not fully informed, they sense that something is seriously wrong when it is.

Remco's parents (he is 12 years old) tell their four-year-old daughter that her brother can no longer get better and will die soon. His sister jumps up and says, "Then I will take my wand and make Remco better again!"

2.2 COMMUNICATION WITH SCHOOL

Usually, the school is informed shortly after the parents receive the terrible news. Initially, emotions are shared. Later on, it will become more clear what the consequences are for the school.

The school will face many questions: What expectations do parents have regarding school and education? Can we still mean something to the student and the family? These questions can only be answered by involving the parents. 'Parents are in charge in such a situation, but they also have to give their own manual of instructions,' a mother once told me. The school can only follow the parents and attune the support as much as possible to what the parents and the sick student desire.

A strong relationship of trust is the basis for the communication between parents and school. If this relationship is already strong, it will directly benefit the support of the sick student, but also the school. It is also possible that this confidence does not (yet) exist. The school has the responsibility to invest in a good relationship.

In many cases the teacher is the contact for the parents. However, it may also be that the parents feel more familiar with someone else at school, for example, the teacher of the previous school year. Then this teacher can be the contact for the parents.

However, it is also desirable to involve an internal supervisor, coordinator and/or a member of the school management. Particularly in matching the help and program of the school to the wishes of the sick student and his parents. This person has the responsibility to support the directly involved teacher(s) and to coordinate the communication within the school team.

Discussing the following questions with the sick student's parents can help to ensure that the school deals adequately with the consequences of the student's situation.

In conversation with the parents: meaningful questions



What information did the parents receive from the doctor and how do they deal with this?

It is very pleasant for the school when parents inform the school as complete as possible, even if the sick student him or herself is not (fully) aware of the poor prognosis. In the conversation it is agreed how the school will deal with this confidential information. It is also important to discuss the emotions of the parents and siblings (even when they do not attend the same school), so that more insight is gained into the perception of the family.



What does the sick student know and how does he deal with this?

It is important that the teacher is aware of what the student knows about his illness, the prospects that exists and how the student reacts to this. The teacher can adjust his support to this and better understand the functioning of the sick student.

It is good to also discuss which words have been used (e.g. cancer, tumor) and what information has not yet been given to the student. The teacher obviously monitors the sick student well at school and it is nice for the parents if these observations are regularly being communicated with them. Even when there are (apparently) no changes or problems. In this way, the parents get a more complete picture of the functioning of their child when he is at school. The school also shows involvement and checks whether the school's approach is (still) in line with the needs of the parents.



What do siblings know about the sick student and how do they deal with this?

It goes without saying that special attention must be paid at school to the siblings of the sick student. For their teachers it is also important to know what information the siblings have and how they deal with this, so the teacher can adjust his support accordingly. Even when the siblings attend a different school, it is important to define an answer to the question stated above. Coordination between the school of the sick student and the school of any siblings often has enormous added value for all involved.

? What can be told to the (involved) teachers at school?

Support of a seriously ill student is a responsibility of all teachers at school. Especially when a student is in a phase of terminally illness, the support cannot be limited to the concerned class only. It is important that all teachers (or the involved department) are informed. The teachers who teach the sick student and any siblings are the most important to be informed first of the situation.

In addition, there are often students who are personally involved with the sick student, for example former classmates, friends, or cousins. It is wise to determine, together with the parents, who needs to be informed.

? What can be told to classmates, other students and their parents?

In practice it appears that open discussion of the situation works best in the long term. Openness about the situation provides clarity and a certain calmness for students, because they are involved in the disease process.

For the parents and the sick student however, an open approach can be very confrontational. Suddenly, everyone knows about their situation.

Remco's parents really want his teacher to talk about the course of Remco's illness in class. Remco (12 years old) would rather not be there himself. The sad news is also told to the children in the groups of Remco's two brothers. One brother (8 years old) wants to tell the story himself, the other brother (6 years old) does not want to be in the room when the teacher informs the class. His little sister talks about it in kindergarten, sitting on her teachers lap. That same afternoon, parents of all children at school receive an e-mail. The rapid spread of the news suddenly draws a lot of attention to the family. That is quite confrontational for Remco and his parents. In retrospect, Remco's parents nevertheless felt supported.

Informing classmates (and their parents) of the sick student requires a careful and well-prepared approach. For communication, it is also important that the message is adapted to the developmental age of the students. The other classes (of siblings, cousins or former classmates) also need the same careful approach. In primary education it is more obvious to inform the entire school (including parents) than in secondary education.

After the classmates have been informed about the situation, it is desirable to send their parents an e-mail (or a letter). A letter proposal is included in this book. It is essential to discuss with the parents of the sick student how open school may communicate, so that rumors are prevented. A general rule in all communication about the disease and future expectancy is to let it run parallel with the communication within the family. At all times it must be prevented that the outside world is informed more comprehensively than the sick student or siblings.

In some cases, parents are told by the doctor how much time they - approximately - have left with their child. For communication at school it is extremely important that this is handled very carefully. In many cases it is better not to distribute this information, since a prognosis is never certain and can change over time.

Children and young people mainly live in the present and hold on to concrete information. When a life expectancy of a few weeks is mentioned and the student dies sooner, this is extra confusing. In the opposite situation, where the student lives much longer than has been expected, this also creates confusion.



In what way are all those involved informed?

Not only what is being told, but also the way in which it is told, requires customization. The starting point is that the form of communication must match the parent's approach. The parents may choose to distribute a personal letter, but also a short notice in the newsletter from school is possible. Other parents prefer the school to distribute an e-mail. In addition, a growing number of parents keep a weblog about their experiences, on a special website or for example on Facebook. In short, the parents determine the mode of communication, whereas the school can support parents in their choice by pointing out the effects and consequences.

Hakan's parents (he is 6 years old) want the parents of his classmates to be informed. They have experienced this as enormous support in the past, so they opt for an open approach. There are many students of various nationalities at Hakan's school and not every parent is proficient in the language. The school and Hakan's parents therefore choose to invite all parents to a meeting at school. During the meeting, father himself tells the news to the other parents. There is enough time for questions and sharing emotions.



What expectations do the parents have?

The expectations parents have, stem from their own vision on life and education and are therefore very personal. The parents know their child best and are the only ones who can estimate what is best for him. But in this extreme situation it also happens that parents are insufficiently able to look at the role that school can play from the perception of their child. By specifically discussing the students and parents' expectations, concrete agreements may arise. Good feedback to the parents during the course of palliative support is essential to see, whether the expectations of the student and the parents are changing and if expectations are still met.

The above questions can help to have the first conversations with the parents. As indicated, it is wise to discuss the questions again when the situation of the sick student changes.

And note that school is not the only one with questions. The parents have questions too: (How long) will my child still be able to go to school? How do we support the siblings? How do we protect our family against all the attention of the outside world? By talking to each other openly, the school can be a huge support to the family.

2.3 COMMUNICATION DURING AN APPROACHING FAREWELL

Julian is getting sicker. He spends his days on the couch and in bed, close to his parents and his sister Anna. Going to school is no longer possible. I decide to visit to see what expectations Julian's parents have from school and whether I can support them. Julian's parents would like it if the teacher continues to visit during this phase. In the meantime, she has become a familiar face in the family. Fortunately, the teacher wants this as well. A few months ago, she did some schoolwork with Julian. Now she reads him from the picture book that she also reads in class. This way the link with school remains intact and meaningful.

When the student becomes increasingly ill and the farewell approaches, the family often turns strongly inward. The parents focus on caring for their sick child (at home or in the hospital) and contact with the outside world is increasingly via a family member or friends of the family.

At school, this new phase gives a shockwave. For many fellow students, the approaching farewell is now really noticeable and tangible. This is also evident from the example of Chalid (10 years old). He has cancer and cannot be cured. When it is clear that Chalid will die soon, his teacher discusses this in class.

“It was one of the most difficult conversations I ever had. In addition to my own grief, anger and disappointment, I could barely watch the emotions of the children. They expressed themselves so directly, so honestly that it was as if you felt their pain too. They felt defeated. Some began to cry, others looked at me in disbelief. Not long after that a rapid shooting of questions broke out: Whether there was really no more medicine, whether there were no new inventions in Russia or America, or if we could collect extra money, or, or, or ...? All of this led to that one question: whether or not it was really irrevocable?” - Dorinda Roos (teacher)⁹⁻

During this phase parents are - more than ever - in full control of all communication. This may mean that the action plan has to be adjusted. It can cause unintentional tensions, because school might face challenging questions the parents are not aware of. Some parents choose to minimize contact with school in this phase. In such a situation, it becomes very difficult for the school to talk about it with the students and to prepare them for the inevitable farewell.

When the parents do not want the school to talk about the impending death of their child, this poses a dilemma for the school. At school, students often express their concerns and questions about what can happen to their sick fellow student. It is therefore even more important at this stage that the school respects the frameworks set by the parents. Try to support the students and the teachers as much as possible within these frameworks.

Teun (16 years old) had been going to school for a few days during chemotherapy. Over the weekend he became sicker and he had to be hospitalized. There, it turned out that the disease had returned in all its severity and that it was no longer possible to cure it. Teun deteriorated rapidly. Teun's uncle called the vice-principal of the school during the weekend and indicated that students and parents could be informed. On Monday morning, the teachers told the news in all classes, and after school their parents received an e-mail.

2.4 IN CASE PARENTS DO NOT COMMUNICATE OPENLY

The previous section shows how important it is to keep in regular dialogue with parents about their sick child and the communication about the situation. Parents who spend time on this, help the school to deal with the situation. However, it becomes more complex when parents do not (initially) involve the school. In this section we pay attention to some backgrounds that may underlie a more close attitude of the parents.

The temporary withdrawal from society

The sadness can be so overwhelming that some parents shut themselves off from the outside world for a while and focus entirely on their family. Only the immediate environment is then aware of the situation.

Not being able to accept the inevitable yet

Sometimes the transition from a curative treatment to a treatment or a phase where healing is no longer possible is very gradual. For example, when a sick child receives chemotherapy and the doctors have not (completely) ruled out that this treatment may still be effective. Some parents then stick to this last straw and do not give up. To be able to come out with the terrible news that your child can no longer be cured, the parents must first recognize this themselves.

Elin's parents (she is 7 years old) do not want the school to inform anyone she is dying. Students at school notice that Elin is less and less at school, and when she is present, she is very tired. Her appearance changes and as Elin's vision deteriorates, the tension increases. Not only classmates, but also students from other classes wonder if Elin will die. The teachers also see that Elin has to hand in more and more. And from the signals of her parents they conclude that is not going well. However, due to the clear position taken by Elin's parents, the school cannot fully answer the student's questions. Unfortunately, this causes a lot of stress at school. After Elin's death, her mother says how she couldn't admit her daughter would die. If she would have admitted this, it would have felt like she gave up on her child.

Protecting children from grief and loss

Every parent wants to protect his child from grief, pain and loss. Losing your child is the most unnatural situation that a parent can experience. Telling your child that he can never get better and will die is almost an impossible task. Some parents cannot handle this and therefore withhold the information (for a while).

Remco's parents (12 years old) have told him that the cancer has come back. Remco remembers very well what the doctor told him two years ago: the chances of getting better would be slim if the disease came back. His parents now tell him that treatment is no longer possible and that he can no longer get better. Only if the pain increases, he may be treated with radiation therapy. After a few weeks the parents feel that the meaning of the bad news has not really dawned on Remco. They decide to tell him in clearer words that he will eventually die from his illness. Only after this conversation Remco realizes what is going on. Remco's parents describe this conversation as the most difficult thing they ever had to do.

The cultural and religious considerations

In western culture, it is assumed that it is better to be open to children about their illness, even if they can die from it. This is a very difficult issue for any parent. In many non-western cultures however, there is no openness, or only to a certain degree. In some cultures or religions it is explicitly forbidden to talk openly about death, implicitly this ban is always present. In the Islamic faith this is partly due to the Islamic basic rule that 'only Allah knows the time of death'. When someone makes a statement about it, it is considered a sacrilege. Islamic parents of a sick student can therefore communicate less openly with the school.

"As amazed as I have been by the reactions of many adults, I have been surprised by the years of uninhibited involvement and love of Chalid's classmates. Children with Hindu, Christian (Roman Catholic and Protestant), Islamic, as well as non-religious or philosophical backgrounds were not hindered by any prejudice or cultural interest in their relationship to Chalid and his family. They saw one of them sick and suffering and did everything in their power to contribute positively to it. Their emotions are and were genuinely pure." - Dorinda Roos (*teacher*)

Every parent tries to deal with the inevitable on the basis of his own convictions on life. A situation in which the environment of a sick student is not involved, is ultimately unsustainable. The sick student's parents will sooner or later talk to people, after which the information can spread uncontrollably and often in a distorted way. Parents who do not (yet) want the situation at school to be discussed, unintentionally present the school with a dilemma. Teachers feel the anxiety and fear in students (and their parents) and feel responsible for the support. They would prefer to accommodate all questions and emotions as well as possible. On the other hand, they also want to respect the wishes of the parents as much as possible.

In this situation it is important that the school talks to the parents of the sick student. Of course, the parents are not responsible for what happens at school. Nevertheless, there is a great opportunity to find a solution when the school and the parents join together. It requires a lot of tact and empathy from the school to get that far. Only in very exceptional cases (when parents still hold their position after consultation) the teacher will, supported by his colleagues, have to make the choice that seems best for the class.

Tips and considerations

Choose a contact person in school who has both a good relationship with the parents and is able to take on this task. Ensure that this person is supported internally by a supervisor, coordinator or a member of the school management (see also chapter 5).

Communication is a two-way street. Make good agreements with the parents about who will initiate the contact. If the initiative is with the parents, the school may sometimes be deprived of information for a while. If concerns or doubts arise, please contact the parents.

Realize that the sick student's response, responses of their siblings or fellow students to the sad news may change during the disease process. Processing sad news requires space and time.

Ensure that everyone involved keeps abreast of important changes, even when they take place during school holidays. This prevents uncontrollable and distorted information.

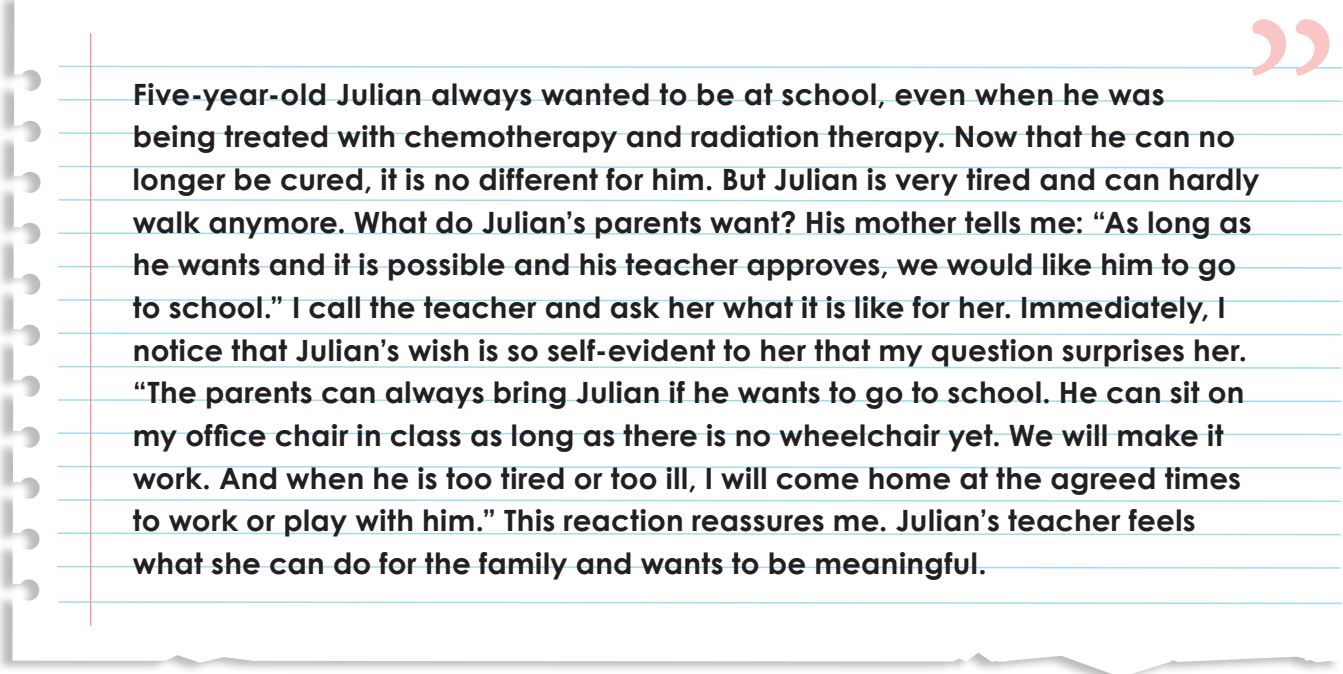
Involve an external expert in setting up communication between the family of the sick student and the school. Most likely a hospital teacher or a specialized counselor for sick students is consulted.

When parents of other students have many questions about their child's perception of the situation, it may make sense to spend an evening on this topic at school with parents of all students in the same class.

Be extremely careful when specifying a prognosis. In practice, forecasts rarely match, which can cause confusion. In any case, do not inform young children too soon.

The school can be an enormous support to the family, if they attune their involvement to the needs of the parents.

3. ATTUNE TO THE BASIC PSYCHOLOGICAL NEEDS



Five-year-old Julian always wanted to be at school, even when he was being treated with chemotherapy and radiation therapy. Now that he can no longer be cured, it is no different for him. But Julian is very tired and can hardly walk anymore. What do Julian's parents want? His mother tells me: "As long as he wants and it is possible and his teacher approves, we would like him to go to school." I call the teacher and ask her what it is like for her. Immediately, I notice that Julian's wish is so self-evident to her that my question surprises her. "The parents can always bring Julian if he wants to go to school. He can sit on my office chair in class as long as there is no wheelchair yet. We will make it work. And when he is too tired or too ill, I will come home at the agreed times to work or play with him." This reaction reassures me. Julian's teacher feels what she can do for the family and wants to be meaningful.

It seems contradictory to engage in education when a student is life-threateningly ill. But for sick students, the school remains an extremely important basis. School gives perspective, distraction and regularity, which helps to deal with the situation. Children and young people naturally want to continue with their normal lives as much as possible. They cannot and do not want to be occupied with sorrow and pain all the time. At school, they get the chance to be a normal student, instead of being the sick son or daughter or the patient. At school the student comes first, and then the illness. This is usually a pleasant experience for the sick student.

School is more than a meaningful daytime activity. In order to understand why sick students value school and education so much, we need to look at the situation from a developmental psychological perspective.

Three basic psychological needs are distinguished: **the need for relatedness, autonomy and competence**. These basic needs are the starting point of pedagogical action¹⁰⁻¹¹. In this third chapter we address the question how the school can meet these needs.

3.1 NEED FOR RELATEDNESS

When life has been dominated by medical treatments for a long time, children and young people sometimes feel exclusively like ‘patients’. All attention is on the disease and less on the person behind the disease. While sick students have a great need for recognition, appreciation and confirmation. At school they feel equal and accepted by peers, they can be themselves and feel a sense of belonging.

A sick student will not be able to attend school every day. Especially in the period that he cannot be there, contact with his classmates and teachers is very important. In this way, classmates remain involved and it becomes easier for the sick student to make the step back to school, when physically and mentally possible.

Contact with the class can be maintained in various ways: via postcard, visits, telephone, e-mail, a digital video conference or a digital learning community. The sick student can encourage the involvement of the class himself, or with the cooperation of his parents, by letting them know – on his own initiative – how he is doing. This can be done via a postcard or e-mail to the class or for example a message in the school newsletter.

Shortly after Remco (12 years old) heard that he was seriously ill, he started his own weblog. On a daily basis, he blogged how he was doing. When, more than two years later, it became clear, that the disease had come back, he also posted that message on his weblog. While writing, Remco was able to release part of his feelings and it became a way for him to deal with his disease. At the same time, he made it easier for his environment to keep in touch with him. The digital guestbook was supplemented daily with messages, which gave him and his parents a lot of support.

Even during school hours, there is the opportunity to make contact with the sick classmate, by sending e-mails or talking via the webcam. The school has a guiding and coordinating role. The teachers ensure continuity in communication between the class and the sick student.

Tamara (9 years old) was no longer able to attend school. Everyone was waiting for her to return. For Tamara, that threshold only got higher as time went on. Her appearance had changed so much that she felt ashamed. Her mother discussed Tamara’s anxiety at school and it was agreed with her teacher that he would show some recent photos of Tamara in class and openly talk about why she looked so different. Subsequently, a teacher visited Tamara every week with a few classmates, making the step back to school less scary for her after each visit.

Wendy (15 years old) has a brain tumor. She sends daily e-mails to the class. One day she writes: “Hi, I am almost too ill to get well now. One day I want to die, the next one I don’t. It is so unfair that no one can do anything about it, it feels so powerless! Wendy”¹²⁻

3.2 NEED FOR AUTONOMY

The need for autonomy means: the need to influence your own life and feeling independent. A child partly loses his sense of self-control due to illness. He must undergo painful procedures, take medication and cooperate in all kinds of physical examinations. All this brings a strong sense of insecurity.

Sick children try to maintain or regain control in that situation, e.g. by resisting hospital procedures or by arguing with their parents about food. Occasionally, even the issue of 'going to school or not' may become a starting point of the complicated struggle between child and parents.

Max (13 years old) did not cooperate when the doctor wanted to examine him. He yelled and threw pencils through the examination room. The doctor knew Max well, sat down and took the time to talk to him. He asked him how they would solve this now. After a while, Max calmed down and said, "You can measure my blood pressure, if I can measure yours first."

The school is a safe and familiar environment where children are able to have influence on their own lives. There, an appeal is made to the skills and competencies of students that are not directly related to the disease. There are always opportunities to make independent choices and take initiatives. For example, the student can decide for himself on which subject he makes a paper and with whom he interacts during the break. These seem evident, but this is absolutely not the case for sick students. The sense of autonomy is essential for them to feel safe and build self-confidence. Therefore, it is important to involve students with limitations due to illness, in any adjustments that are needed.

Evert (15 years old) has limited energy and cannot fully attend school. He tries to take as many lessons as possible, but he feels constant pressure to keep up with his homework. He is not able to keep this up. His teacher therefore proposes in an open conversation to drop some subjects. Evert immediately knows which courses he wants to drop. He then dedicates himself to the most important ones that can easily be combined in the weekly timetable.

His teacher notices that Casper (10 years old) has a clear opinion about what he wants to do when he is taught at home. The teacher does not have to put on grammar, as Casper refuses this. Casper likes mathematics, reading and world orientation, on the other hand.

3.3 NEED FOR COMPETENCE

The need for competence means that the student wants to be successful and attributes successes to his own effort or qualities. In the hospital, the focus is mainly on the sick part of the student and there are few opportunities to meet this need. School appeals precisely to the healthy part of the student. Because he is challenged and stimulated, he experiences success. These experiences give him self-confidence. Moreover, this implicitly offers a future perspective.

Although healing is no longer possible, Hakan (6 years old) is receiving chemotherapy to limit the physical complaints as much as possible. During hospital admission, he daily receives reading instruction from a hospital teacher. When he returns to class, he has learned the same letters as his classmates. He makes good progress and enjoys school.

An education system is aimed at contributing to the physical, motor, cognitive, social and emotional development of students. And development cannot be stopped by a limited life expectancy!

The physical condition of the student has a big influence on the student's ability to develop. School and parents will always have to look together for the most appropriate measures for the sick student. This could include:

- **Stimulating measures**, such as the use of online education. This makes the student more involved with class.
- **Compensatory measures**, such as a modified assignment or the use of a computer for writing assignments.
- **Remedial measures** for subjects the sick student needs extra tutoring.
- **Dispensing measures**, such as adjusting the package of courses or prematurely dropping one or more courses.

The most important thing is that the sick student feels supported and continues to belong to the group.

3.4 DEVELOPMENT TOWARDS AN UNCERTAIN FUTURE

Sofie (6 years old) is in her first year at school when she gets an incurable form of cancer. The school teachers wonder whether or not the school creates false hope to Sofie when they would teach her at home.

Every child is naturally eager to learn and inquisitive and from the outset on aimed at social bonding, knowledge and skills. A child wants to know and master his environment and is therefore always focused on development.

The term 'development' implies there is a future perspective. If a student can no longer be cured, this perspective is undermined. It has to make way for a new, uncertain perspective in which the term 'future' has a completely different meaning. It is uncertain how long the student will live. Will he grow up or die this school year? And what does this mean for the way in which you complete education?

No one knows exactly how long a child can live if it turns out to be terminally ill. Even for a doctor, it is difficult to predict exactly how a disease will affect a child.

However uncertain and limited it is, there is a certain future perspective. The school therefore retains the important task of shaping the sick student's future. If adults - well-intentioned - stop to think about the student's possibilities, but only want to 'give them a good time', we take the risk of depriving the student of this future perspective. In this way, a student can - for the second time - feel given up.

Martine (16 years old) missed a lot of school due to medical treatments. In between courses, she tried to catch up on some tests and assignments. However, the treatment was unsuccessful and was ended. At the end of the school year, Martine did not receive a school report. Her teacher did not think it would be useful to assess Martine on the basis of only a few marks. Martine felt left out...

In order to know what the individual student requires, we have to tailor the support to the student's basic psychological needs. The key question is: What does this student need in terms of relatedness, autonomy and competence?

Jiro (8 years old) was not able to go to school. Every day he looked forward to the moment the teacher came to visit him at home with a bag full of school stuff. Together they worked, laughed and played a game. His mother enjoyed the laughter at home as a welcome interruption of the day.

Subsequently, it must be examined how the needs of the sick student can be met. This attunement must be very precise, because not only the wishes and possibilities of the sick student (and the parents) are leading, but also the possibilities of the school.

Remco (12 years old) is in a development phase in which he fully understands that he will die of his illness. He also knows that this will happen soon. Although he wants to participate as normally as possible at school, he is most concerned during individual work in class. Then he wonders what he is working for. He no longer experiences his need for competence in school tasks. In fact, it confronts him enormously with the future that is so limited for him.

3.5 EDUCATION IN THE FINAL PHASE OF LIFE

Sick students can be very determined in their desire to be taught, even in the terminal phase. If the sick student is used to the teacher visiting or teaching at home, it can almost go without saying for him to continue.

Jiro (8 years old) had been studying at home for the last few months, but he became increasingly ill. I asked the teacher if she dared to teach in the final phase of life, if Jiro wanted to. She replied: "At first I said A, so now I have to say B." Apparently she felt a moral obligation. I therefore explained to her that she did have a choice in this situation. She thought about it and said, "If Jiro wishes it, I am glad that I can do something." Then we discussed which support she needed as a teacher to take on this emotional task.

Some parents notice that their sick child withdraws more and more during the last phase of his life. He may show less interest in things that were previously important or fun for him. It may be that the sick student no longer wants to stay in touch with friends and the school. Teaching in the last phase of a child's life is an intensive task that requires support. It is important that the school pays attention to the personal needs of the accompanying teacher(s). An external expert can also give support. This is discussed in more detail in chapter 5.

Tips and considerations

When it is too demanding for the student to go to school, see if it is possible for a teacher to teach at home. Remember that it is not just about that math lesson, but also about the distraction and the permanent contact with school. If possible, arrange and support online education.

Due to varying complaints it can be difficult for parents to let their child go to school according to an agreed schedule. Sometimes a whole school week is possible, sometimes half days or only an hour a day. Discuss the options with the student and the parents, be flexible and always keep the door open.

Observe the student closely and give room.

Let the student be himself in the group.

Do not immediately intervene in case of problems or negative interactions with other students. Have the student try to solve this himself. A student who is only found 'pathetic' may feel left out.

Stick as much as possible to applicable agreements and rules in class. This gives the student a sense of security.

Let the student participate in search of any necessary adjustments, such as participation in certain lessons (e.g. gym class) or activities.

Prevent a student from being overprotected and thereby excluded.

Consider whether the sick student can help other students. For example, making homework together or explaining a mathematics equation.

Discuss with the student whether he likes to talk about the disease himself and whether it can be discussed in class when he is there.

Use the strengths and qualities of the student.

Set requirements for the student and assess the efforts and results achieved. Adjust the requirements when necessary.

Homework can be a support for a student and therefore important. Agree with the student and his parents what would be reasonable.

Even though there are individual contacts between students and the sick student, the teacher still has the responsibility to maintain contact with the whole class.

Involve an external expert in the support, for example a specialized counselor of sick students, or a hospital teacher.

4. EMOTIONAL SUPPORT

The teacher is hoping that Julian will come to school every day. At the same time, she wonders how the other children in class will respond: ‘Maybe they will ask him very directly if he dies. How do I deal with that?’ In the other classes, children are also asking questions about Julian and express their emotions. The teachers try to respond to this as well as possible, but are unsure whether they do this the right way. I notice that it is no longer enough to support Julian’s teacher. The entire team of school teachers needs support. During a meeting, we talk about how children deal with loss and about what they can do to support. It is an emotional and meaningful meeting.

4.1 THE SICK STUDENT

“Children want happy moments. They do not live in the persistent sorrow that some adults can carry for weeks and months. Children long for fun. Kelvin and Sofie were sometimes sad and depressed, but in their sorrow they never completely excluded happy moments. Most children keep a stunning zest for life until the last day.” - Lut Celie¹³

How do students deal with the message that they will not be cured? And what factors influence the way they deal with this? Children and young people deal with their illness in many different ways. One denies it for a while, the other seeks support, desperately adheres to making schoolwork or withdraws. The behavior fits that student in that situation. When circumstances change, behavior can also change. It is possible that the student only realizes that he is terminally ill when he experiences physical complaints.

Joyce (15 years old) did not want to talk to anyone about what the doctor had told her. When her teacher asked how the hospital check-up had gone, she answered with an apparently casual attitude: “Oh, the usual.” She put all her energy into her homework, got good grades. Until she failed a mathematics test. At that moment she began to cry inconsolably.

As described in Chapter 2, young students do not always fully understand what it means that they can no longer get better. This partly depends on their age and level of development. When students still receive medical treatment (e.g. chemotherapy) despite the fact that they can no longer be cured, this can be very confusing. Some students therefore assume for a while they can still be cured.

The same may apply to students who have not (yet) been told. Although parents indicate that at some point their child does notice that something is not right. If the sick students understand the situation, they need time to process exactly what this means.

John's father (John is 6 years old) has told him that the doctors can not cure him. With medication (chemotherapy) they can ensure that he feels good for a long time. For John, everything seems to remain the same. He goes to the hospital for treatment, just like he did before. He does not yet understand that the purpose of the treatment is no longer to cure him. The parents want John to be treated as a regular student at school. Additional support is not required now. At school, they don't notice any change in John's behavior. He feels good and is as lively as ever.

Emotions at home and at school

Children deal with loss and sorrow in a somewhat different way than adults. One of the differences is that they live more in the present and much less in the future. They are therefore somewhat less occupied with questions about the future. Young people are more forward-looking. Already in the first years of secondary education, they make choices that have consequences for their final exams, further education and career choice. In addition, children and young people are not sad all day long. They can temporarily 'park' feelings of grief. This way, the feelings of grief become manageable and not overwhelming. Moreover, children do not often express their emotions in tears, but in other ways. For example in playing, drawing, listening to music, playing sports or going out with friends.

Children often feel the safest at home to show their emotions, often in short moments. Young people show their emotions much less to adults. They try to come to terms with their fear, sadness and worries by themselves or in contact with friends.

Sometimes parents realize that their child shows few emotions. This may have to do with the 'law of double protection'¹⁴. Children protect their parents from grief, just as parents want to protect their child. Sick children and young people do not want to hurt their parents. They try to hide their grief somewhat or express it elsewhere: when they are with friends or at school. Because it is an act of love, I also call it 'the wall of love'¹⁵.

Parents and professionals often have the idea that children do know what to expect, even if they do not want to talk about it. They let them know by means of casual remarks such as 'Rabbits can die too, right?'

However, children with whom the seriousness of the disease has not been spoken about (for example, for religious reasons) may feel lonely.

Indirectly, however, there are always ways to get in touch with children about their emotions. For example, by talking about a story with fictional characters, having stories written, drawing or making music.

As described earlier, the school is an important anchor to ordinary life. There, students have the opportunity to be a child, a normal student, friend and classmate, not to be a 'sick child' or a 'patient'. Especially at school, students will try to participate as normally as possible and control their emotions. Their behavior and working attitude however often shows that the students are emotionally less stable.

In three specific roles, the school can provide emotional support for students¹⁶:

1. Providing care and continuity

Everything seems to have changed for the student when he cannot be cured. It is therefore so important for them to notice that at school everything remains the same. If the program continues as normal and the student can participate as much as possible, this gives a sense of safety.

Ensuring continuity (and predictability) also means that agreements and rules must be followed. It is important to maintain this for the sick student as much as possible. This gives clarity for the student about what is and what is not expected of him.

2. Showing love and understanding

Although the normal rules remain the starting point, it is important to be able to deviate from this when the situation requires it. Some rules are prohibitive for the sick student. If this can be deviated from, the sick student feels acknowledged. For instance when an assignment can be finished a week later.

3. Acknowledging and sharing feelings

The student can show all kinds of emotions: sadness, anger, fear or show withdrawn behavior, for example. Do not reject these feelings and behavior, but acknowledge that they are part of the situation.

At Ivan's school (12 years old) it is a school rule that students who fight have to stay in class after school. Ivan has more and more often confrontations with other boys in the schoolyard. The teacher does not want to punish him with detention for this, but does want to address his behavior. In consultation with Ivan and his parents, the school buys a boxing ball. When students feel angry, they are allowed to box on the ball, guided by the gymnastics teacher. A few times a week, Ivan indicates that he wants to box for a while. By this approach, Ivan himself prevents a conflict with fellow students.

In summary, we can state that the pedagogical climate of the school is the foundation for good emotional support. In addition, it is important to form a safety net in case extra support is needed. This safety net consists of people who can be deployed for help, coaching or advice. In addition to school staff, these can be external experts, such as a hospital teacher, a child psychologist or a grief counselor for children. By keeping in touch with the parents and the student, it becomes increasingly clear what the student needs and which help is best suited.

4.2 SIBLINGS

Anna is 8 years old when it becomes clear that her brother Julian can no longer be cured. Anna's teacher is aware of the situation. He asks Anna if she wants to tell something about this in class. Anna would like this and tells her classmates exactly what is going on. Afterwards, children ask her questions that they openly discuss. And when all questions have been answered, the teacher returns to the school program and Anna joins in again. She feels relieved.

Being a sibling of a seriously ill child is a very probing experience. Siblings very closely experience how their own lives change due to illness. If it turns out that their sick brother or sister isn't cured, another dimension is added to their life. They not only experience the impact that the course of the disease has on them and the sick sibling, but also feel their parents' fear. The healthy sibling may feel responsible to lighten up that fear and wants to help. It is also possible that they completely ignore themselves in an attempt to improve the atmosphere at home. Siblings may act as essential pillars, but they can also flee and avoid the situation.

At school, siblings get the chance to be themselves and to focus on other things than their sibling's disease. This does not alter the fact that they do want to share their story as well.

In essence, the points of attention described in section 4.1 for the sick student also apply to siblings. The understanding of the severity of the situation also largely depends on their developmental age.

In addition, the psychological basic needs also apply to siblings. Especially when the home situation is dominated by a sick child, it is important to ask yourself what the brother or sister needs.

- **Need for relatedness:** for siblings, school is the place to be a regular student, not 'the brother or sister of ...'.
- **Need for autonomy:** siblings almost silently adapt to the situation at home, sometimes effacing themselves. On the other hand, at school there is room to stand up for oneself.
- **Need for competence:** siblings may experience that their parents' interest in their school performance decreases. Parents often feel satisfied when siblings are able to keep up well at school and that school is a positive distraction for them. If siblings put in extra effort to please the parents with an extra good grade, it can be very disappointing when the parents cannot pay enough attention to this¹⁷⁻¹⁸. Not only for the parents, but also for siblings, performance can be experienced from a different perspective.

The contradictory element here is that school performance for siblings can provide an important anchor. A good grade confirms that they have achieved something positive despite all adversity.

‘Since my sister is ill, I can no longer concentrate well at school. During the lessons my thoughts wander quickly and I gaze through the window frequently. Soon I will get my test results, probably with a lot of bad grades. How should I explain this to my parents?’ - Sam

The three key roles, described in section 4.1, also apply to siblings: providing care and continuity, showing love and understanding and acknowledging and sharing feelings. Siblings often wonder what their teacher(s) exactly know(s) about the situation. Even if the teacher is well informed, it makes sense that he asks the sibling about their own story, their individual experience of the situation. This gives confidence and creates a bond. Moreover, the teacher thus gets a broader picture of the experience of his student. The brother or sister can also agree to such a conversation whether and when he wants to tell something in class. If he doesn't want this, then the teacher can do it, with or without the student being present.

In the case where the sick student is not in the same school as the sibling, the first reaction of the sibling may be to avoid the subject as much as possible. Siblings absolutely do not want to be found pathetic. The result, however, is that they may encounter incomprehension from peers who hardly know what is going on. For example when a sibling is less present, receives adapted tasks or behaves differently. The teacher can help by talking to the sibling and (together) explaining to the class what is going on.

Paul (12 years old) is very restless and hyperactive at school now his younger brother Tom has been ill for so long. He can hardly concentrate on his work and often plays the clown in class. Tom is deteriorating more and more and everyone is very concerned. One day, when Paul is not in school, the teacher explains to the class how Tom is doing and that this is why Tobias can be so hyperactive. His classmates understand the situation and accept that the teacher is less strict with Paul.

Also discuss with the parents and siblings what support they need at school. It is helpful when the brother or sister knows that there is support available from someone they know in school, if necessary. Parents greatly appreciate that extra attention is paid to their other child(ren) at school, because they often feel they can't support them sufficiently at home.

4.3 FELLOW STUDENTS

‘If it is the task of a school to prepare children and young people for life, then learning to deal with loss and sadness is an explicit task for every school.’ - Manu Keirse¹⁹

We cannot protect students from loss, but we can help them learn how to deal with it. It is not self-evident that every teacher is sufficiently equipped to take on this task. Support from internal care, school management or an external expert may be necessary in these circumstances. Chapter 5 focuses on this.

In this section, we address the question of how the sick student's school can support his classmates and other involved students. As stated in section 2.2, it is important to know what may be told to the other students about the situation. When students are fully informed, they should also be given the chance to respond and ask questions. It is also a good idea to tell classmates about changes in the situation. For example, when a medical treatment has started, during hospitalization or an increasing absence of the sick student. This way, classmates can follow the disease process in steps.

Remco's teacher tells me that his classmates hardly seem to worry, as long as Remco is at school. If he is not there, however, the students are immediately afraid that there is something wrong, even if he is only away for an hour for a routine blood test.

In addition to the level of development, which largely determines what children and young people understand about the situation, the visibility of the physical limitations also plays a role. Young children link the seriousness of the situation to what is visible from the outside. When the sick student has no visible (new) limitations, young children may have difficulty understanding that he is likely to die. The information about the seriousness of the disease remains too abstract for them. The result is that when the student does get obvious symptoms, it suddenly evokes a lot of emotions among the classmates.

Every student reacts differently to these emotions. One person asks confrontational questions, while the other wants to continue the regular curriculum as quickly as possible. Sharing emotions in the classroom ensures that students express themselves. They also learn that not everyone reacts the same and that this is okay.

Many teaching programs on 'dealing with feelings' from lessons or programs for social-emotional development can be used to help the students express their feelings. A program that is often used is the Worry Tree²⁰ (or the worry box, suitable for secondary education). This tree can carry the worries that are heavy to carry alone. This model does not have to be focused specifically on the situation of a sick classmate alone, but also lends itself to other concerns that students have. These concerns can sometimes be triggered by the sick student's situation (see chapter 4.4). When the sick student still regularly attends classes, it is important to discuss or prepare the use of teaching programs and materials about emotions with the parents and the sick student.

Classmates sometimes find it difficult to determine how they should behave towards the sick student. This can be addressed in class. Sick students do not want to be found pathetic. They want to be treated as normal students as much as possible, but hope that other students understand their situation. In addition, classmates want to do something for their sick classmate.

It is important that there is enough space and time for sharing at school. Ask classmates what they would like to do and what could help the sick student. This often results in very special initiatives. However, realize that a class is not a unit, but a collection of individuals. This means that there are students who initiate a huge project to invent or make something. On the other hand, there are always students who (for their own reasons) prefer a less prominent part in such an initiative. It is the task of the teacher to let all students participate in their own way.

Milan's class teacher had bought a large postcard on which all students could write something for Milan. He emphasized that everyone was free to decide what and how much they wanted to write. Some students wrote a poem or a short wish. The classmate who cycled to school with Milan every day only wrote his name on the postcard.

The Worry Tree

A program that is suitable for discussing dealing with loss in class is the Worry Tree. In secondary education the Worry Box can be used, as an alternative. The description below is taken from Weijers and Penning (2001)-20-

Every person worries sometimes. Things that keep you busy and go with you wherever you go. Even when children and young people go to school, they often have large or small worries.

These are often all kinds of things that can keep them very busy. In school, however, we require students to focus on school matters. Even when there is an argument at home or when they are worried about something else.

Unfortunately, we cannot magically vanish these worries away, make them disappear or dissolve. We 'just' have to deal with it. What we can do, however, is acknowledge the students' concerns and create a place for them. We can take the concerns seriously and pay attention to them. The worries are allowed to be there, simply because they exist.

NEEDED MATERIALS

- colored paper or cardboard to make a tree, grass and flowers
- or a cardboard or wooden box
- wood for a wooden tree
- notes, envelopes
- adhesive tape, buddies, rope, elastics
- scissors, glue, markers
- different colors pens
- plastic bags for an outside tree

METHOD

Make a flat tree by sticking paper on a wall or drawing on a wall or blackboard. You can also place a real willow branch or make a tree from a trunk and some branches. A real tree outside is also an option, then the notes have to be hung in plastic bags.

The students are then asked to write, draw, scratch, or color their concerns or what is on their mind (and what prevents them from focusing attention on their work). Nobody else needs to understand as long as they know what it says. It may therefore also be in a secret handwriting or code. They may also seal the note when this gives a sense of security that no one can see.

EXAMPLES OF NOTES FROM THE WORRY TREE

- My cat did not want to eat this morning. I hope he isn't sick.
- This afternoon I have my first piano lesson. Will I be able to learn this?
- I had a fight with my best friend. How can I make it up with him?
- Jane is often ill. Will she get better?
- School sucks, I can't keep up.

Making notes takes about ten minutes. Then ask the students to find a place in the tree where their worry should hang. Does the student think that the worry needs a thick branch, thin branch, high in the tree, in a hole or maybe close to a nest? You hang the worries in the tree with adhesive tape or rope. Then you can ask who wants to tell something about their worry, which of course is not obligatory for the students.

PURPOSE

Working with the Worry Tree is a way to give students' concerns a literal and figurative place. The tree helps to bear the worries. It teaches students that they do not have to do it on their own. You acknowledge the concerns and literally give them space. That fact alone will help in many cases.

You can start every week or school day with the Worry Tree. You can get back to it at the end of the week (or the day) and ask: Does your worry still exist? Is your worry still in the right place or does it perhaps need a thicker branch? Reactions can then be: 'Well, that fight with my friend is over, so the worry can be taken out of the tree' or 'Jane is still ill and is now in the hospital. I'm afraid it will not be all right. My worry should therefore be hung in a thicker branch.'

This way, students can learn how to put things into perspective. They learn to realize that there are concerns that last longer and that some concerns pass. Students only tell about their concerns when they want to (ensure safety and privacy). It is often the need of adults to hear everything in words, but other ways also fit.

Again, just acknowledging the concerns already works wonders. It is a useful way to show students that you are open to them and respect them.



Tips and considerations

Ask for the student's own story (either the sick student or the sibling) even if you are fully informed. That way you get an idea of the experience of the individual student and you can acknowledge their feelings.

Provide a safety net for emotional support at school. Who can students go to? Who identifies when extra support is needed?

Give open and honest answers to student's questions, even if you do not know the answer. Students do not expect answers to all questions, but mainly want to share their concerns and want to be taken seriously.

Do not force students to talk. They often express emotions in a different way. Make sure that there is also room and understanding for this.

Have siblings choose whether they want to talk about the situation in class, do it together or if the teacher will do it. Does the brother or sister want to be present?

Siblings need space to be themselves. However, do have an eye for deviating behavior. Concentrating and participating in the group is quite difficult when you have other things on your mind.

Note signals in the (task) behavior of students. Discuss notable changes or standstill in a meeting with colleagues and with the parents.

Sometimes it is necessary to request extra understanding from classmates. Make sure you explain to them why some arrangements for the sibling are different or why it is that the sibling behaves differently than usual.

Do not burden brothers and sisters with questions about the sick student ('How is your sick sibling doing?'). Just ask them: 'How are you?'

Involve an external expert in supporting the school. This may be a hospital teacher, a child psychologist or for instance a grief counselor for children.

Parents may want to take a trip with the family or go on holiday. Sometimes this is offered by a wish organization. It is important that siblings get permission for this without restrictions.

During the last phase of the sick student's life, parents may also want their other children to be at home, so that they can be together as much as possible. Parents are not always able to discuss this request with the school. It may be wise that the school takes the lead in this.

Give students the reassurance that tears will be dried. Not forever, but every time again.

5. WHAT DOES THE TEACHER NEED?

I get a call from the school: Julian passed away an hour ago.
I knew this phone call would come, but nevertheless I'm grounded.
An immense sense of powerlessness overtakes me. The school asks if I could come and talk to them about what needs to be done next. On the way to school, I put aside my emotions for a while, so I can focus on what I can offer the school team. Fortunately, that turns out to be enough.

The confrontation with a student with a limited life expectancy does not only affect a teacher as the professional. It also affects the 'person in the professional', who is attached to the student. It may push the teacher out of balance, so that he no longer dares to rely on his own expertise, talent, (life) experience and intuition. In this last - and perhaps most important - chapter, we therefore focus on the 'person in the professional'. What does the teacher need to give good palliative student support?

5.1 THE PROFESSIONAL'S EMOTIONS

Defeat, powerlessness, fear and sadness are emotions that many teachers feel after the news that one of their students can not be cured. Riet Fiddelaers-Jaspers writes about teachers²¹: 'Because of this concern their emotional balance may fluctuate. They tend to choose between two extreme reactions. The first is to distance yourself emotionally ('It does not affect me') in order to protect their mental balance. This reaction does not lead to an empathetic attitude. The other extreme reaction is to get 'into the other person's skin' and experience the event as if it happened to you. You can then sympathize, but not help. Professionals such as teachers have to find the middle between being near enough to be able to empathize and have sufficient distance to be able to help effectively.' The middle that we can denote as 'professional involvement'.

People are not a blank page and every teacher carries his own backpack with life experiences. This plays an important role in the search for balance and ensures that one teacher tries to avoid the situation and leaves the responsibility to the management, while the other intuitively feels what he can do for the student.

Pete is the teacher of a final group of elementary school. With the secondary school principal he discusses the students who are transferring to this new school next year. Of course the situation of Ron (13 years old) is also discussed. Ron has a short life expectancy and will probably live for only a few months. After listening to the story, the manager wonders whether he should accept Ron to his school.

Before taking any measures, it is necessary to consider the experience of the teachers involved. After sharing the first emotions, it is important to discuss what the teacher needs to be able to perform the necessary tasks²². What do you need to be able to talk to the parents, tell your class what is going on, teach the student at home, also perform your regular teaching tasks and guide this student? What support do you expect from colleagues at school?

Focussing on and considering the teacher's experience gives him the space to give the necessary support and it acknowledges his emotions. If this is ignored, there is a risk that the support for the sick student (as well as for the other students) will not be effective.

Pete explains the secondary school principal that their school is assisted by a specialized counselor in Ron's support. This expert supports not only the sick student and his class, but also the school team. The manager decides to meet with this counselor to discuss the support needed for Ron, his classmates and the school team. In this conversation the confidence grows that his school has enough to offer Ron. He accepts him as a new student.

In this situation, the teacher must consciously look for the balance between keeping distance and seeking involvement and the balance between work and private life. It is his own responsibility to ask support at school for his position and to indicate what he needs. This may be support from a colleague you can ask for advice. It may be an appropriate program to discuss the subject of 'loss' in the classroom. It may be attending a specific course on palliative student support. Or it may be a reduction of workload on other school tasks. Every situation asks for specific measures.

It is very important to know that asking for help is not a sign of weakness, but rather a sign of professionalism. Certainly, in a situation like this it is in everyone's interest that the teacher gets the support he asks for. One might be helped by being exempted from participation in a meeting, so that he can go on a home visit after school. Another may (in addition) need coaching. Not only the teachers are responsible for monitoring the load and its load capacity. After all, these aspects are partly dependent on the support offered by the entire group of colleagues and management at school.

5.2 SUPPORT FOR COLLEAGUES

The support that a teacher gives to a student in the palliative phase does not only depend on empathic talent and personal sense of responsibility. The possibilities and resources that the school can offer are also an important condition. No school management can and should expect a teacher to 'just' do this intensive task.

Palliative student support affects the whole school and is therefore a joint responsibility of everyone working in school. The school management has the task of ensuring time, attention and resources for the teachers involved. As a result, the teachers involved also receive recognition for the emotional burden that the support entails.

In addition, school management must ensure that colleagues continue to be updated on the disease process, even if the situation does not directly affect their tasks or students. Often, the necessary measures have an effect on other areas, so that colleagues will receive a (temporary) increase in their duties. This only works if there is broad internal support.

In Jack's class, Claire is seriously ill. Claire attends school when she is able, but her condition continues to deteriorate. Some of Jack's colleagues openly wonder whether it is not too stressful for the classmates that Claire still comes to school. For Jack, this question comes out of the blue, because he feels he still has enough leads to continue with his class and Claire. Jack does not feel completely supported by all of his colleagues, even though he really needs them now.

5.3 SUPPORT FOR THE SCHOOL

Palliative student support demands a lot from a school. Aligning the needs of the sick student, possible siblings and the other students with the possibilities of the school requires a very careful approach. This book can serve as a basis for this. In addition, it can be very useful to engage an external expert to support the school.

External experts can support in setting up an evening for the parents, training the team in the area of loss and bereavement in children and young people, as well as finding suitable programs and materials for students. Also, they can try to arrange that (online) education is continued when the student cannot attend school.

5.4 EXPECTATIONS OF PARENTS AND STUDENT

Parents with a child in the palliative phase expect health care professionals to respect and understand the thoughts and opinions of the student and themselves. In addition, these professionals must listen carefully, communicate clearly and know their position. Parents have the same expectations of school professionals. It seems obvious that a good relationship of trust is the starting point between school and the parents from which the dialogue and the support can be build. However, no matter how good the relationship is, it is important to realize that parents go through a different emotional process than the teacher.

The parents are sometimes not (yet) able to recognize that they are going to lose their child, while the teacher already has ideas about what the class can make after the student has passed away. It may also be that parents are already much further and bring up things that the teacher is not yet emotionally ready for. Then, the teacher might insufficiently match the expectations of the parents with the possibilities of the school. Sharing thoughts, concerns and emotions with colleagues, manager or counselor can help the teacher to make these differences visible.

Jean, an active child of almost six years old, has been complaining for a while about pain in the same spot as two years before. At that time, it was discovered that he had cancer. A few weeks later, it appears that the disease has indeed returned and that it is no longer possible to cure it. Jean likes to go to school. His parents ask the teacher if she wants to take pictures of Jean at school. The teacher explains to her colleagues how difficult this wish is for her. For her, it feels like she is already saying goodbye and she doesn't want to do that just yet. At the same time, this is also an opportunity to do something meaningful for the parents. And so a day later she picks up her camera in the classroom and lots of pictures are made. And Jean's classmates? They find it quite normal.

Finally, in a troubled, confusing and uncertain period, teachers are beacons of light on a dark sea. Large and small ships can hold on to this. But the beacons also need to be checked from time to time: Are they still firmly attached to the bottom? Should there be more beacons? Only when a teacher takes care of himself, he will be able to give intensive support to students.

5.5 TEACHER'S EXPERIENCES

Teachers who have intensively supervised a sick student in the palliative phase generally look back on this with a positive feeling. They realize that they have been able to make a significant and meaningful contribution to the quality of a student's life.

"I found teaching to be quite emotionally stressful at times. It is difficult to stay in your role as a teacher and make demands when you know that a student is so severely ill. But it is very rewarding to see how proud and happy the student is, when he has learned something again. Learning gives the student the feeling of being fully alive. He can look ahead, set goals. That is why it is important to stay in your role as a teacher and continue to make demands. The student expects that from you too. You give him a sense of self-worth, something that 'just' continues despite being sick." - Moniek (teacher)

"I found it emotionally very stressful, especially when I realized that Sidney was going to die. You teach while you realize that every time can be the last time. Still, it was satisfying every time, because you see that he is counting on you to visit. This gave me the strength to keep going! It was very clear that Sidney liked being taught and looked forward to it every day. Until the end he tried to work at the table. He enjoyed his school work, such as reading, writing and math games. At first I was not so aware of it, but Sidney really wanted to learn everything, even though he was very ill." - Astrid (teacher)

'When news came that Julian could not be cured, I did not know what to expect when I came to visit. I had several small school tasks with me that he could choose from. Julian chose the embroidery, which would also be the last piece he would make. He quickly deteriorated, but I kept visiting. Fortunately this could be arranged at school, because my colleague took over my class during those visits. Teaching Julian was very special for me, never a burden. I have learned that in collaboration and cooperation with the student, his parents and my colleagues it is not difficult to take on such a special task. However, it is difficult saying goodbye and close the book.' - Aad (teacher)

Tips and considerations

Form a support group of colleagues who share experiences and emotions. They can also arrange practical and educational matters. It makes sense to involve the colleagues who have a sibling of the sick student in class.

At regular times (e.g. in a team meeting), pay attention to the student's situation and the student support, even when no changes can be reported. This way, everyone can continue to follow the disease process and remains involved (even if it is just an encouraging pat on the back).

Consider if the teacher can be exempted from some non-lesson related tasks, so that he can focus more on the support.

Have regular conversations with the teacher. Do not overload him with advice, but rather ask for his needs. As the student's farewell approaches, a script or protocol is required on what actions are needed. It is recommended to write this at an earlier (more quiet) moment and (in general terms) discuss it in the school team. It is the first step to prepare for the loss of the student.

The interests of the class also play a role in finding solutions for the wishes of the sick student and the parents. This is not visible to the parents. Discuss this openly, so that the parents can (easier) understand certain choices.

Involve an external expert in supporting the team and management.

Give the teacher the opportunity to attend a course, professional development day or to study literature about seriously ill students.

Do not be afraid to show your own emotions to students. It is important not to let yourself be totally overwhelmed. By showing emotions you show students that you are open to sharing feelings and that adults can and may feel sad as well.

WHEN THE STUDENT PASSES AWAY – SOME SUGGESTIONS

It works best to think and talk about what steps have to be taken when the student finally passes away. Below are some suggestions, that can be useful. [21]

This list is far from complete, but is a good starting point.

Prior to the loss

It is important for every school to make a script or protocol in case a student dies. With this protocol, the school can act quickly and adequately in crisis situations. In any protocol, the following issues should be worked out in a scenario:

- What should be done when the notice comes in?
- Who are the members of a crisis team and what tasks does this team have?
- Who should be informed?
- In what way should the news be brought to students?
- What organizational adjustments are needed?
- Who will contact the parents of the deceased student?
- In what way should school communicate with the parents of other students?
- How do we support our students the coming period?
- What administrative completion is needed?

Informing classmates

- The way in which the death of a classmate is explained, is of great importance to students. Consider in advance how you are going to do this.
- As a teacher you cannot put off your feelings and you don't have to. If necessary, ask a colleague to support you in class.
- Make sure there is enough room for students to respond to this message. It is nice if you can fall back on all sorts of programs and materials to draw, write or create something that helps students expressing all emotions.
- Realize that the way in which students deal with loss depends, among other things, on their developmental age. And so they need ways to express themselves (see also 2.1).

Period between the date of death and the funeral

- In close consultation with the parents of the deceased student (sometimes through a family member) the school discusses what contribution the parents expect from the school, such as attendance and/or contribution to the funeral. Take cultural differences into account.
- Students may be emotionally full of what has happened. Give room to emotions and adjust the school program accordingly. Some students would also like to be taught regularly again. Try to meet both needs by, for example, having a group work separately.
- Not every student is able to talk about his emotions. You can let them deal in a different way. Let them draw, write, craft and play.

- Usually a comfort corner is set up at a central location in the school building, where students, employees and parents can go to. In the affected class, the student's table may be a comfort place for classmates.
- For siblings it may be supporting to go back to school during these days. The school can discuss with the parents when and how this is best possible.
- The school itself can hold a farewell service, so that all students and teachers have the opportunity to say goodbye. This way, there is some kind of closure for the school.

Aftercare

- After the farewell, the main thing is that the school keeps the presence of the student alive. The teacher can leave the chair and table in class for a while, leave their name on the class list, return the student's work to the parents.
- Regularly talk about the student in class and discuss how to proceed as a group: What should we put on the table? What is a good place for the photo?
- Look for a lasting memory of the student that fits the school. This may be a special tree or a bench in the schoolyard or a painting in the hall.
- It is not possible to indicate how much time it takes for processing the loss. Students usually indicate when they need to talk about it.
- At school, students often do not express their emotions in tears, but in a different way, in their behavior, different emotions and working attitude: e.g. anger, restless behavior, withdrawn behavior, concentration problems. Try to find a way to let these emotions be expressed, such as running outside or by giving a shorter assignment. Acknowledge and recognize these emotions as grief.
- The teacher, who has intensively dealt with the sick student and the class, may feel exhausted after the funeral. He may have ignored his own limits. It is important to pay attention to the individual experiences and how it is being processed. When possible with an external expert.

SAMPLE LETTERS

SAMPLE LETTER FROM THE SCHOOL

To all parents,

Also on behalf of the parents of ... [name student] we want to inform you about ... [his / her] situation.

As you know ... [name student] has been treated for some time because of ... [name of disease].

[Yesterday / a few days ago] ... it appeared that the disease has become worse, despite all treatments, and that there is no more curative treatment available. That is why medical treatment has been stopped. Despite the sadness, the parents, [name student] and ... [name(s) sibling(s)] try to enjoy each day together.

We try to support them as much as possible in this difficult time. The parents of ... [name student] have indicated that ... [he / she] would like to continue to attend school. As long as the situation allows it, we will of course ensure that this is possible.

This morning, the teachers have told their students in class about the situation. In the coming period we will continue to pay attention to ... [name student] in all classes, if the situation calls for it. Your child may come home with questions about the situation or you may notice something in your child's wellbeing or behavior. If you have questions about this and/or find it difficult to talk to your child about this, you can always contact us.

We wish ... [name of family members] a lot of strength in the coming period.

The management

SAMPLE LETTER FROM THE PARENTS

To all parents,

As you know, ... [name child] has been treated for some time because of ... [name of disease].

Recently it appeared that the disease has become worse, despite all treatments, and that there is no more curative treatment available. That is why medical treatment has been stopped. We can not estimate how much time we have together, but we hope ... [...]. Despite our grief, we try to enjoy every day together.

... [name child] would like to keep attending school. As long as the situation allows this, we also think this is the best for ... [him / her].

We have told ... and ... [name(s) sibling(s)] how the situation is now. They are also very sad. But like all children, they do not think about this all day. Especially at school, they are able to take some distance in their own way and seek distraction. We hope they get that opportunity and hope for your understanding.

We had hoped that we never had to write this letter, but unfortunately it is the case.

*Sincerely,
The parents of ... [name child]*

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