

The courage to tell the truth



Close to You
Romania Foundation
(Alături de voi
Foundation)



For every child
Health, Education, Equality, Protection
ADVANCE HUMANITY

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ARGUMENT

The mere fact that you are reading these very lines makes us think that you are a parent preoccupied with disclosing the diagnosis to your child. More and more parents are becoming aware of the necessity of breaking the silence, but this is a big step that creates much anxiety and fear. This brochure is aimed at helping you make the right decision. We have tried to put together the experience of other parents who have already undergone the same process and that of the experts in the field.

What can you learn from this brochure?

- Why? When? Where? How? would it be best to tell your child the truth?
- Who is the right person to tell your child the truth?
- How can you prepare yourself for the disclosure?
- How can you prepare the child?
- How can you tell if your child is ready to know?
- What kind of information about HIV/SIDA should you disclose to your child?
- How can you get closer to your child, how can you improve your communication with him / her?
- Testimonies from other parents and children who have faced the same situation.
- How to react to unexpected situations?
- How can the psychologist help you?

We hope we have aroused your curiosity and we are confident that you will find brochure to be a source of hope and positive thinking. It will help you realize that you are not the only one on this very difficult path. You

can learn from the experience of others and so you will find it easier to overcome all obstacles.

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I. PREPARING FOR DIAGNOSIS DISCLOSURE

I.1. Dispelling the myths

The HIV infection in children meets the criteria of a chronic disease, having an uncertain forecast. As with any other chronic diseases, the child's suffering will take its toll on the life of his family, and that outside it.

One of the many problems that affect the family of the HIV positive child is that of diagnosis disclosure. It is still a controversial topic and people have very strong personal opinions about the righteousness of the task. There are experts who advise on telling the truth. Others feel that its only possible outcome would be the loss of hope. Other specialists, more conciliatory, suggest we should reveal some, but not all the truth.

However, we feel that the child has the elementary right of knowing the situation he/she is in, without overlooking a series of characteristics that you will discover as you read along

Why do you hide the real diagnosis?

The answers to this question vary from case to case. No doubt you are scared. You fear the reactions that you or your child might have.

Our experience has taught us that many of your fears are shared by other parents dealing with the very same situation. That is why we shall try to analyze them one by

one, in order to clarify their presence and dismantle their logic:

Lack of trust in your own ability to take this step: "I will break down, cry uncontrollably and scare my child".

Unfortunately many parents underestimate themselves. As we will point out in numerous occasions, it is very important that you maintain a positive attitude and believe in your abilities as a parent. You know, of course, that in the best interest of their children, parents often prove remarkable control and strength. When the time comes, you too can be strong if you remain optimistic and if you have prepared yourself in advance. This means that you should know what to expect and most importantly, you should know *what* and *when* to tell the child. This is what we are trying to teach you in this brochure.

"I will be blamed for not telling him/her earlier and this will destroy our relationship".

The longer you wait to disclose the diagnosis, the more likely it is that this is what will happen. That is why we advise you to tell the truth as soon as possible. Unfortunately though, many of you have been hiding the truth for a long time. We feel that in this case it is recommended that you spend more time with your child before actually disclosing the diagnosis. This will help you strengthen your relationship with him. It is necessary that you explain to him that there are cases when people are afraid to tell the truth because they are trying to protect the people they love. Even parents make mistakes sometimes. The child must be informed that by telling him the truth, even if it is later than it should be, you prove that you trust him and his ability to understand. He might not see your reasons right away, but in time he will be able to understand you better. But you need to start

communicating better with him, showing him that you understand how he feels. You have to be honest and open with him.

What we have noticed in most of our cases is that the children have become more open and communicative after the disclosure, they have even started to support their parents' moral and showed a lot of optimism. Consequently, the parent - child relationship has improved considerably.

"My child will commit suicide."

Doctors, social workers, psychologists who work in the field and parents who have confronted with this situation show that this is highly unlikely, especially if you son/daughter is a psychologically balanced person (as much as a teenager can be). Even if the sudden reality bite will come as a shock, and it will be followed by a difficult period of sadness and despair, you mustn't underestimate your child's ability to adapt to difficult situations. In the end, your child will come to terms with the reality, and he will start taking his treatment voluntarily, understanding why he needs to go to the doctor and why he has to look after his health.

"I fear he will tell our neighbors and friends about his sickness, and that will be the end of his social life."

To avoid such an occurrence, you have to explain to your child, in simple words, why it is better for him not to talk to anyone about his condition. You have to tell him that there are people who lack the complete and accurate information about HIV and who can hurt him unknowingly. Also you can assure him that he can always talk to you, you family and his doctors from the hospital where he receives his treatment.

“He will lose interest in school, family, friends, and life in general.”

After you told him the truth, it is normal that the child should feel the need to isolate himself and organize his thoughts. He needs to process all the information he has been given, he needs to adapt and gather his strength to face this situation. Do not expect him to behave as if nothing has happened! Give him some time alone and don't spy on him! And make him understand that he can talk to you or any of the members of your family any time he wants to. The child will learn to accept the situation and he will get engaged in his usual activities, because most of the children choose to be active and to live their lives to the full.

Although they vary, parents' fears about diagnosis disclosure gravitate around the topics we have discussed here. Regardless of the nature of your own fears, it is of the utmost importance that you realize that in order to face this moment you need to build a very close relationship with your child. This relationship will be based on real communication and trust.

Also it is equally important that you maintain an open and positive environment at home. Remember: the reaction that your child will have is entirely up to you. It depends on your attitude towards the disease and life, in general. You are the one who teaches him most things in his life, and that is why you can be his source of hope and positive thinking. “We can all decide if we will have a creative life, if we can be a model of wisdom, or of despair and rebellion for our child.”¹

¹ Constantin Ana - Maria, “HIV Infection or the Well-Hidden Secret”, The Teenager Association and Fundacio Salut i Comunitar, Constanta, 2000

I.2. Characteristics of diagnosis disclosure

First and foremost, you should come to terms with the fact that sooner or later your child will find out about his diagnosis. The way your child finds out about his disease is of the utmost importance and can have major consequences. Thus, the child can learn about his condition:

- by accident;
- through direct answers he receives to his direct questions;
- through direct communication (and in this case it is very important who, when, where and how does it).

There is no established pattern or model as how you should inform your child about his diagnosis. Every situation is unique and you as a parent know best how to answer your child's needs.

Deciding to let your child know about his disease allows you to control the circumstances in which he will be informed. Being able to decide when and how to tell him is a crucial advantage that will help you to present him with the right information in a positive and comforting way.

Due to the special context of this particular disease, there are many cases of parents who are hesitant and even refuse to talk to their child about HIV. Sometimes they come up with trivial explanations for the child's frequent visits to the doctor, his medication and even his life style. What's worse, some of these children believe what they are told and do not concern themselves with this topic any further. Most of the time, children are told they suffer from another disease, usually one associated with HIV:

“you have cronical hepatitis”, “it’s a blood disease”, “there’s a problem with your red cells”, “you suffer from epilepsy”, etc. Most of the times the child really does suffer from these opportunist infections, and so he is convinced of the truthness of his diagnosis.

By failing to speak up the “whole” truth, and by adding up other such omissions, the family will not only postpone the moment of the truth, but it will also make it much more difficult. This is the beginning of a vicious circle, a circle of lies with no way out. What you have to remember is that no parent has ever been able to master the art of lying so well as to find a ‘suitable’ explanation for everything. No doubt, sooner or later the child will find out he is being lied to.

And regardless of your arguments for hiding the truth, we feel it is utterly important that you inform your child about his disease, and also to call it by its name.

WHY?

Your child must know about his disease in order to be prepared to face discrimination and fear, all medical procedures and the painful side-effects. Open discussions about HIV will allow your child to become aware about the seriousness of the disease, to express his fear, to ask questions and to tell you when he gets sick or needs help.

The most traumatic and painful way your child can find out about his disease is *by accident*, from his medical charts or from collateral discussions or from ill-intentioned people who throw the truth in his face.

Your child can become a victim because he *lacks essential information* and this lack can lead to a very stressful condition. Your child sees his parents unhappy; he hears whispered discussions about him at home, in the hospital, in the classroom. What can a child think under these circumstances? "My parents are very unhappy because of me", he will probably think, and he'll blame himself - without knowing what he did and how he should act in front of his parents and brothers, how to stop them from being unhappy. He is bound to realize the existence of a conspiracy and most likely he will misunderstand it. He sees that something is wrong, and most importantly he feels it: frequent visits to the doctor's office, the continuous treatment, long hospitalization, the worried and often sad eyes of his parents, the fact that one day he starts feeling tired and can't keep up with his mates anymore. He will get very worried, and will rarely express it in words, because he is only surrounded by embarrassed, fearful or hesitant looks. The consequence of that - *mistrust, fear, anxiety*. Diagnosis disclosure after a long time of denial and secretive behavior will produce a *brutal shock* to your child, who will believe that his trust has been broken and will not be able to believe in his parents again. Keeping his disease a secret is the worst thing you can do. And what's more, if he doesn't know he is HIV positive, *he won't pay any attention to his treatment or protection*.

Here is a real example of the point we are trying to make.

This is the case of a little girl we will call Maria, and who is 13:

Maria was diagnosed as HIV positive in 2000. This news has changed the balanced relationship between her parents into one of conflict and tension. The little girl noticed this change and furthermore she realized she was the cause of their rows. Being a

smart and observant child, she started asking her mother about her disease. The often visits to the doctor, her mother's worried looks after the discussions with the doctor forced Maria to search for the truth by herself.

The first time she ever heard about AIDS, it was from a roommate when she was admitted in hospital. She started asking more questions, but nobody wanted to tell her she was suffering from this disease. When the new school year started, Maria noticed her classmates avoided her and they even started calling her names. Extremely worried and upset Maria asked her mother more and more questions. But mum still refused to talk to her. Until one day...

She had returned with her mum from the hospital, where she went for further investigation. When they left, the doctor handed her mum two discharge notes: one to account for her missing school and one for the family. One day when Maria was left alone in the house, she found the note that her mum was keeping hidden. She looked and looked for it, and then she found it hidden behind a painting on the wall. She realized that her suspicions were true, she understood her mum's and dad's tears and she understood and accepted the attitude of her clas mates...

And so Maria became surer of herself and is now able to face her classmates and her friends. She forgave her mother for hiding the truth from her.

WHEN?

The first criterion you need to keep in mind when you decide to talk to your child about his condition is his age. There are parents who use their child's age as a viable argument for keeping it a secret ("he is too young for this"); they also fear the effect on his mental state ("he would suffer tremendously").

a) In the first years of life, communication about HIV/AIDS is very limited because children under the age of 7 cannot understand why there are such horrible illnesses that cannot be cured.

b) In primary school the child can understand much more, and he starts to think by himself. However the level of information provided must be according to his ability to understand. He can understand, for instance, that it is an internal disease and its cause is exterior. At this age children assimilate a lot of information through drawings. That is why it might be useful if you decided to draw together with the child images reflecting the virus entering the body and how we can protect ourselves from it, etc.

c) Starting from the age of 12, the child is capable of understanding the mechanism of the infection and the co-existence of several causes. He needs complete information: the name of the disease, its history, etc. Knowing how to read, he will most definitely see the word AIDS written. He will discuss with other children who have heard about HIV/AIDS, or he will find out from a "well-intentioned" mate in school. There are many cases in which the child thinks he has AIDS, when in fact he is only infected with HIV.

On the other hand, a very strong incentive for you to give detailed information to your child about HIV/AIDS is the fact the virus can be sexually transmitted, and this is a very dangerous age. The young teenager will start asking questions about the development of his body and his sex life. Discussing with him about sexuality does not mean that you need to scare him or warn him not to start his

sexual life, so early, if ever. The moment you notice sexually related questions, it is your duty to tell your child that an unprotected sexual contact can infect his partner with HIV. Also he needs to know that he should tell his partner about his condition, as a sign of respect and responsibility.

A second criterion that affects the disclosure is the *time of infection*:

a) your child was born infected;

A child born HIV positive will understand more things about his health from a very early age because he will notice the frequent medical check-ups and the unusual treatments he is subjected to, unlike other children his age. He might not know the name of the disease, but he will know, even before you tell him, that he is sick.

b) the child was infected as a young infant;

The younger he is, the simpler the information you give him has to be, according to his level of understanding.

In diagnosis disclosure, a good principle to guide on is "*better sooner than later*". Research in the field has shown that those children who suffer from serious illnesses and who are informed about their diagnosis sooner rather than later are likely to cope better with their condition, compared to those children who learn the truth later.

To support our case, we present you another situation with serious consequences, about a child whose parents did not inform him on time about his diagnosis:

Michael is 18 years old. He is HIV positive, but he doesn't know it. He abandoned school a while ago and he has started working

with his father to help his family. This is how he met Veronica, a young girl his age and with similar preoccupations. No one in Michael's family took this friendship seriously, and so his parents ignored the consequences and did not start a conversation with him. After a while, Michael's mum finds out from a neighbor that Veronica was pregnant. The news came as a shock to her. She could already imagine the future...

When she got home, she asked Michael if that was the truth, hoping that he would deny it. But Michael tried to comfort his mum and told her that he plans to recognize the child as his when he is born. His mum was now faced with two options: to tell him or to keep lying. She thought that it would be too late now, and she didn't want Michael to have an adverse reaction and lose faith in his parents.

After weeks of sleepless nights, his parents decide to tell Michael about HIV and its implications. After this conversation, Michael ran away from home...

WHO?

Children feel better around people with whom they have a continuous, affectionate relationship that offers them security and protection. If they learn about their diagnosis from someone they trust and if they are explained exactly what their situation is, they might accept it better. Usually, but not in all cases, this person they trust is their *parent*.

As a parent, it is not easy to tell your child he is infected. And this is because you too are affected by his disease.

That is why you need an *experienced person* who can give you the right support you in this situation.

This expert, usually a psychologist or social worker, can help build an emotional support and can also help you find the right words. He can encourage the child to express his thoughts and feelings, and ask you all the questions he will want to ask. The answers and the attention you give to your child will let him know that you are taking him seriously.

Depending on the person that initiates the disclosure, there are two types of such disclosure: *reactive* (when the child initiates it) or *proactive* (when the parent makes the first step):

a. reactive disclosure: experts agree that when the child suspects his diagnosis and the questions he asks are more and more direct, then he is prepared to find out the truth. Even when the disclosure is an answer to his questions, you still need to be careful, as he still may have “unpredictable” reactions;

b. proactive disclosure: the disclosure will be made gradually and progressively, every step revealing a bit more of the information that the parent wants to reveal to his child. Very important in this case is the emotional, verbal and non-verbal support (gestures, mimics, posture, etc).

Here is the case in which the support of an expert made the disclosure easier:

Johnny, a 13 year old boy, diagnosed HIV positive two years ago, has just spent a few months in hospital.

Unused to spending so much time in hospital, Johnny started to ask his mother what was happening to him. When he asked his doctors how long he had to stay in hospital, they gave him evasive and often contradictory answers. The days went by and Johnny started to feel homesick. He also missed his parents very much and was worried when they visited him, because of the sadness in their eyes. Very soon Johnny started crying and begged his mother to take him home.

“Why do I have to take so many pills? Why can't I go home? What's wrong with me? Why won't anyone tell me?”

His mother feared his reactions and didn't know how to tell him. She couldn't do it alone... she just couldn't face it. On the other hand, she knew there would come a time when she would have to tell him. Up until now, she hadn't realized that Johnny had become old enough to know that something was wrong. Should she tell him...? Or not?

Finally she braces herself and seeks expert advice. She realized she needed help if she wanted to tell her child about his disease. She didn't know how to tell him, or when to tell him, and above all, she feared his reaction... will he be able to understand... Will he be able to cope with it?

The moment she feared most has come. She takes Johnny by his hand and leads him to the counseling office. They sat on the couch and the counselor started to talk to Johnny, encouraging him to talk about his worries. Step by step they started talking about HIV. Mum was surprised to find out that Johnny knew more than she thought he did: he had heard about HIV from other children, but didn't know for sure that he had it. When he found out the truth, Johnny calmed down and looked at his mother, grateful to her for telling him the truth.

From that moment on, Johnny's attitude towards the hospital and his treatment has changed radically. He didn't complain when the doctors told him he had to stay a while longer he

didn't have the same adverse reaction to his pills... and he forgave his parents for telling him the truth... and now he trusts them ;

... now he can talk openly about his disease;
... now he knows how important his treatment is;
... now... HE KNOWS THE TRUTH.

WHERE?

If diagnosis disclosure is well-planned and therefore initiated by you (proactive), it should be done in a *secure environment*, familiar to the child (home is the best choice), where he is surrounded by personal things (toys, books, etc.). Avoid crowded places or places where you can be interrupted. The place where you choose to reveal the truth must not inhibit the child from expressing his feelings, his anxieties, but it must increase his emotional comfort.

After you tell him about his condition, you might want to spend some time together, at least immediately afterwards, in his familiar environment, surrounded by his close ones. The presence of the family is a support in itself, although older children might need to be left alone, or might want to go for a walk. Give them the space they need, if they ask for it! Don't expect him to act as if nothing happened. And don't follow him to make sure he is OK, or if you do, be very discrete!

HOW?

There are several stages to diagnosis disclosure that you need to be aware of:

Stage 1: Discovering what your child knows or suspects

When you think your child knows or suspects his diagnosis, the best way to deal with it is to admit to him that there is a problem and invite him to talk: "I've noticed you have been asking more and more questions about your visits to the hospital. I'm happy you are so interested..."

Answering your child's needs and questions is necessary at the beginning of a reactive disclosure (initiated by your child), and it is your task to answer and comment on his questions.

If the child is completely unaware of what you want to tell him, you can start with the next stage.

Stage 2: Telling your child about the disease he has

It is recommended and useful that you tell your child what has happened, what is happening, what can be done, and what will happen. Children need to understand the situation they are in, in order to face it.

The information that you give your child has to be presented in simple and delicate terms, using a narrative approach. It's best to keep things simple and short, and in a chronological order. You may begin by mentioning facts from the child's own personal experience: "Lately you've been very sick and the doctors have been doing tests..." Knowing what has happened and what will happen, the child can meditate on these events and on the way he might feel.

This stage is very problematic in terms of: *how much of what is likely to happen should we reveal at one time?*

- The explanations you will give your child should be formulated according to his vocabulary and his ability to understand. Be very careful when you explain medical terms, as it is a well known fact that stress can lead to misunderstandings. Be receptive to what your child says, and pay extra attention to what he does not say (posture, gestures, etc).
- Partial information is an intermediary level of communication used by parents to tell their children about their infection. This way they make a compromise between the child's necessity to understand what is happening and the parents' preoccupation to avoid pain and suffering for their child. It is also a comfortable means to evaluate the child's perception about the disease before you go into more details.

Stage 3: Explaining your child everything he wants to know

You should ask your child if there is anything else he would like to know and you also should give him the possibility to talk about his thoughts and feelings. That is why he needs sufficient time to meditate, before he talks to you again.

Stage 4: Meeting your child's needs and wishes

All the information and explanations you give to a child infected with HIV must be answers to his needs and wishes. All children feel vulnerable: especially the child

who has just found out that he is HIV positive. That is why your presence gives him security. But be careful: paying attention to him and comforting him are not a substitute for a truthful conversation.

Telling your child about what other children in his situation did can be helpful, determining him to think about what he himself could do, but at the same time it could be stressful. You need to avoid too much optimism and discussing only the positive aspects. Also, the strategy of giving the child unrealistic hope and telling him only parts of the truth is usually inefficient, as it can become a source of stress and mistrust. *Your child doesn't need false hopes. And don't ignore what he feels!*

Be careful what words you use to talk to your child, and don't be evasive or condescending. For instance, when a parent feels incapable of answering truthfully his child's questions, he says things like: *"I will tell you one day..."* or *"You are too young to understand..."* This type of answers must be avoided. It is more useful to tell your child that: *"I see you are very concerned but it is very hard for me to talk to you about it now"*, or *"What you are asking me is very important, but I don't know what the answer is"*. Under these circumstances you must assure your child that the problem won't be postponed or avoided.

Now that the child has got used to the idea, you can be the one who starts a new discussion: *"You know how we talked about your disease the other day. Would you like to know more about it? If you don't, just tell me when you feel the need, and I'll answer all your questions"*. This way you are leaving the gate open for more discussions, and when he is ready to know more, he won't hesitate to ask you.

Maintain eye contact with the child, use a comforting tone of voice and try to make the communication reciprocal; the child will be unsure of himself at first, but he will soon start asking a lot of questions. Make sure you answer to all his needs, depending on the perception he has about the situation.

Now that you have read this new information and you found out about these real situations, do you still think it is impossible to tell him?

Coming to meet your needs, here is a story that you can use to explain to your child what is and how does HIV work, and how important it is to follow the anti-retroviral treatment to the book:

For you to understand what HIV is, I have to explain to you a few things about the way our body works.

Starting from birth, all people live in an environment full of little tiny microbes... they are so tiny that we cannot see them: viruses, bacteria and parasites that can attack our body any time. Our body is fighting against these microbes through its army (immunity system), an army formed of many little soldiers (the so-called white cells). They are always on patrol, ready to defend and fight for the wellbeing of the body. Their enemies are the foreign substances that somehow enter the body (like microbes). These little soldiers have a captain, and his name is T4.

HIV is a virus that enters our body and when it does that it attacks the captain himself, T4. If T4 surrenders, then the whole army will surrender too because without their captain, they cannot organize their defense. And so, HIV will paralyze our whole immunity system consequently our body won't be able to protect itself from other enemies. And so more enemies will enter the body and make it weak.

*You have asked me several times why you have to take so many pills every day: because we are trying to protect captain T4 and his army. And these pills you are getting, and a good alimentation, are allied forces that help the body fight the infection. The allies are stronger when you take your pills on time and when you eat the right food. If you forget to take your pills and if you refuse to eat, the army will be left alone to fight the battle and will lose. That is why you need to listen to what the doctor says, take your pills and eat good meals. It's up to you if you want to be a **WINNER!***

After all these explanations, you should expect the child to ask you a series of questions, such as: Is my captain dead? Is my army still fighting? Will I get better?? Am I going to die? Is HIV the same as AIDS? Who can I tell about my disease? Who else knows? How long will I have to take the pills? etc.

It is also important that you explain the child the difference between HIV and AIDS. You can do it this way:

- *HIV and AIDS are not the same thing. If you are infected with HIV, this doesn't mean that you have AIDS ;*
- *HIV is a microbe. It is called Humane Immunodeficiency Virus. Once it enters our body, HIV will attack the army (that is our immunity system), and especially captain T4. The purpose of the virus is to take over the control of the army and to replace the captain. The little soldiers (the white blood cells) are fighting and are trying to defend our body. But they can't do it for a very long time, they need help. The captain cannot resist to repeated attacks and as the army surrenders that is when you go from the status of infection (HIV) to that of the disease (AIDS).*

- *This is AIDS. It means Acquired Immunodeficiency Syndrome. Through a series of signs (the so-called opportunist infections, such as kidney disease, liver, skin or stomach), the immune system shows he is defeated and cannot defend himself anymore.*
- *It will be a hard fight but I will be here with you and together we will face everything.*

I.3. [About unexpected situations](#)

As a parent, I am sure you want to protect your child the best you can. Maybe you thought that if you don't talk about it, you won't think about it anymore. As long as the child didn't know, it would have been easier to deny the existence of a problem. You felt that if he didn't know, he wouldn't suffer.

But now the child is all grown up. Now you realize that he is becoming an adult and you won't be able to keep it a secret from him anymore. This is when you realize you need to tell him, but you keep postponing it by telling yourself "*no... this is not the right time...*" And so here you are...

Every day that passes, your child is more likely to find out the truth from somebody else, or even put the pieces together and understand it by himself. Maybe he already did... In this case, he is likely to face you and ask you to confirm or deny their suspicions. You have to get ready...

You need to take advantage of this opportunity that our child gives you and tell him the truth. You no longer have to lie to him. He already knows what is happening and if you keep avoiding the discussion, he will stop trying to talk to you. Your relationship will be damaged and he will

look for his answers somewhere else, where the information he gets will more likely be misinformation. That is why he has the right to get the answers he wants from a loved one, someone who has the love and patience to explain everything to him.

At the time of the confrontation, please remember to stay calm. In the discussion that will start you will have to offer clear information while keeping a positive and hopeful attitude.

“The first pieces of information you give the child are essential.” They will determine the way he / she will accept the disease, his attitude towards it... That is why, if you feel you have to, take a break before you continue the discussion. Tell him you will discuss with him everything he wants, but that he'll have to wait a little time. Go to another room and try to find your peace and equilibrium. Maintain a positive attitude and start the discussion believing that everything will be OK and that you will be able to face it.

Recommendations for the discussion with your child:

- Pay attention to his questions and answer them as clearly as possible;
- Don't offer too much information at one time; there will be plenty of time for that; for now just answer his questions;
- Be honest in what you say and in your reactions; admit to him that this causes you pain and fear; this is how you encourage him to express his own feelings;

- Try to maintain a positive tone of voice;
- Let him understand what you told him and start the conversation again when you feel he is ready;
- One discussion is not enough; talk to him as many times is necessary and give him accurate details; make sure he understood everything;
- Your child has to know that he can talk about this with you any time he wants.

There are some extreme cases when parents still feel incapable of telling the truth, even after they have learned all this information. If you are one of these parents, you should ask someone in the family to talk to him, or perhaps an expert in the field (psychologist, social worker or doctor). Still, *remember*:

“You are the right person to tell your child the truth.”

II. REACTIONS TO DIAGNOSIS DISCLOSURE

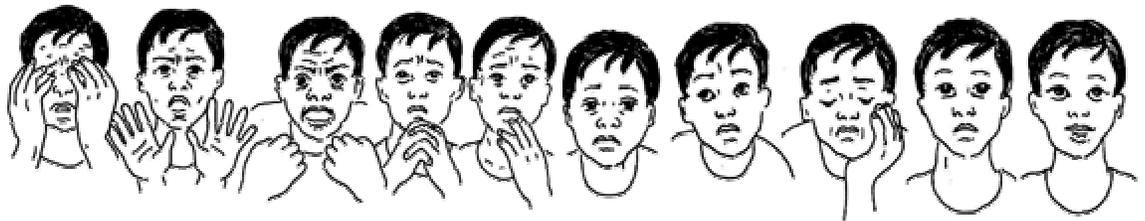
You have often wondered how your child would react when you tell him the truth about his diagnosis. You fear the negative consequences that such news might have on him. All the more since you remember perfectly how you reacted when you found out: tears, anger, pain, fear...

But don't forget that it was very unexpected news for you. Your child, however, has already had time to "prepare" himself for the news, and this preparation includes frequent visits to the hospital, medical exams and the pills he has been taking, the discussions with the other children in the hospital (you have no idea how much they talk about...), his weak and ill state, etc. Certainly your child already has a pretty good idea that he suffers from a very serious disease, even if he lacks the courage to tell you.

Your child can have the very same reactions you had when the doctor informed you of the diagnosis. They are natural reactions to shocking news, however the intensity your child will feel them with is likely to be smaller. In what follows we will closely analyze the attitudes and reactions that can appear when the diagnosis is revealed

hoping that it will help you parents to identify and better understand your state, or that of your child.

Experts agree on a few stages in the process of accepting a chronically or deadly disease. These stages take different amounts of time, depending on the person, they are not strictly limited and their occurrence is not linear. They are as it follows:



1. The initial shock

From surprise to deep disturbance, HIV is perceived as a deadly threat. Shock is a normal reaction when all your future dreams and plans fade away. At first the person is terrified of the unexpected news. The child infected with HIV feels confused. If some children seem unaffected, that is because they haven't begun to realize what it means. This is a very short phase, because hospitalization, medical investigation and treatment will impose themselves on his life as his new and inevitable reality.



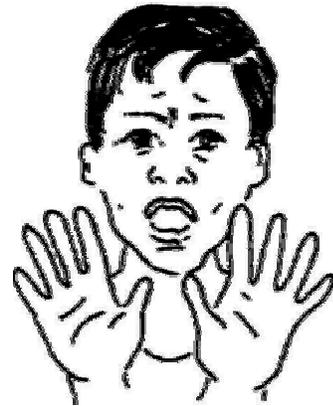
How can we help the HIV infected child in this stage?

It is useless to start giving your child too much information at this stage, because he will probably not be able to hear or understand anything. It is better if you help him get a grasp of the situation, support and encourage him. The amount of information you give him at this

particular stage depends on his level of understanding.
But you must not pretend it is not a serious situation.

2. Denial

Inevitably denial is an intermediary stage, which must be followed but not encouraged. It is a mode of defense that the individual uses to protect himself from the feelings and thoughts that trouble him by denying their existence. Reality is too threatening and therefore it is refused. In fact they are unconsciously denying the truth: *"It can't be real, I'm not feeling ill ..."*, *"The doctor must be mistaken ..."*. This news will disorientate him. It announces the sudden and dramatic change of his whole life. By denying the existence of the problem, the child thinks he will have a healthy, normal life. Your child might appear detached, stating on numerous occasions that he is feeling very well. He will neglect medical check-ups, especially when he has no symptoms. Others around him might think that he regards his illness as trivial, and try to make him realize the seriousness of the situation. But what they do in fact is they fuel up the state of denial, which is very unhealthy and dangerous.



Denial can occur anytime, and especially in crisis situation.

A more subtle way of denial is avoiding the words HIV and AIDS, as if words had the power to inflict pain themselves.

How can we help the HIV infected child in this stage?

When confronted with denial, act carefully and try to create a trusting environment, and begin to analyze the

reasons for which the child feels threatened. Positive, encouraging, but never trivializing information can have a favorable effect.

If you yourself continue to deny your child's disease, then you are only making him sicker!

3. Revolt (anger)

Situated between the initial shock, the denial and the final acceptance, this phase starts with a deep feeling of helplessness and unhappiness. The child who has just found out he is HIV positive will be overwhelmed with fear and will try to find someone responsible for his situation. But no



one knows why some people get sick and die, while others live happily. Consequently he will be enraged, will act aggressively through behavior, contradictory attitudes, which are hard to accept by the people around him. When he starts acting aggressively, it means he is beginning to fight his anxieties by believing that he was treated unjustly. Some of them even wish that others around them got sick, too.

The sudden crushing of all dreams and expectations will produce fear, pessimism, despair, insecurity, self-blaming. The child infected with HIV might blame himself for his disease, and will most certainly fear stigmatization and isolation, which is why he will keep his infection a secret. His fear will be directed towards the world outside, by a frantic search for the guilty party, or inside, towards himself. Some children secretly wish for others to get sick, as well. And they feel that the treatment is a punishment,

especially when accompanied by discourses of the type: *"I'm telling you to do it for your own benefit ..."* Still, this phase is a necessary step for the infected child, which shows that he is starting to understand. It symbolizes the effort of the family and child to get rid of this feeling of helplessness.

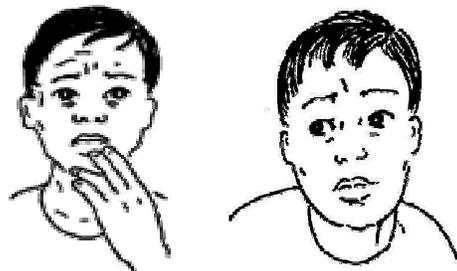
How can we help the HIV infected child in this stage?

If you have read carefully these lines, then you realized that the aggressive attitudes the child has are in fact directed at the disease itself. When he gets angry, it is important that you allow him to express his anger, and not try to bury it!

That is why it is useful that you try, together with a counselor, to stimulate the child and encourage him to develop his ability to search and find acceptable solutions.

4. Negotiation

This phase develops in the case of older children and adults. It manifests through tendencies to manipulate the exigencies of the treatment. It is a phase less noisy than anger, and it is another way of dealing with the reality. The child is trying to accommodate the information, which he can't stand. He tries to act through it, in as different ways as possible.



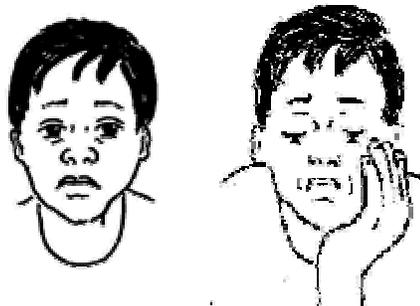
How can we help the HIV infected child in this stage?

Through negotiation, the child uses a strategy that exploits the differences between the opinions of the

members of the family and that of the specialists. That is why, the specialists involved (doctors, social worker, psychologist) and you, too, must show tact and lead the negotiations towards secondary topics.

5. Hopeful depression

It is a very important phase that sometimes passes unnoticed. It mustn't be confused with clinical depression, when the individual cannot face his daily problems, looks more towards the inside, feels discouraged, and suffers from insomnia and lack of appetite. Being a phase in the process of acceptance, this depression is a step towards the right direction. If you see your child getting very sad, it means that he starts to become aware of the risks he is taking.



This is the time when he gathers his forces to face the future, but careful: it can also be an opportunity for him to become self-destructive, an idea favored by his feeling useless and futureless.

How can we help the HIV infected child in this stage?

First and foremost you should try to identify the depressive moments, and then show interest and support for your child. You and your child should participate in a support group formed of people who are confronting the same situation. Within the group, your child will find out he is not the only one on this situation and above all, he will find out he is not alone!



6. Acceptance

It is the time when your child that his disease cannot be or eliminated and it represents a huge success. In phase the child infected with express his fears, his helplessness in front of the disease and the society around him that discriminates against him. By accepting it, he admits that his disease involves constraints and risks that he must be aware of, without becoming obsessed with them.



realizes
stopped

this
HIV will

By finding his emotional equilibrium again, your child will start to get involved in personal and social activities. Accepting HIV as part of his life, he will want to live his life to the fullest: "What other good things could I do?", "What other medication would help me more?"

This phase is not final. The progress of the disease, the appearance of new symptoms will lead to a new loss of trust and hope, and then this process will have to be resumed.

How can we help the HIV infected child in this stage?

Your child, like any other human being has made a few plans for the future. Don't hide the truth and don't simply forget his dreams. Encourage and help him make them come true!

III. EFFICIENT COMMUNICATION METHODS

I.4. Encouraging your child to express his feelings

It is of the outmost importance that you encourage your child to express his emotions, feelings, fears, anger or anything else that comes as a reaction to diagnosis disclosure. Sooner or later he will begin to ask you all those questions in his head.

No matter what you think that your child will react like, you must find the best moment to tell him. Don't start this conversation if you yourself cannot follow it through, or if you are pressed for time.

Another important detail is to make sure that your child feels very close to you in those moments, a good idea would be if he sat on your lap, if he is of a younger age. He must see that this news is distressing for you too, but don't exaggerate with it. Sometimes the parent starts crying while he tells his child he is HIV positive, or he even starts before that. That is not a problem, you should express what you feel. You can both cry together. The idea is to make sure he understands that he is not to blame for what has happened and that his family doesn't think of him as a burden. Try to eliminate this feeling that children get, that their disease comes as a punishment for something they have done.

Sometimes the emotional shock is so big that the child won't react any way. He needs to be encouraged to talk about what he feels by asking him simple questions. Otherwise he will shut himself out from the world and

this will only make it worse. You can ask him, for instance: *"What do you feel now that you found out?"*, *"What do you think about what we talked?"*. These simple questions can open a sincere dialogue between the two of you.

Another possibility is that the child already knows or suspects his diagnosis, in which case he will be relieved when you tell him the truth: *"I knew it already. Why did it take so long for you to talk to me about it?"* This is a happy case and you should take this opportunity to re-establish the bond of trust between your child and yourself.

But this doesn't happen all the time. Sometimes children feel anger, pain, helplessness, anxiety, injustice, etc. You mustn't be very pushy and force him to talk to you *immediately*. Give him time to get used to the idea, if he needs it. If you've tried to get him to open up and he was resistant, you can tell him: *"We can talk about it later, if you want to"*, this "later" meaning 1-2 hours, a day, but not more. When the child doesn't try to talk to you about the countless feelings he has, than that means he is creating negative scenarios in his mind, which can sometimes lead to self-aggressive reactions.

Show him that he can talk to you openly. Don't lock all your feelings inside after you communicated your child the diagnosis, because that doesn't solve the problem. You will feel relieved once you do it, but your child's feelings are much more important than yours.

It is always a good idea to offer the child as much medical information as you can, about the difference between HIV and AIDS, about the necessity for his treatment, etc. Also you can give him brochures, or you can encourage him to talk to his doctor. You don't have to talk about everything at once. And you don't have to tell him immediately about

the evolution of the disease. Be ready, as he might shock you with one question: *"Am I going to die?"*.

That is why you need to get ready for any type of questions and simply try to remain calm. Don't lie to him, but give him hope and teach him to believe in the effect of his medication and in his desire to fight the virus. Don't forget that positive thinking is part of the treatment and try to make him aware of that!

Show him that his feelings are not wrong. Whatever he may feel, it is normal. Frustration, pain, whatever he goes through. And show him you are sympathetic to him (you understand him and you are there for him): *"I know you are upset now and it's normal that you be like that, but I am here for you and I will help you all the way"*.

Children are capable of dealing with very hard situations and emotions, if they see the same in the people around him, especially the close family.

If in the immediate period following diagnosis disclosure your child refuses to talk and all your effort in encouraging him to do so have failed, then try another strategy: stories, drawing, etc. You can tell him: *"I know you feel it is unjust and I know you'd like to punish someone, but we have to try to go past this. I felt the same thing when I found out"*.

Only then will the child know he is taken seriously and that whatever he may feel, is entirely normal, therefore they will be able to express their pain. Be close to him, express your understanding, help him discover the normality of their feelings and only then will he find a safe environment to open up.

Children must be encouraged to express their feelings continuously, and not only at the time when you disclose their diagnosis. Even if your child has accepted his disease and has learnt to live with it, he must continue to tell you what he feels so that he can maintain his emotional equilibrium. Don't neglect it, because your child can go through an unexpected crisis and if you don't communicate with him permanently, then you might lose him from an emotional and relational point of view.

After you have prepared both yourself and the child for the moment of truth, the next step is obviously the disclosure.

But how can you actually tell him? Here are a few recommendations:

- Look into his eyes from his own level! How would you feel if someone four times your size would suddenly come down on you when you are already scared?
- Talk directly to your child or teenager.
- Be honest. Hiding the truth from your children, even with the best of intentions, will result in you losing your child's confidence.
- Identify, allow and respect the normal expression of your child's thoughts and feelings. Crying is normal, and so is rage. Children will be able to face a hard situation better when they are allowed to express their feelings.
- Allow your child to choose, but offer him only real alternatives. Your child can choose if to take his pills with water, or tea... and that's great! But he can't choose not to take them at all, so don't infer that he can.

- Talk to him about things he is interested in. All children go to school, have friends, pets and hobbies they like to talk about.
- Don't neglect your child. All children, even teenagers need their parents the most, and all parents are experts as far as their children are concerned.
- Hold it together. If you feel you can't refrain yourself, ask for someone's support (a relative, a specialist).
- Give your child his right to privacy. Everybody needs a little space, both emotional and physical. Teenagers are very sensitive about their privacy.

*And here is how you are **not** to communicate with your child:*

- Avoid comparing your child with others! Nothing upsets your child more than something like: "You should be able to do this. Alex is younger than you and he can do it".
- Be careful when you caress your child. Do it only when they show they want it.
- Don't feel sorry for the,. People need support and affection, not exaggerated sympathy.
- Refrain yourself from treating your child like a baby. Behave according to their age. There's no need to raise your voice at them, either.
- Try not to say "You're a big boy". Children will do as much as they can. If you put pressure on them, the child will get a negative attitude towards himself.
- Not all children are raised the same. Don't expect other people to use the same methods to raise their children as you do with your own.

- Do not threaten them. Saying to them “If you don’t behave, mummy will have to leave” could work for now, but this will have important psychological consequences in the future.
- Don’t get grumpy! Preserve a positive attitude at all times. Humor is very useful in maintaining a good relationship with children and teenagers.

I.5. Metaphorical approach of the disease

When you don’t know how to encourage your child, what words to use to help him overcome the difficult moments of the disease (physical, medical, psychological or social), then remember you can use metaphors and stories. Using metaphors is a useful way of inferring new meanings that will ultimately change your child’s attitude and behavior. Here is one such story:

The Much Desired Tree

“Once upon a time, in a very far far away village called Hibiscus, there was a very special tradition, which said that when someone wanted to plant a tree, they should start with the planting of the seed. Two young people, who were in love with each other, decided to plant a little tree in front of their house. They prepared the ground with care and love and on the set day they went to the eldest and wisest in the village and he gave them the precious token of their love... the seed.

The couple looked after their seed and watered it as many times as it needed.

But as it was striving to push through the ground, the little tree met an obstacle... It was trapped under a big rock and couldn’t break out. Very worried, the two young people called an expert in trees and he dig in and pushed the rock away and helped the

little tree come out. Before he left, he told the couple that from then onwards, the tree would need more attention and love.

Time was passing by and the tree was getting bigger, but it had more problems than other trees his age. Several experts examined him, but they didn't know what to do. And since the tree wasn't growing straight, they tried to help him with some props, but none of them worked.

Soon our friends saw that one of their neighbors had a similar tree, but this tree looked happy. They decided to go talk to their neighbors and find the 'recipe' for happiness.

Their neighbors told them that they worried and made a lot of efforts for their tree in the beginning... And only a little later they decided to let the tree grow by itself, but without abandoning him. They continued to look after him, and permitted the tree to look after himself.

Our friends decided to do the same thing and sure enough their tree started blossoming and growing, too.

Two years later they organized a contest where several trees from the Hibiscus village participated and our friend's tree won the award for the best leaves. His parents were very proud..."²

I.6. [The importance of positive thinking](#)

Perhaps when you started reading this brochure you already had your mind set on talking to your child openly. Or perhaps in your heart you felt you weren't ready for this kind of a discussion. You should be aware that there are many parents out there, who live with this burden and who feel too weak to take this *step* and wonder what will happen to their child when he hears the truth.

² Dufour, M., *Allegorie pour guerir et grandir*, Nanterre, LES EDITIONS DE L'HOMME, Paris, 1997

Fear and concern only make you lose your objectivity. Your worrying will not make the future better but it will make today worse. Your fear consumes a lot of your energy and will lead you nowhere.

Positive thinking is an attitude that allows us to discover solutions or the good side in all our problems. It does not necessarily mean optimism, but it refers more to constructivism, of the type: *“let’s see what we can do in this situation”*. This attitude starts from *“let’s see how we can solve it”* and not from *“no matter what I do, I can’t find any solutions so I’d better give up”*³.

All people have problems, life itself is a problem! But we all carry our own crosses in life. Your child’s problems are indeed very serious, but why spend all your time thinking negatively? Can’t you see the happy moments you miss out on by focusing entirely on the difficulties?

If we ask people what they want, they will often say *they want what they don’t have* and *they don’t want what they already have*, thus ignoring the good things in life, and paying attention only to the bad ones.

Each of us has at least once seen the “empty half of the glass”. Negative thinking comes from a vulnerable state of mind, usually caused by an unhappy event. And it’s normal! But up to a point. It stops being normal when our problems persist a long period of time and affect our whole bio-psychic equilibrium.

Someone who thinks positively will always make an effort to prevent problems or to transform them and he will

³ Holdevici, I., *Positive Thinking*, Ed. Stiinta si Tehnic_, Bucuresti, 1999

more likely be able to face stress and illness easier, he will make difficult decisions and he will carry them out.

Scientists even think that optimism is a “magic trait” in maintaining health and well-being, positive emotions and recovery. Here are the results of a study made by two American scientists about cancer patients. They discovered that the patients with a higher degree of optimism had a faster and steadier recovery after the operation and also had a higher survival rate.

Optimism won't help you do absolutely anything you want. But it will help you do it better than when you think negatively. Positive thinking will make you become more efficient in using your abilities.

The moment you found out about your child's diagnosis everything around you crumbled down, you felt guilty and helpless. But if you persist in this crisis, and exaggerate all negative aspects, if you have the tendency to look for and discover the negative, then sooner or later you are bound to enter a permanent stage of pessimism and helplessness. And the first thing you need to do to prevent this is to identify the unrealistic traits of your negative thoughts and start examining the evidence.

How can you stop thinking negatively once you realized you're doing it?

- Ask someone close to draw your attention every time you speak out loud these negative thoughts;
- When you speak them out, just say to yourself: “stop!”;
- Replace negative thoughts with realist, knowledgeable information;

- Trust your ability to change.

There is a psychological theory that says that the way you think will ultimately affect your life, meaning that there is a tendency that the thoughts we have will evoke behaviors that will lead to their confirmation.¹ In other words, when you really convince yourself of something, then there is a very strong chance that that something will happen.

If, for instance, you think that because of the nature of his disease, your child has the “right” to feel helpless, then you will have the tendency to behave around him as if he were helpless. As an answer to your attitude, the child will indeed become helpless and will need a lot of protection from you.

This theory can change your way of thinking!

For this theory to become a starting point for your new positive attitude, you must keep in mind a few recommendations:

- Measure up your true force and your chance of success;
- Don't accept sadness as a constant in your life, because it might become just that;
- Look for people whose presence you enjoy;
- Impose things on yourself, be decisive and perseverant;
- Make good use of our Christian values: faith, hope, love;
- Don't be overwhelmed, better try to find a way out of it;

¹ Dafinoiu, I., Suggestion and Hipnosis, Ed. Stiinta si Tehnica, Bucuresti, 1996

- Give yourself some time.

If you think change is possible, then you do have the resources to change. Moreover, we can even say that in your case “*change is not just possible, it is inevitable*”¹.

It is vital to raise your child in an optimistic environment. So put your worries away, like an old coat, and *think positively!* Your child will sense your change and will become more open. Use this to strengthen your relationship with him.

Thus, the discussion you will have with him will not be as hard a task. When we asked you how you imagined such a talk with your child, most of you described catastrophic scenarios, in which your children had terrible reactions which you couldn't face, and it all ended in tragedy. These images will create a self-defense barrier that will stop you from moving on. And the more you think about them, the stronger and more horrifying they become and in the end they will start to paralyze you at the mere thought of disclosing the truth.

The first step you need to take is to learn to use your imagination positively. It won't be easy but still, let's remember that as long as it is all in your imagination, nothing bad can come out of it.

Start by modifying that terrible scenario we were talking about. Every time you run it in your head, try to modify one of the elements and change it in something good. Imagine for instance how you find your words easier. That can happen only when you start believing that you are doing a good thing. Visualize all the positive effects of

¹ Erickson, H. M., L'hipnose thérapeutique, Paris, E.S.F., 1990

your discussion, such as: a stronger bond between family members, the burden of the secret will turn into a reciprocal support, all the power you invested in hiding the truth will be put into the fight against the illness, and this time you won't have to do alone.

Your child will understand the necessity of taking the treatment, of caring for his health and alimentation. For the first time you will see that he can look after himself, and you won't have to worry as much when he goes out playing. From now on you will confide in each other and support one another.

This will happen only when you start *thinking positively*. A lot of parents have been in your shoes. It is their experience that we use in sharing this with you, they have accepted the big challenge: *honesty*, and they came out as winners ...

IV. LIFE GOES ON...

**MOTTO: "Open you hearts.
Communication is the key"**

"Although God has put us to a big test when Cornelia fell sick, we did not fall as victims of this hardship.

With her we learned how to fight it and we understood that sick people are not as helpless as we thought.

This illness is not an obstacle in our desire to have friends and to make ourselves loved by others; it does not keep us apart but it gets us closer and it makes it easier to understand suffering and pain.

God loves more those who try harder; so let's not fear it, let's not let ourselves be defeated!

Faith in God and in his power to cure the disease, the treatment and the support from those around us give us the strength to move on and to smile when we're sad.

We are not ashamed of anyone, we're not hiding away and that is why Cornelia wanted to let the whole world know about the energy she is fighting her sickness and thus inspire more to be strong just like her. She's never been discouraged, she hasn't lost her faith, she keeps going to church, taking her treatment, writing poems, and painting. She is one of us, despite her disease.

When our bodies are sick, let's not sicken our souls and let's keep the faith alive. We can help ourselves and make it better.

We hope our story and Cornelia's example will help you regain your strength and confidence in overcoming all hardships."

We shouldn't let the disease rule our lives, so let's live it as we want!

These lines were written by Elena Anton, mother of Cornelia Mariuta, an HIV positive girl whose parents already told her about her diagnosis.

Here are 2 of Cornelia's poems:

Because you love me

I live because you love me.
Without this love I would die,
I would have died.
The love you have for me, and I for you,
Scared away
The death that, so often, tried to take me away.
I love you so much,
And I can't
Say good bye and walk away
Far away from you, mother and sisters,
Away from the home of my birth,
Away from the place where I used to play, and laugh, and
cry
Away from where I grew up.
I know that in the sky, among angels and saints
Life has no pain and suffering,
Heaven is filled with songs and flowers
While earth is full of thorns and sorrow
Most of the times, too many times.
In spite of all, dear God, I can't,
Part so easily
With my birth place, my dearest place,
Every one who has been and still is
So dear to me here on earth.
I would like to tell You, God, what I believe
And think
And please forgive me if I'm wrong.
I believe, dear God, that, even in heaven, beside You,
I might die once again
Missing and loving them.

I won't let the joy to die

Suffering I learned to love,
Every moment of my life,
Every evening, every morning
I learned to enjoy
Everything that surrounds me,
And I won't let my joy to die,
Not ever!

I learned to endure and to hope that

God will relieve me of sufferance
One day,
Here on earth or up in heaven.
And the hope,
I will never let it stop.

I learned to fight even without wining
And I learned to hope my victory would come one day.

The next poem belongs to Ioan Alin Dragomir, another HIV positive child, who knows his diagnosis.

When I found out

When I found out I was ill
I spent all day crying
And I wondered
Where did I get
Such a terrible curse.

And when I'm thinking
At the disease I'm suffering from
I pray that You, oh, Lord
Help me feel better again.

Until then, I pray that You
Make me forget of me
Let me forget I am ill
And let me be like others.