What if my child has an eating disorder?

Guide for parents by parents

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Every parent wants the best for their child. Eating disorders are not a part of that. Unfortunately, helping a child with eating problems is not as easy as it looks.

In order to give parents a hand, we wrote this guide. We hope it can provide you with some insights into how to support your child, often with little things, during their recovery. Recovering from an eating disorder means learning to love yourself. Learning to realize that you are fine just the way you are. Learning to say ‘I matter’. Taking your own space. Developing positive beliefs about your appearance and about who you are. This does not come to a child at once. What a child will need is the love, support and understanding from their family.

We are convinced that nobody should have an eating disorder. And that children who do have an eating disorder deserve suitable help as quickly as possible. The concerns of parents about a child’s weight is understandable. A child needs, besides the acknowledgement that they have a fear of eating, a lot of support and a space to develop themselves. This is not easy and your child will need you for this.

This guide came into existence due to parents who dared to go to parent evenings. They deemed it necessary that you, as a parent of a child with a suspected eating disorder, know a few things.

We wish you luck with applying the tips that speak to you. It is our wish that your child will soon be healthy and happy again.

The initiators
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The Travel guide

Recovering from an eating disorder can be a challenging journey. Parents who speak from experience would rather describe it as a survival trip, because that represents more accurately how they perceived the journey. If you are literally going on a survival trip, what is the first thing you do? You make sure you are well prepared. What do you bring with you and what not? At what pace do you go? And do you take some time to rest? Do you ask for advice from others on how they experienced the journey? What do you do along the way? Are you alert? Do you look around? Do you listen? Do you think about things?

There is not one clear road to recovery that we can lay out for you. There is not one counsellor who can help all the children. What you will read in this guide are suggestions that, based on experience, have shown that they work. Maybe they will work for you and your child as well. Questions that you may encounter along the way are:

- Does my child actually have an eating disorder?
- How severe is my child’s eating disorder?
- What should I do? And what can I do?
- What kind of help will suit my family best?
- Where can I find the right help?
- How do I maintain the bond with my child?
- How do I survive this myself? What is the best way to deal with it?
- How should I act towards my other children?
- Am I handling this correctly?
- When can I get help from whom?
- How can I contribute to a speedy recovery?

In this travel guide we share our answers to these and many more questions. You can read and use parts of the guide randomly. The travel guide is supported by information on the website www.buropuur.nl.

It is smart to already pay attention to aftercare now. We can not overstate the importance of having enough pillars for the child after treatment ends. Will you make sure to pay attention to this once the time has come?

One ‘golden tip’? Really listen to your child. He or she, in your specific family situation, is asking for specific help where the child wants to feel noticed and heard!
“It is already so nice that I don’t have to explain anything to all of you, the experience experts.”
How do I find out whether my child actually has an eating disorder? And if they do, what kind of eating disorder?

In order to help you recognize an eating disorder, we have created a list with characteristics that could be relevant to your child.

My child...

1. has an immense fear of gaining weight    yes/no 
2. is extremely unhappy with their appearance   yes/no 
3. thinks they are only ok when they are thin   yes/no 
4. feels very insecure    yes/no 
5. does not think they are good enough    yes/no 
6. is perfectionistic    yes/no 
7. has very little self confidence    yes/no 
8. is extremely underweight/overweight    yes/no 
9. has lost/gained a lot of weight in a short time period  yes/no 
10. has noticeable fluctuations in their weight    yes/no 
11. is frequently dieting    yes/no 
12. skips meals    yes/no 
13. lies, especially about food    yes/no 
14. vomits and/or uses laxatives    yes/no 
15. exercises excessively    yes/no 
16. has menstrual irregularities or a loss of menstruation    yes/no 
17. is uncomfortable eating around other people    yes/no 
18. has a need of control    yes/no 
19. has rituals during food consumption    yes/no 
20. feels bullied    yes/no 
21. does not talk about their thoughts and feelings    yes/no 
22. is constantly preoccupied with food and weight    yes/no 
23. visits pro-ana websites regularly    yes/no 

You should seek help if your child displays several of these characteristics. The earlier a child with an eating disorder receives help, the better their chances at recovery are. If you are in doubt, then you can refer to the warning sign card of Buro PUUR, have a conversation with a doctor or other specialist, or take one of the tests at www.buropuur.nl.
It is the doctor who can officially determine whether your child has an eating disorder. Our advice when you suspect an eating disorder is to make an appointment with your general practitioner (GP). For young children it is important that a pediatrician is involved quickly. For more information and useful tips for your appointment at the GP we refer you to part 5 in this guide. Additionally, in this guide you will also read about what you can do to support your child.

If the GP establishes that your child does not have an eating disorder, but can be characterised as perfectionistic, over accommodating, introvert, competitive and/or impulsive, then you can still do something. These types of children are very susceptible to eating disorders. Teach your child to take care of themselves better through their personal strengths and to find a balance between giving and taking.

As a parent you can encourage the development of self confidence. A confident child can handle events, thoughts, feelings and personal behaviour better. You can ask your GP to assist you on this as well.

Stimulate the development of self confidence and a positive self-image. A good self esteem is a healthy base for your child’s future. Self esteem can be developed. There are books and courses that you could use and a therapist can also guide you.

Definitions of eating disorders
Buro PUUR defines an eating disorder as ‘an unpractical way of dealing with feelings and thoughts’. This is the case for every kind of addiction. Stress that is being relieved in an unhealthy way or trapped and unexpressed emotions can cause people to “choose” for the addictive solace.

An eating disorder is worldwide regarded as a psychological disorder. Out of all psychological disorders, anorexia is the one with the highest mortality rate. Every year, 5% of anorexia patients and 2% of bulimia patients pass away. Suicide is the cause of death in 1 out of 5 times for both disorders. Approximately half of the eating disorder patients will recover completely.

Definitions of the several eating disorders are listed in the Diagnostic and Statistical Manual of Mental Disorders, abbreviated to DSM. The DSM-5 is the most recent version and was published in 2013.

The DSM-5 includes the following eating disorders:

1. Anorexia nervosa
2. Bulimia nervosa
3. Binge eating disorder
4. Specified feeding or eating disorder
5. Non-specified feeding or eating disorder

Anorexia nervosa is the most well known eating disorder. Nevertheless, binge eating disorder is as prevalent as anorexia, and bulimia nervosa is just as dangerous as anorexia. A child with bulimia nervosa usually has a normal weight and can suffer in silence for years. All named eating disorders can also occur in men. For them it can be even harder to ask for help, because they may feel ashamed for carrying a ‘women’s disease’.
Anorexia nervosa
Anorexia nervosa is an eating disorder characterized by having a significantly low weight, because the energy uptake is lower than the energy expenditure. Someone can feel hungry, but does not allow themselves to eat and suppresses the hunger feeling. No matter how much weight they have lost, a huge fear of gaining weight remains. This leads, for instance, to over exercising, despite being underweight. In addition, a disturbed body image is present. An extinction can be made between the restrictive type (does not binge on food) and a purging type (has regular binges and/or compensating methods such as vomiting or laxatives).

Bulimia nervosa
Bulimia nervosa is an eating disorder characterized by having regular food binges and compensations through, for example, vomiting, fasting, laxatives, diet pills, medicine and/or excessive exercise. During a binge, it is impossible for someone to stop eating. The binges and compensating behaviour are regarded as bulimia nervosa when they occur at least once a week in a time period of three months. The self esteem of someone suffering with bulimia nervosa is overly connected to their weight and shape.

Binge Eating Disorder
The binge eating disorder is characterized by episodes of binge eating where one cannot stop eating. To be diagnosed with binge eating disorder, binging has to occur at least once a week over the course of three months. Marked distress is present and no compensating behaviour is executed. Moreover, the binge eating episodes are associated with three or more of the following characteristics: eating faster than normal; eating until feeling uncomfortably full; eating a large amount of food without feeling hungry; eating alone, out of shame for the consumed quantity; feeling depressed, disgusted or guilty.

Specified and non specified feeding and eating disorders
This category covers a few feeding and eating disorders that can not be placed under any of the other categories.

Orthorexia nervosa
Although this eating disorder is not diagnosed officially, it seems to occur with increasing frequency. Someone with orthorexia has an extraordinarily big fear of unhealthy food and becomes very strict for oneself. This means they have an obsession with healthy eating.

Anorexia athletica
These disorder is also not recognized in the DSM-5. People with anorexia athletica exercise intensively and eat too little, which will cause weight loss. Doing sports becomes an obsession and thus compulsive behaviour.

Muscle dysmorphia
Muscle dysmorphia is an obsession that is focussed on gaining muscles. Someone suffering with muscle dysmorphia has a fear of being insufficiently muscular. This person can become addicted to gaining muscles which, in turn, is accompanied by an unhealthy eating pattern.
“It is not what happens to you that counts, it’s how you respond to it!”
You want to help your child with their battle against an eating disorder. What can you do to make this journey as ‘comfortable as possible’?

**Emptying my backpack**
What do I (as a parent) carry with me that would make my child’s road to recovery easier? What can I throw away from my imaginary backpack that will slow us down? Some examples we would like to give you are: denial, anger, blaming, forcing or promising miracles. All of these will slow down the journey. Jump to acknowledgement immediately and focus on helping your child. Becoming angry with your child is useless.

*Denial*
Sometimes it seems easier to not face the fact that your child has an eating disorder. The temptation is big, because there are so many reasons to deny it. Your denial during the starting phase can slow down your child’s recovery. You know that they are suffering from an eating disorder, but you cannot or do not want to face this yet.

*Being afraid of rumors*
What will others think when they hear that our child has an eating disorder? Did we treat her badly? Everybody will say that it was the parents’ fault or ignore us.

Quotation from a mother: “Out of everyone, it was a medically trained colleague who judged quickly: “Oh, the problem is probably in the upbringing”, as a parent you are just completely humiliated when that happens. Luckily, I am smarter than that and I realize that such a condescending comment should not influence me. It says more about the person who made the comment than about me as a mother.”

*Thinking it will resolve by itself*
What if I do not do anything? Maybe my child will start eating normal again? The chances that these problems will just blow over are quite small.

*The question: why our child?*
If you focus too long on the question ‘why?’ you will not be able to move forward. And maybe you will discover some reasons along the way.
The question: is it my fault?
Spending a lot of time on this question is useless. Let us reassure you: there is still little to no scientific evidence to point out the exact cause of an eating disorder.

Quotation from a mother: “As a mother of a prototype anorexic daughter, you blame yourself for everything. What did I do wrong? But you know, after you give birth, nobody gives you a book with rules and laws about raising a child. Yes, I am divorced and I thought I did everything correct. I probably made some mistakes, but why does one of my daughters have anorexia and not the other one? It makes no sense to blame yourself. It doesn’t benefit anybody. It is only draining energy which you need to help your daughter.”

Becoming angry
Of course you have the right to be very angry. You have the right to all your emotions. However, we do want to point out the following. There is a difference between being angry as a result of love and being angry as a result of blaming. Your child is allowed to feel and know that you feel powerless. Turn it into something you can talk about. If you show your child that you are not perfect either, it gives you space to build a bond.
One important tip: explain to your child that you love them, but disapprove of their behaviour. In our communication ‘Who is someone?’ and ‘How does someone behave?’ are usually used interchangeably and this can be very harmful. We say: ‘He is a disaster’, when we actually mean ‘I love him, but he is behaving disastrous’. When someone is talked down too often, they can feel like they have no right to exist.

Threatening
Chances are that threats will only push your child away from you. Is it not better if your child learns to take responsibility? Besides, setting limits is something else than threatening.

Promising miracles
There is no helicopter available that will fly you straight to your goal. So you cannot promise your child that recovery will be easy and that you will just give them a hand with this.

Treating with pity
If you treat someone with pity, then you judge someone. Everyone can change, including your child. Your child’s recovery will be harder if you do not believe in them.

Fear: What if my child cannot recover?
Many people have recovered from an eating disorder. It is important to know that someone can truly heal from an eating disorder.

Quotation from a recovered experience expert: “Recovering from an eating disorder is a long road filled with obstacles. Sometimes you fall and it seems like you are back at the start, but along the way you will start to notice that the obstacles are getting smaller and the distances between them bigger. The acceptance of a setback is very important.”

Comments that hurt
Something you definitely do not need on your journey are the well known comments that people often ‘blurt out’ without realizing how much pain they can cause.
Comments that can harm your child:

“But you are not even fat!”
“Do you wear such oversized clothes to hide your body?
“Just make sure you gain ten kilos first.”
“You look fine, you shouldn’t worry so much about it.”
“So how much do you weigh now?”
“It is not so bad, because you face is still chubby enough.”
“I can’t even see that you are not doing well, you are always so happy.”
“Wow, you have become slim.”
“Oh, you have gained weight, didn’t you?”
“How much weight did you lose?”
“You are eating again, so you don’t have an eating disorder anymore. Stop complaining.”

Quotation from an experience expert: “When they gave me compliments, because I lost so much weight, I thought: I found it. I am get appreciated for this and this is what I’m good at. So that was a huge stimulus for me to keep going with the not-eating.”

Filling up my backpack
Besides emptying your backpack, we also want to give you some advice to simplify your journey. Bring a compass, magnifier, warm blanket and camera with you.

**Compass**
There are many different ways to reach your final destination, your child’s recovery. And we, the writers of this guide, truly believe that this should be possible for everyone. Perhaps it will be possible for us to improve this guide in the coming years, leading even more people to the final destination. We hope you will have a successful journey and that this guide may be your compass.

Many parents’ compass is their primal instinct. It is often called the ‘maternal instincts’ for mothers. This primal instinct usually ‘knows’ what is right. Listen to it. You got it for a reason.

Quotation from a mother: “My daughter was in treatment for 7 months. Her weight was slowly going up, but psychologically she was going down. At some point she started to cut herself (self mutilation). I asked her counsellors if it was possible to look into different directions, but I was met with resistance. They had experience so this was the way it had to be. My mother’s heart was telling me otherwise. I looked for different treatment options and I’m glad I did. She doesn’t cut herself anymore and she is doing a lot better mentally. Step by step we are getting closer to recovery.”

**Give your child some space**
There is only one person who can choose to recover: your child. The recovery process is your child’s work. What you can do is help your child in the best possible way. Your support is invaluable.
Quotation from a mother: “My child hit the point that she ‘wants’ to eat again, but she really can’t afford it to lose more weight. It is difficult to give her the space to take her own steps towards eating...”

Quotation from a mother: “My daughter was very offended by someone who estimated her 5 years younger than her actual age. He thought she was her friend’s younger sister, while they are actually the same age. That conversation had a really big impact on my daughter. She is done with her eating disorder and wants nothing to do with it. She started eating again and says she doesn’t need any help anymore.”

The magnifier
The magnifier provides the opportunity to look closely at your own doings along the way. You may also be able to look at your child from a different perspective. Sometimes it is important to concentrate on a few matters a bit longer so you can change your actions.

Take a closer look at your listening skills!
Take a closer look to determine whether you are capable of actually listening. This means that you are listening in a way that your child feels heard. Despite what you may think, this is often not the case. Ask yourself: when do you really feel heard?
Most children feel helped by their parents if they feel like their parents really want to listen to them. And that is more important than having parents who provide solutions immediately. Really listening entails:
• make clear you heard what your daughter/son said
• be capable of summarizing your child’s story
• have compassion for what your child feels or thinks
• share what your own thoughts and feelings are and that they can sometimes be different than those of your child.

Good luck with really listening!

Quotation from a mother: “Listen to your child, don’t look for answers, just listen! You will create a safe space for your child which is incredibly important. If your child does something you don’t understand, then ask them about it, because trust me, they have a good reason for it! For instance, my daughter never wanted to go to the hairdresser. It took me an entire year before I asked her: “What are you afraid of?” It turned out that last time she had a haircut, she was bullied it school about her new hairstyle.”

Take a closer look at your own child!
How well do you know your child? Do you know what really interests him or her? Do you know how their thoughts and feelings work? What is your child’s fears are? What your child likes about you? What your child is looking for? What their friend’s interests are? How it is really going at school? Has anybody else expressed concerns about your child?

Blanket
A blanket of love. A warm blanket. That is generally what brings children happiness. That blanket will provide children with warmth, safety and trust, so they can take small steps to the ‘big, bad outside world’. Children with eating disorders have often chosen the eating disorder as a sort of ‘protection’ to deal with the outside world.
Ask for help
Try to create a list with (household) things that you could ask others to do for you. Who could help you and with what? Get over your possible embarrassment. Taking good care of yourself involves asking for help when you need it. This will also set a good example for your child with an eating disorder. It is not always easy to ask for help. Do it!

Support group for parents
If you often feel the need to talk, sharing experiences and finding support in people with a similar situation, then join a support group for parents. You can find more information about this at www.buropuur.nl.

I am here for you
Tell your child that you also do not know what the journey will exactly be like. But that you are prepared to conquer this road with them even when it seems impossible. Your child will feel immensely supported by you. They are not alone!

Quotation from a mother: “The first setback is a fact. Yesterday, she went over the edge again. The trigger was that she wasn’t capable of creating Christmas stockings. I really wanted to throw those stockings away at some point! But well, they had to be finished for her two best friends that she was meeting up with last night. She had a Sinterklaas party with her friends. She was really excited about it. Then stress hit her and she didn’t want to go anymore. Eventually she came around and actually had fun. However, she came back with a headache, probably due to all the commotion there. Going to bed was a dramatic... She didn’t ever want to eat again, felt miserable, etc... She cried first at first and only calmed down after I laid next to hear for a while.”

Be patient with yourself
If you can show patience in this difficult period, then you will be a huge help to your child. We often notice that it cannot go fast enough for parents. Sometimes the parents are even ahead of their children. The speed of recovery is decided by your child’s pace. And this means for you as a parent: be patient.

Teach your child to be patient
Sometimes the recovery goes too slow for your child. Your child can be tired of the continuous ‘fighting’. You can help your child by explaining that one learns through trial and error. There are therapists who assume that a ‘relapse’ is part of the recovery. Accepting this ‘relapse’ will create more peace and patience.
Quotation from an experience expert: “It’s not what happens to you that counts, it’s how you respond to it!”

Quotation from a father: “This horrible disease has been here a few years already. It seems like we finally got to a turning point. Having patience is definitely useful.”

*Be involved*

For example, how well do you know your child’s friends? Show that you care about them, because they are your child’s friends.

*Ask regularly how your child is doing*

Once your child gets treatment, the G-scheme is usually used. It is useful if you, as a parent, also know what that means. Let your child explain it to you if the chance arises. For now we would like to explain to you that the G-scheme is built up from the following steps:

1. Event: something happens in your child’s environment.
2. Thoughts: your child has certain thoughts connected to this.
3. Feeling: These thoughts are accompanied with a certain feeling.
4. Behaviour: Based on this feeling your child will choose a certain behaviour.
5. Consequence: This behaviour has certain consequences.

Example from an experience expert: “I remember very well that a friend of mine told me that a boy from our class liked me. He only thought that I was a bit fat.” (event) “I knew that I was fat.” (thoughts) “But it did hurt me a lot.” (feeling) “I didn’t eat anything that day (behaviour), however that was not the solution. Dieting didn’t work. I even started vomiting to lose weight.” (consequence)

Your child learn which thoughts and feelings they have during certain events. In the former example a therapist can go through the G-scheme step by step. For example, by discussing with the child ‘I am fat, is that actually true?’. It can also be discussed how realistic their feelings after certain comments are. A child can learn to choose to handle situations better.

The fears, sadness, loneliness, etc. often explains why your child displays certain behaviour during certain events. You will be a great support for your child if you learn to respect your their thoughts and feelings.

Of course you need to really listen to what your child says!
Your child will know exactly when you are pretending to understand them compared to when you really understand. So do not lie, but be honest.

Tell your child that you cannot imagine how it is for them, but that you would like to learn how it works. Although you may never completely understand, you still want to do be there for your child in the best possible way. It can help if you, for instance, ask the therapist to explain the G-scheme to you.
Camera
Stop at special moments. Take pictures and give yourself space to enjoy some moments during this bizarre journey. This may sound strange, but it broadens your horizon. It will teach you some things about yourself and about your child.

Be a good example
This means that you will also have to take time for yourself. Do not shove everything aside for someone else. Think about the safety measures in the airplane. Whose oxygen mask do you put on first? Your child’s or your own? You know that if you are falling apart as a parent, you cannot be there for your child. So this means that during this, already energy consuming, time, you have to say ‘no’ more often to things that you cannot handle right now.

Indicate your limits
It is good to let your child know what you can and what you cannot do. Sometimes your powerlessness may make your feel desperate. Or are you trying to spare your child too much? Your child is allowed to know that you sometimes do not know the answer either. Your child is allowed to know what it does to you when the eating disorder is ‘harassing’ your child. The principle is: watch your wording, because a child should not be burdened by their parent’s problems.

Set boundaries and be consequent
One of the hardest tasks, but a very important one: set boundaries and stick to them. Teenagers have a need for boundaries. For example, if your child is asking you repeatedly if they are too fat, then tell them lovingly, yet clearly, that you are not ‘playing this game with them’ when it has already been discussed before.

Quotation from a father: “My heart and my mind were fighting each other frequently. They were often not agreeing with each other. However, if I learned one thing during all of this, it is that children need predictability in order to survive.”
“If she gets an 8, she will ask the teacher if she can redo the work, because she could easily have a 9.”
Loneliness and fear
Imagine that it is extremely cold. Then you notice that you are crouched on a stone floor with bare feet. You are wearing very little clothes. It is pitch black. You see a bright light through an open door in the distance. You stay where you are, because that is familiar. You do not dare to go towards the light, where it may be warm. You actually know that it will be warm. But you do not dare to. You are afraid. Extremely afraid. If anyone would ask you of what, you would not be able to tell them immediately. You would rather stay trapped in the cold in the darkness.

When children are asked to describe how they experience an eating disorder, they often illustrate a ‘prison’ or something similar. It is often accompanied with loads of fear, insecurity and sadness.

It is a big task in your life as a parent and aid worker to get contact with the person in the darkness. Supporting from outside the prison, from the light, takes a lot of empathy. Sometimes it may even result in sitting next to your child, crouched with bare feet on the cold floor in the darkness. Just to be there for a moment, closely, to make them feel that you are there, like the mother in the following quotation.

Quotation from a mother: “She laid down crying on the kitchen floor, because she refused to eat anything. I didn’t know why, but I decided to lay next to her on the floor and hold her. She must have been so afraid.”

Perfectionism
Wanting to do things too well and not allowing yourself to make any mistakes can become a very big thing in a child’s life. Perfectionism is one of the typical character traits of many teenagers with eating disorders. As a parent you can learn to handle this and assist your child when they make mistakes. A healthy portion of perfectionism can be used in positive ways.

Quotation from a child with an eating disorder: “I am only talking to you, because my mother wants this. She is already having such a hard time.”

Part 3
Your child
Your child is not the eating disorder

Disapprove of the eating disorder, not of your child. Your child already wants to do everything as good as possible and will feel like they are failing again if you disapprove of them. Show your child how much you love them. It is very likely that your child is extremely disliking him- or herself. It is important that the child feels that you really think from the bottom of your heart that they are good enough just the way they are.

What is everyone’s main basic need? We want to be deemed good enough. Sometimes children will do everything just to be considered as good enough by their parents.

Quotation from a mother: “When the scale was showing a lower number again, I couldn’t always hide my frustration and anger. Why couldn’t she ‘just’ do her best to gain some weight which is the road to recovery? Sometimes I felt like I wanted to shake her. “Don’t you understand how you are destroying yourself?” Nails are breaking off, hair is growing on your back, your growth is stagnating, etc. “No mom, I am doing fine, my grades at school are fine and I can still do everything. Why are you worrying so much?” And as a mother you have to stay calm and think like her, but sometimes that just doesn’t work and then I explode. Doors are being slammed, I scream that I find it stupid!! Luckily I immediately follow with: “I think the anorexia is stupid, not you!”

Where does my child stand with regard to help?

There are three factors that play an important role here.
1) Does your child acknowledge that they have an eating disorder?
2) Does your child want to recover from their eating disorder?
3) Does your child want help with their recovery?

Does your child acknowledge that they have an eating disorder?

There is often a period of dieting before an eating disorder. The child has set a goal and that is usually connected to losing weight. Reaching that goal can seem like the only way to happiness for the child. They can choose to name their behaviour as ‘dieting’ and deny the existence of an eating disorder.

It seems like the more you want your child to eat, the more they become dedicated to losing weight. Breakfast is skipped and arguments about eating often arise in the household. Especially then, it is important to call in a professional aid worker. They can often use a different angle to make the consequences clear to the child.

Quotation from a mother: “Yesterday, I took her scale away and she got very angry. She is refusing breakfast as of this morning. I can’t get her to eat anything at all.”

Does your child want to recover?

At the moment that your child has an eating disorder and also acknowledges it, the next question will arise: Is your child motivated to recover? We are convinced that deep down every child longs for love and happiness. And that somewhere inside every child lies a motivation to recover. We consider the unwillingness to recover as a fear to let go of the eating disorder.

Sometimes a child needs a ‘pat on the head’ and sometimes ‘a kick in the pants’. So it is not always easy to find to right therapist that can help your child to become motivated.
How can we find the right help together?
In part 5 and 6 we included a lot of information about help. It is desirable that the child is agreeing with their aid worker’s choices. It is important that there is a connection between the aid worker and the child. We would also like to bring the existence of websites where you and your child can share experiences with others to your attention. For more information you can look at www.buropuur.nl.

It is crucial that parents unite in the fight against an eating disorder. Once a child notices that one parent is fine with something while the other is not, then there is space for manipulation. Often times one of the parents will be excluded.

Quotation from a father: “I didn’t recognize the manipulation from the eating disorder at the beginning. I suggested to eat alone with my child, because my daughter would eat more when it was just me and her. I didn’t realize that I was excluding my wife with this proposal and gave the eating disorder even more space. It is very important the parents are on the same wavelength, sticking together and supporting each other.”

Extra danger for young children
How fast you search for help or treatment depends on the age of your child. The younger the child, the quicker you should reach out for help. Especially since a young child needs a lot of energy for growth. If your young child hardly eats anything for a few days when their weight is already low and they also move a lot, they can get worse quickly. Risks like passing out and being unable to communicate with your child are lurking.

Quotation from a mother of a 10 year old child: “Seeing your child fade away and hardly having any contact with your child is unbearable.”

Quotation from a father: “Despite the fact that I thought I lost the contact with my daughter, she didn’t want to have anything to do with me and was always angry at me, she responded very enthusiastic when I asked her if she wanted to go away for a weekend with me. It turned out to be a huge success. We became a lot closer and we are planning on doing it more often. At parent evenings I found out that dads are often pushed away by children with eating disorders. This reassured me somehow. I can handle it better now if she doesn’t want to engage with me at all.”

Quotation from an experience expert: “I remember being in the hospital and that I got a huge urge to exercise when I was gaining weight.”
People often think and say: “Stop whining, just eat!”
My family’s world turned upside down
An eating disorder influences the entire family. A lot of stress can arise. The siblings of the child with an eating disorder will be influenced by it. The pain and fear that they may feel can be unbearable. They can be afraid to lose their brother or sister.

It is important to notice this and find a way to spare your children as much as possible. These children often try not to bother their parents and will keep all their worries to themselves. How do you deal with all of this?

Make sure that you talk about it. If you cannot do this as a family, then try to find an expert or professional to help you. They can guide you with addressing it in your household and give you tips.

Quotation from an experience expert: “I asked her little brother: “How do you feel?” This brave boy didn’t start crying, although he could hardly hold it back. He said that there was a lot of stress in the house. That he often couldn’t sleep at night. He was also suffering with migraines. We started talking about his older sister with an eating disorder during our conversation. He didn’t want to discuss it with his parents in order to spare them.”

Exercise: When the brother or sister has a stomach- or headache, you can do the following exercise. Lay your child down on the bed. Put some relaxing music on, dim the lights and make them comfortable. Tell them the following: “Imagine that there is a little panel on the painful area in your body that you haven’t seen before. Open this panel and let the pain, stress, nasty thoughts and feelings flow out. Feel how great it is to let the warm sun rays go into your body. There is more than enough space. The energy is flowing. Close the panel and feel the warmth.” You can do this exercise together with your child, comfortably laying on the big bed. Your child can also do this on their own in the room before going to school or to bed.
I want to be there for the other children as well
My child keeps asking me for my attention, how do I deal with this? Of course, this is not easy. This is often making this period in your life difficult as well. Our experience shows: learn to set limits. Communicate about what is and what is not possible and explain why. Be sure to have time for your other children, not only to do fun stuff, but also to talk about everything. The therapist can often help you with this. It is not a surprise that many therapies involve the entire family during the recovery process.

Quotation from a mother: “Sometimes I get very angry when my child has a binge period. When she finishes all the food, there is none left for the other children. And she will lie about it.”

This is a situation where you can set limits. Make some rules about the binges. Explain to her that it is her responsibility to find a solution. For example, she can buy and refill the food with her own pocket money. You will have to judge what is possible for every situation.

Environment: What can you expect?
The environment often seems to have little sympathy. This stems from ignorance and a lack of knowledge and experience. Although an eating disorder is not about food, you will often hear “But your child can just eat, right?”. The lack of understanding is big. It is important that you do not become isolated due to this.

Sometimes you will hear comments that hurt, and sometimes you will be surprised by good friends who are doing everything they can to help you during this bizarre journey. Friends, colleagues and others who really want to support you, will often try to learn something about it. Refer them to informative websites or other good sources, so they will learn to have more empathy for you as a parent. After all, you can use all the support.

Quotation from a mother: “It is so nice that I don’t have to explain anything to you, experience experts. That I don’t have to answer questions like “But have you done this or that yet?” I know everyone means it well, but it is not what I need.”

Quotation from a father about this guide: “Piece by piece we try to put our life back together: have a little walk, and last Friday we went to a concert. It felt like it had been ages, we really needed it. This must surely be part of your guide, because it is so important. Sometimes you just lose yourself completely and nobody benefits from that. But oh, it can be so hard sometimes.”

Family members outside our household
Our society discusses physical looks and food a lot. This becomes very clear once you have a child with an eating disorder and you try to avoid these subjects. When you can get your environment to talk less about appearances then you are ‘lucky’. Try to give the information, but do not try to change your family members’ behaviour. However, you can tell them when something they said is painful.
Quotation from a mother: “Grandma can be very bland in her statements and she did it again the other day. Now she doesn’t dare to say anything at all. It is hard for her as well to realise what it really means to have an eating disorder. People often think and say: “Stop whining, just eat!””

Friends
In our opinion, real friends will ask you how they can help when your child has an eating disorder. The best thing you can do is being creative. When you do not know the answer immediately, then tell them: “Just be there for me”. This is often enough. We listed a few tips you can give to your friends. Be creative with these and see which ones could help you.

Call your friends in! Things they could do for you:
- Hug me and give me a space to let it all go, so I can be strong when I get home again and have be there for my family.
- Can you get me some groceries every week so I have to do less household tasks and have more time for my family?
- Will you help me make a list with things you and other friends could do for me?
- Listen in a way that I feel heard.
- Show empathy and don’t worry about solutions yet.
- Give me a warm hug.
- Just hold me for a moment.
- Give me some space so I can just be me for a moment.

School
Can the school also help? Yes, the school can actually do a lot. Of course, cooperation will be needed. Here are a few real life scenarios that will hopefully stimulate you to have a better understanding of each other and to communicate.

Example: The parents of a girl are angry at the school, because a teacher already knew about their daughter’s eating disorder. However, the teacher promised the daughter not to tell anyone. The daughter kept promising the teacher that she would tell her parents.

Example: Buro PUUR gave an informative lecture at a school. Classmates recognize the eating disorder of a friend and they immediately call in help. They notify the lecturer that their friend vomits daily. Her mother has recently told the worried GGD (Municipal Health Services) that her daughter is eating fine and that nothing is wrong. However, by reading the brochures that her daughter brought home, she recognizes the symptoms. Both the school and parents are huge contributors now, especially the classmates did very well.

Using schools for prevention
A school can help to trace children who have a (starting) eating disorder through, for instance, giving informative lectures about eating disorders. Classmates can identify symptoms of their friends. Students who have an eating disorder can be stimulated to ask for help. The school can teach their staff how to recognize eating disorders in early stages and how to handle this.
Using schools during the recovery
Schools have a care policy. This is executed by the advisory care team (zorgadvies team) which is abbreviated to ZAT. The care coordinator usually controls the ZAT. You can check a school’s website to see how they secured their care policy. This will also clarify whether the tutor, confidential counsellor or other school professional can support you during your child’s recovery.

Make an appointment with the contact person at school to discuss the best way to support your child. Keeping an eye on their food intake or not, will they be in PE or not, what homework is scheduled, etc. You can also decide whether it is important to inform the fellow classmates. It is not easy to give one general advice for this, because every situation surrounding a child with an eating disorder is different.

Make sure you talk to your child’s therapist before you make an appointment with the school. It has been shown that parents sometimes appreciate it when the therapist and school have direct contact and discuss the child’s recovery when it is necessary. Again: United we stand stronger.

Outpatient care
Too little use is made of, for example, ambulatory carers. If your child is absent from school for 25% or more, then it is possible to arrange an outpatient carer through your school at a regional expertise centre. There are several outpatient/ambulatory carers that have been trained to guide your child with an eating disorder in the best possible way.

The pressure is building at my work
It is logical that the stress that develops at home will be noticeable at your and your spouse’s work. Only you can estimate the support you will receive from your employer. We encourage you to share your situation with someone at work that will be sympathetic and understanding. This will be beneficial if the pressure becomes even higher and your performance at work may start to suffer.

Some parents consider quitting their job so they can be at home for their child. “What if my child gets a binge attack while I am gone.” or “What if she doesn’t eat anything when I am not there.” In the end, it is your decision, but do not let the eating disorder rule your entire life. Do not hand this ‘power’ to the eating disorder.
Training eating disorders

Responses from participants:
‘skilled teachers, good interaction with participants and very enthusiastic trainers.’
‘the answers that I needed were given. And so much more has become clear to me.’

Recognise an eating disorder and know what to do
“The doctor must be right’ is an attitude that many parents have. Even worse, many people are afraid of the doctor. So dear parents, be sure that you know what you want to ask.”
Part 5
The general practitioner

The first person to ask for help is your general practitioner (GP). The GP can refer you to a pediatrician or other specialist. Make sure that you are prepared for this conversation with your GP.

When do I go to the GP?
You make an appointment with your GP when you suspect that something is wrong with your child, like a possible eating disorder.

What can the GP do?
You can expect the following from your GP:

- Examining your child’s physical health (in his capacity as a GP). He can also decide to run a blood test. These results can give a lot of insight into your child’s health.
- Examining your child’s mental health (again in his capacity as a GP).
- Referring you to specialized help when needed.
- Informing you about the different options you have regarding specialized help.
- Supporting you during the treatment.

And ask your GP what else he/she can do for you. Together you stand a lot stronger.

When a child has an insufficient nutrient intake over a long period of time, they have a high risk of low potassium levels. Ask your GP to check for this through a blood test. Potassium is needed to live. Food that contains a lot of potassium are: vegetables, (dried) fruit, fruit juice, potatoes, pulses, tomatoes, milk products, coffee, cacao and nuts. Products that contain these items this like fries, chips and chocolate also hold a lot of potassium.1

Be aware: sometimes a GP cannot ‘see through’ the eating disorder. This happens when, for example, the child is trying to hide the eating disorder, or because the GP is not used to having patients with eating disorders.
Referral or no referral?
The GP sometimes does not want to give you a referral. There are several factors that can be at play:
• it is not clear enough for the GP that there is an eating disorder.
• your child is ‘avoiding’ the truth or is lying. This is often due to fear.
• your GP senses different problems.
• your GP is not informed enough.

Again: be well prepared for you appointment with the GP so he can receive as much information as possible. He will need this to make a correct decision.

Preparing for the appointment with your GP
What information will you bring to the appointment with your GP? You can find a list with questions down below. Preferably, you do not ask these to your child, you often know enough already. This is a list to help you support your suspicions.

1. Eating behaviour
   • How long have there been difficulties with food?
   • Has your child been on a diet before? How did that go?
   • Has your child made schemes for exercise and weight loss?
   • How big is their urge to lose weight, overeat and not eat?
   • Have you noticed lies about your child’s eating pattern?

2. Environment
   • Are there family members or friends who following extreme diets?
   • Has your child lately lost interest in doing fun stuff?

3. Your child
   • How does your child see his/herself?
   • Is your child confident or only when it is socially desirable?
   • Have there been any crucial moments in your child’s life?
     • Divorce of parents
     • Death of a family member
     • Anybody with a disease
     • (Sexual) abuse
     • Bullying
   • Do you recognize your child in the following?
     • Perfectionism
     • Introvert
     • Competitive
     • Fear of failure
     • Sensitive
   • Does your child struggle with sleep?
   • Is your child low on energy during the day?
   • Does your child take laxatives or diet pills?
   • Does your child have problems with their digestive tract
   • Does your child worry about something?
   • Is your child active on pro-ana2 websites?

Once again: you do not have to be able to answer everything. Please do not try to get all the answers from your child beforehand. Your GP can often already do a lot with the information that you are able to give him. Eventually you will be the one to decide whether you are satisfied with your GP’s final decision or whether you find it necessary to go further.
Quotation from a mother: “The doctor must be right’ is an attitude that many parents have. Even worse, many people are afraid of the doctor. So dear parents, be sure that you know what you want to ask. Be aware: there are still many GPs that are unable to recognize an eating disorder. And yes, this can also be due to the person with an eating disorder, because they are trying to hide their problems.”

Quotation from a mother: “For me as a mom it was clear. My child has an eating disorder. I searched the internet and made an appointment with a specialist. This specialist told me that a referral from the GP was necessary. Meanwhile, eating/not eating became a battle at the dinner table. My daughter refused food more and more often. To my great surprise, my GP advised us that we first had to solve the disagreement ourselves as mother and daughter. According to the GP my daughter didn’t have an eating disorder. It is already so hard and then the GP is even working against you! It was unbelievable, this was incredibly disencouraging. Luckily I found some other people for support and together we found a way to get to the specialist without a referral from my GP. He immediately understood how serious the matter was and proposed a treatment plan.”

Quotation from a mother: “My daughter often suffered from bowel issues, sore throats, weird ailments and was extremely afraid when she felt a ‘weird bunions’. Luckily my GP saw through this after a few visits with strange health complaints and he asked more questions. She turned out to have boulimia nervosa symptoms although her appearance didn’t show any signs.”

Questions for your GP

Bring a list with questions that you would like to have the answers to and decide whether you will ask them during the conversation or whether you will return another time without your child. Some possible questions that you may like to ask are listed here.

Our starting point: adult subjects are discussed by adults. You do not burden a child with the issues of adults. Consider which topics are suitable to ask with your child and without your child.

- How severe is the eating disorder?
- Can my child continue to play sports?
- Can my child bike to school?
- Are food supplements necessary?
- Is it important that I inform the school?
- What does the recovery process look like?
- When do I have to call the GP immediately?
- What can you tell me about the options regarding different specialists?
- What will happen next?
- What is the best way to deal with this as a parent?
- What should be my rules about food as long as my child isn’t in therapy yet?
- What can I expect from my child with regards to food?
- What are the potassium levels of my child? (low potassium levels are very dangerous)
Who can determine how severe the eating disorder is?
Either the GP, or the pediatrician can make an initial estimation of the severeness of the eating disorder. After which the pediatrician or specialist can decide, with help from the GP’s referral, whether treatment is necessary. The specialist can also decide what kind of therapy is needed.

Be aware: there are many forms of therapy. Make sure you are well informed. It can be useful to speak to more than one treatment provider before you choose the right therapy for your child. Part 6 will provide you with the needed information for this.

Quotation from a father: “The difficulty around the eating disorder is the battle about food. What’s even more difficult is that you can often not ‘reach’ your child. Your child builds a wall around them and it takes ages for them to answer your question. GIVE IT TIME. Your child sometimes has so many thoughts in her head and so many feelings in her body that it can be difficult to give an answer. It often helps if you learn to actually listen.”

School doctor
Your school can of course also send your child to the school doctor. The care coordinator works in the advisory care team at school. This team with specialists can, after the parents’ permission, discuss your child. Referral to the school doctor is one of the possible outcomes. As a parent, you can also contact one of the members of the care team to discuss your child. They often have a broad range of experience that can give you a lot of support.

Pediatric nurse as a link in the CJG
Since 2011, every municipality has a Child and Family Centre (Centrum voor Jeugd en Gezin – CJG in Dutch). This is a place for parents and children to meet each other and exchange experiences. The youth health care plays a central role in the CJG. The CJG is a place for both parents and children to ask for help. The pediatric nurse can immediately ask the pediatrician for advice. The pediatric nurse is not only available at the CJG, you can also reach out to this nurse through your school. Most schools will share the information about their pediatric nurse through their website and/or school guide.

Quotation from a dad: “It would be amazing if this guide for parents would be in every GP’s office. Research has shown that many GP’s are unable to recognize the symptoms and therefore sometimes even miss the diagnosis. Especially at the beginning a lot of valuable time is lost, with all the consequences that it entails.”
Do you want to bring this guide to the attention?
That is possible! For instance, make sure that there are flyers in the GP’s office. Or inform your school about the existence of this guide. We can also send you images that you can use as banners on websites.

For more information: send an email to info@buropuur.nl

What if my child has an eating disorder?

Read the free guide for parents on www.buropuur.nl
“The effect of the intervention depends on the inner state of the therapist.”
Hitting the road alone or together?
In many cases it is valuable to call in a specialized therapist. Some people can recover from an eating disorder through reading self help books or reading information on the internet. However, more help is needed in many cases.

The fastest and most effective way to recover is, in our opinion, to call in suitable help as soon as possible. We would like to give you the following information for this.

Help for just my child or also for me?
How do you, as a parent, deal with everything surrounding the eating disorder? How do you learn to understand what happens to your child during the therapy sessions? What is the best way to support your child?
Parents who reach out for help for themselves, often indicate that they are very grateful for this. It gives them a place to let off some steam, find support, get an understanding about their child, ask for advice and much more.

As a parent, you can find help in several ways. You can get into contact with fellow-sufferers through information evenings and learn from each other’s experiences. There are treatment options that involve family therapy/system therapy.

Information evenings for parents
Different organisations frequently organize information evenings for parents of children with an (developing) eating disorder. A calendar of gatherings throughout the entire country can be found on www.weet.info.

Finding the right kind of help
The different kind of therapists come in many ‘flavours’. The right therapist for your child depends on your and your child’s wishes and needs. It is important that the therapist suits your child’s recovery. The available budget will also play a roll. On www.buropuur.nl you will a database with therapists.

Transition youth care
The consequences from making municipalities responsible for the care of children under 18 years old are big. Look in the database ‘about eating disorder’ (over eetstoorhissen) at www.buropuur.nl for more information about this.
Further explanation on the phases
The phases that you will go through when you are looking for the right therapist for your child are:

Phase 1: Gathering information
Phase 2: Limiting the choices
Phase 3: Discussing the choices with your child and GP
Phase 4: Making appointments with therapist(s)
Phase 5: Deciding upon a therapist

Phase 1: Gathering information
You only want the best help for your child. Our advice is: make sure that you know what is available in the world of specialized therapies (see the search engine at www.buropuur.nl). Do not decide until you have done this. Do not limit your search to the most obvious choices, but look further. If you have to change your therapist, it will usually lead to a delay in recovery and you lose valuable time.

There are many different kinds of care. Here is a list with possibilities:
1. GP, pediatrician and school doctor
2. Youth workers, like a school social worker and school nurse
3. Self help books
4. Self help groups
5. Treatment center
6. Aid workers with personal experience
7. Help through the internet
   a. forums with people with similar problems
   b. therapy with professional guidance
8. Independently established therapists
   a. from various disciplines, like psychotherapists, dieticians, psychiatrists and/or psychologists
9. Mental health care (GGZ)
   a. therapy for several hours a week or signing in for several days a week
   b. individual and/or group therapy
   c. with or without family therapy
10. Involuntary commitment to a psychiatric facility

The aid workers above can be divided into specialized or not specialized in eating disorders. We advise to use therapists who have experience with eating disorders and who know how severe they can become.

As a parent you can make a first selection of therapists that seem suitable according to you. You can think about the wishes and needs of your child while you do this. If needed, you can use the search engine on www.buropuur.nl to find specialized therapists. Your GP can also advice you. Afterwards you can discuss the selected options with your child and GP.
**Phase 2: limiting the choices**

In order to limit your choices, you will need a list with criteria. Underneath we mentioned some criteria points. You can use this list when asking questions to the possible future therapist of your child.

1. Is the person who you have to conversation with also the person who will be treating your child?
2. Is he/she specialized in eating disorders?
3. Does the therapist have personal experience?
4. Are experience experts involved in the treatment?
5. What is the goal of the therapy? Goals can for instance be:
   a. dealing with the underlying problems
   b. developing a positive body image
   c. developing self confidence
   d. improving the relationship between emotions and food
   e. improving social skills
   f. medical stabilization
   g. stopping destructive behaviours
   h. changing eating habits
6. Therapists can handle the following points differently. Ask how they approach these items:
   a. focus or no focus on food
   b. relapse
   c. motivation
   d. aftercare
   e. do they work with a punish reward system
   f. are all remedies or only limited remedies used?
7. Who is involved during the treatment?
   a. individually
   b. groups
   c. family
   d. combination of above
8. How severe is your child’s eating disorder and what can you expect?
   a. life threatening condition
   b. not life threatening, but very severe
   c. not life threatening and not severe
   d. light form of an eating disorder
9. Financial compensation
   a. through health insurance
   b. other, like personal budget
10. Location of the therapist
11. Environment where it takes place
   a. private setting
   b. independent practice
   c. clinic
   d. hospital
Phase 3: Discussing the choices with your child and GP
It is important to see which options appeal to your child. After all, the child is the one who will have to be in therapy. The most important part for your child's recovery is, according to us, a good relationship between your child and their therapist.
If your child does not want help or denies their eating disorder, you should still talk to some care workers. Possibly without your child so they can advise you on how to deal with this situation. Involuntary commitment into a psychiatric facility is the last resort. If this is your final resource, then we advise you: “Talk to parents who went through this as well.” (look at www.buropuur.nl for parent evenings).

Phase 4: Making appointments with therapist(s)
What do you want to know about your child’s future therapist? What questions do you have? Sometimes you do not have enough time to prepare this and it can be helpful to use questions that other parents had or questions they realized they should have asked afterwards.

If you are in a position where you can make appointments with several therapists: then do this. You will learn a lot from this. Also explicitly ask about:
At what moment can you, as a parent, contact the therapist, for instance, when you have burning questions or concerns?
What role does the therapist expect from you?
How will you be informed about the agreements that have been made with your child?
Does your child's age influence this?
Will the therapist contact the school as well?
Is there a waiting list? And if so, what should you do while you are on the waiting list?

Phase 5: Deciding upon a therapist
Which therapist will it be? And how involved is the therapist? How badly do they want to help your child? There is a huge difference in this according to the experiences from other parents.

Quotation from an experience expert: “The effect of the intervention depends on the inner state of the therapist.”

As the creators of this document we totally agree. There has to be a ‘click’ between the therapist and the child. This can only exist if the therapist is absolutely involved, has expertise, etc. For more information see www.ntinlp.nl.

Evaluate whether the therapist keeps their promises. Do not hesitate to alert your therapist if you feel like something is wrong and discuss this with your GP if needed.
Trust your parental instincts. Listen to your feelings, listen to your child. It also helps to share experiences with other parents. It can be the case that you have to change your therapist.
Quotation from a mother: “My son (8 years old) who has ADHD and an extreme amount of stomach ache (stress) went to his therapist crying every week. When I discussed this with the therapist, he told me not to give in. However, it didn’t feel right. After a few weeks I went to my GP. He told me to immediately stop and find a new therapist. I was very grateful for this, because with the new therapist, my son asked me every week: “Mom, when can I go to … again?” In no time he learned how to deal with stress and his stomach ache disappeared. To this very day (he is 23 now), he still talks about this therapist. This experience showed me to go with my gut feeling. When my daughter was admitted into a clinic for an eating disorder and I felt like she wasn’t doing better, but only worse, I immediately started looking for a different kind of therapy that would suit her better. This turned out to be a really good decision.”

What does an application procedure look like?
Therapists who are bound to procedures usually have to deal with this:
• The registration form has to be received. If you are fast, you can finish it in one day.
• A referral from the GP is needed. This is doable in one day as well.
• An appointment for an intake session will be made once the paperwork is done.
• This session will be approximately 2 weeks later.
• An appointment to discuss the advised therapy will usually be 2 or 3 weeks later.
• Waiting list?
• Treatment. If you are lucky, your child will be in therapy within 2 months, but in practice it turns out that this can take longer as well.

Therapists with an independent practice can usually go faster:
• The first appointment immediately includes the intake session and sometimes even the first therapy session.
• Within 2 to 3 weeks the treatment should be able to start.

What does therapy look like?
Therapists all have their own work protocols. Ask your therapist about theirs. They have to be according to the ‘multidisciplinary guideline eating disorders’ (Multidisciplinaire Richtlijn Eetstoornissen), which you can find at www.buropuur.nl. The rights and obligations that can support you as a parent during therapy are mentioned in there.

Eating as a powertool
It is up to your GP, pediatrician or medical specialist to decide the what and the how around your child’s eating disorder. Your child can be using food as a ‘powertool’. It is important to inform the therapist about this. Bringing this up for discussion, also the feeling of the parent’s helplessness, can provide a lot of insight. As a parent you can learn to deal with your child’s eating behaviour. This will not always be easy.
The role of a specialized dietitian

Dietitians who are specialized in eating disorders work in both treatment centers and independent practices.

Quotation from a dietitian who is a member of the Dutch Federation of Dietitians and who works with eating disorder patients: "Not every dietitian has the expertise to treat a child with an eating disorder."

It is important that the parent is (partly) involved in the treatment, so you can decide together with the dietitian how you can help and stay consequent. Information about food can provide you with a realistic outlook on food and weight. The specialized dietitian helps your child by giving dietary advices and making agreements with the child on changing their eating patterns. With their knowledge about food, they can make sure that your child can gain weight in a healthy and controlled way.

Be aware: an eating disorder is not about food; you are not recovered until you can really deal with thoughts and feelings properly. Read more about this in the book ‘Herstel criteria voor eetstoornissen (recovery criteria for eating disorders)’ which you can download through www.humanconcern.nl.

Quotation from a girl who is recovering from anorexia nervosa: “When I was at a low point, I tried to manipulate my mum the entire day. And that worked quite well. My mum learned to set limits and be clear during a parent evening. I secretly liked it that my mum set limits. Afterwards, I was grateful that she was so strict on that matter. I needed it.”

A dietitian who is specialized in treating children with eating disorders will ask a lot of questions during first session about the eating disorder and what eating is currently like. In the following session the important themes will be: gaining weight, what is a normal weight, what is a normal way of eating, what happens to food in your body.

Tips from the working party dietary intervention from the Dutch Association of Dietitians to help controlling the eating disorder:

- Keep cooking like you used to and expect your child to eat with you.
- Make agreements beforehand about who serves the food or how much food your child takes.
- Do not agree on special products that your child wants to eat.
- Do not make exceptions on dietary advices. This only provides space for further manipulation.
- Do not let your child eat alone, create a moment together to eat and drink. A regular place and time will provide predictability.
- If needed, set limits on physical exercise: for instance, if you do not eat then you do not have energy to play sports or cycle to school.
- When you suspect that your child throws up after a meal: have your child stay with you in the (living) room for an hour after the meal.
- If your child wants to influence the preparation of the meal: agree that your child stays out of the kitchen and does not cook during their recovery.
- If your child wants to influence the choice of the groceries: do not take your child with you while doing groceries.
- Think: What do I consider as normal? Rely on this thought when you put your child on the spot.
Be aware: Always use common sense and intuition to decide whether you use these tips. Discuss it with your specialized dietician.

Buro PUUR’s belief is that most attention should be paid to the function of the eating disorder for recovery. Besides that, the food pattern has to be tackled as a part of the treatment.

*After a few days the enthusiasm dies*

When your child went to their therapist, it often looks like everything is going amazing for a few days and then it goes downhill again. In our experience, this is completely normal. A therapist can be of huge support for a child and therefore give them a lot of energy to fight for recovery. Everything in life is a choice, including the will to recover. An enthusiastic and positive therapist can often be a big stimulus.

*With ups and downs*

The first appointment with a therapist can be very scary. Fear can lead to an increase in the severeness of the eating disorder, so also around the time that help is brought in. If the therapy works, steps can be taken towards recovery, but you can count on it that there will be setbacks as well. Give space for this process.

Some therapists already expect a relapse. They use this as a moment to reflect on the progress that has already been made.

*Quotation from a boy who recovered from bulimia nervosa:* “Making my binges smaller was my goal, because maybe then I wouldn’t throw up. I managed to stop myself from vomiting a few times already. I was very proud of that. The downside was that I gained weight during recovery. Now I am actually even lighter than when I suffered from bulimia. And I always thought that throwing up would help me to lose weight.”

*Quotation from a father:* “What I found very difficult is that nobody told me at start how to deal with the food. Eventually I found some interesting tips in the book ‘ouders als bondgenoot’ (parents as allies) from James Lock and Daniel Le Grange: setting limits with a loving attitude. The behaviour of parents can contribute to the preservation of the eating disorder.”
“I use my past with my eating disorder as an investment for the future. Now I know when I need to listen to myself.”
It is important that your child gets aftercare after the treatment. Experience has shown that the first 1.5 years after therapy are crucial. A relapse is just around the corner. Learning skills to prevent a relapse are desirable. Especially after a treatment that was just focussed on dietary behaviour and weight there is a huge chance on a relapse. Recovering from an eating disorder entails a lot more than just developing ‘normal’ eating behaviour.

There are workbooks that the therapist can go through with your child to shape the trajectory of the aftercare. The ‘Guidelines relapse prevention Anorexia Nervosa’ (Richtlijn terugvalpreventie Anorexia Nervosa) is available for children and adults. The guideline is created for the therapist.

There are also peer groups that are specifically meant as aftercare. Teenagers often find a lot of support in these groups during the time that many people think ‘everything is fine again’.

Furthermore, documents are available about the recovery process. Because, when is someone recovered? According to the ‘Guideline for treatment goals and recovery criteria for Eating disorders’ (Richtlijn voor Behandeldoelen en Herstelcriteria voor eetstoornissen) recovered experience experts can fulfill an import role in this. Clients and parents can download the brochure ‘Herstellen van je eetstoornis, wat houdt dat in?’ (recovering from your eating disorder, what does that entail?) for free through www.humanconcern.nl.

We want to recommend you to take a look at the aftercare trajectories that are described above. As a parent they will provide tips for you as well.

Quotation from an experience expert: “Food is still my weak spot, but I use it as a ‘thermometer’. The moment that I think about eating an entire package of cookies at once, I know there is something that I don’t want to deal with. I know that I have to talk to someone. So then I call in help. And that is quite useful, more people should do that. I use my past with my eating disorder as an investment for the future. Now I know when I need to listen to myself.”
An Eating disorder is not about food

Dare to ask for help
You are not alone
You did not choose for this
Choosing for recovery is your choice!
You do not have to do this on your own

info@buropuur.nl
www.buropuur.nl

Deze poster is te bestellen via www.buropuur.nl
Het realiseren van deze handleiding is te danken aan het lef van ouders die naar een informatieavond voor ouders van kinderen met een eetstoornis kwamen. Zij stelden vragen en wilden graag van elkaar leren. Zij gaven aan dat ze hun ervaringen zo graag met andere ouders wilden delen. Door te luisteren naar deze ouders is deze handleiding ontstaan. Voorwaarde van de ouders was dat de handleiding gratis digitaal beschikbaar moest zijn. Gelukkig hebben we dat kunnen realiseren.

Verder willen we iedereen bedanken die ons opmerkingen heeft toegestuurd naar aanleiding van de eerste en tweede druk. Hierdoor is de derde druk van deze handleiding nog completer geworden.

Laat u ons uw reactie weten? Stuur een mail naar info@buropuur.nl. Dat stellen we erg op prijs.

De initiatiefnemers
Bénédicte Conijn
Lily Raymakers
Patricia Bos
Useful addresses

Buro PUUR heeft een database met informatie ‘over eetstoornissen’ en een database met hulpverleners gespecialiseerd in eetstoornissen beschikbaar via www.buropuur.nl

WEET, vereniging rond eetstoornissen, is de landelijke patiëntenorganisatie. Bel de Weet hulplijn of maak een afspraak om te bellen met info@weet.info. Kijk voor meer info: www.weet.info

De Nederlandse Vereniging van Schooldecanen en Leerlingbegeleiders
www.nvs-nvl.nl

De Nederlandse Academie voor Eetstoornissen
www.eetstoornis.info

Ziezon, landelijk netwerk ziek zijn en onderwijs
www.ziezon.nl
Bestellen
Deze handleiding is gratis digitaal te verkrijgen via www.buropuur.nl. Ook is de handleiding en de bijpassende brochure per post te ontvangen tegen vergoeding van druk- en verzendkosten. U kunt de handleiding bestellen via het formulier op www.buropuur.nl of door een mailbericht te sturen aan info@buropuur.nl.

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Vrijwaringclausule
Aan deze handleiding kunnen geen rechten worden ontleend.

Opmerking
In de handleiding leest u veel ervaringsverhalen van ouders over hun dochter. Zowel jongens als meisjes kunnen een eetstoornis krijgen. Ervaringsverhalen zijn persoonlijk. Ze zijn niet bedoeld om u te vertellen hoe het moet. Ze zijn bedoeld om uw beeld over gezinnen met een kind met een eetstoornis te verruimen. We hebben niet de overtuiging daarin compleet te zijn.
What if a student has an eating disorder?

Order the guide for professionals: www.buropuur.nl